Ethical considerations in collaborative care in severe and enduring anorexia: an application of an ethical decision-making model

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (Psychology)

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Abstract

Severe and enduring anorexia nervosa (SE-AN) is a mental illness with a high morbidity and mortality rate. It can profoundly affect a person’s quality of life and relationships due to frequent periods of relapses and remissions. Many people become critically unwell and refuse treatment because they fear gaining weight, and they become resistant when subjected to coercion. Psychiatric advance directives (PADs) can reduce treatment refusal and enhance collaboration between health professionals and patients. SE-AN is an ethical concern for health practitioners, families and ethicists. Few qualitative studies have explored the ethical debate of whether to impose forced treatment or respect a person’s right to refuse medical care. This thesis critiques both arguments and explores the ethical considerations. It uses a constructivist–interpretivist grounded theory method guided by a symbolic interactionist approach to inductively build an ethical decision-making model framed under the auspices of PADs. A purposeful homogenous sample of five women with SE-AN and eight clinicians participated in semi-structured interviews and focus groups. All participants were recruited from a hospital in Melbourne, Australia. The results confirmed that coercion is a moral and ethical problem when treating people with SE-AN. The central concern was that they lacked control over the illness, specifically in relation to provision of care, decision-making process, living with the debilitating effects of anorexia and absence of knowledge regarding PADs. The model addresses these concerns by enabling people with SE-AN to collaborate with their healthcare providers regarding their treatment preferences if they lose their ability to make decisions. In clinical practice, if patients’ rights and treatment preferences are not respected, this may result in further acts of coercion, which may damage the therapeutic relationship and leave the patient feeling powerless and not in control of their illness. The sample size limited the generalisation of the findings. Future researchers should empirically test and modify the model for other clinical settings and patient groups to enhance the transferability of findings’.
Declaration

I certify that except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis is the result of work which has been carried out since the official commencement date of the approved research program; any editorial work, paid or unpaid, carried out by a third party is acknowledged; and, ethics procedures and guidelines have been followed.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship.

Signature: Richard Knight          Date: 30/07/2019
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Advance care plan</td>
</tr>
<tr>
<td>AD</td>
<td>Advance directive</td>
</tr>
<tr>
<td>AI</td>
<td>Advance instruction</td>
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<tr>
<td>AN</td>
<td>Anorexia nervosa</td>
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<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
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<tr>
<td>BDD</td>
<td>Body dysmorphic disorder</td>
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<tr>
<td>BED</td>
<td>Binge eating disorder</td>
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<tr>
<td>BMI</td>
<td>Body mass index</td>
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<tr>
<td>BN</td>
<td>Bulimia nervosa</td>
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<tr>
<td>CBT</td>
<td>Cognitive behaviour therapy</td>
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<tr>
<td>CBT-AN</td>
<td>Cognitive behaviour therapy–anorexia nervosa</td>
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<tr>
<td>CBT-E</td>
<td>Cognitive behaviour therapy enhanced</td>
</tr>
<tr>
<td>DSM-5</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>EDNOS</td>
<td>Eating disorder not otherwise specified</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>GT</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>HCPA</td>
<td>Health Care Power of Attorney</td>
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<tr>
<td>ICD-10</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>IPT</td>
<td>Interpersonal psychotherapy</td>
</tr>
<tr>
<td>NEDC</td>
<td>National Eating Disorder Collaboration</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute of Health Care Excellence</td>
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<tr>
<td>NSU</td>
<td>Non-substance users</td>
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<tr>
<td>OCD</td>
<td>Obsessive compulsive disorder</td>
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<tr>
<td>PACFA</td>
<td>Psychotherapy and Counselling Federation of Australia</td>
</tr>
<tr>
<td>PAD</td>
<td>Psychiatric advance directive</td>
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<tr>
<td>PCP</td>
<td>Primary care physician</td>
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<tr>
<td>PT</td>
<td>Psychodynamic therapy</td>
</tr>
<tr>
<td>RANZCP</td>
<td>Royal Australian and New Zealand College of Psychiatrists</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
</tr>
<tr>
<td>SE-AN</td>
<td>Severe and enduring anorexia nervosa</td>
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<tr>
<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>--------------</td>
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<tr>
<td>SEDC</td>
<td>Specialised eating disorder clinic</td>
</tr>
<tr>
<td>SI</td>
<td>Symbolic interactionalism</td>
</tr>
<tr>
<td>SIB</td>
<td>Self-injurious behaviour</td>
</tr>
<tr>
<td>SSCM-SE</td>
<td>Specialist supportive clinical management</td>
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<tr>
<td>SU</td>
<td>Substance users</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>WSAS</td>
<td>Work and Social Adjustment Scale</td>
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Preface

Before proceeding, I would like to make a few comments about the language and sample size used in this thesis. In line with the philosophical tradition of qualitative research, this thesis will use both the passive voice and the active voice (Charmaz, 2006; Evans, Gruba, & Zobel, 2011; Gilgun, 2005; Wolcott, 2009). Specifically, the first-person active voice ‘I’ is used for several reasons: to highlight my journal thinking, to clarify my position regarding the research topic, to illuminate my personal biases and assumptions, and to reflect on my individual experience of living with anorexia (Patton, 2015c). In fact, it is common for qualitative researchers to ‘position’ themselves in their research (Bloomberg & Volpe, 2008, p. 9). That is, the author’s voice should be ‘seen’ in the text (Charmaz & Mitchell, 1996; Creswell, 2013; Denzin, 2001; Dey, 1993; Ely, 1997; Gilgun, 2005; Hertz, 1997; Holloway, 2005b, 2008; Marshall & Rossman, 2010; Maxwell, 2012; O’Leary, 2014; Oliver, 2013; Patton, 2015c; Ponterotto, 2005; Punch, 2013; Ritchie, Lewis, Nicholls, & Ormston, 2013; Smythe, Ironside, Sims, Swenson, & Spence, 2008; Thorne, 2008).

Evans et al. (2011) suggested that the active voice should be used judiciously and without compromising the integrity of the participants’ voices—that is, it should not be overused or dominate the discourse of the analysis. Further, the researcher should not consider the experiences of the participants as if they were his or her own (Holloway, 2005b; Marshall & Rossman, 2010). Indeed, this would undermine the credibility of the findings as well as the philosophical foundation of social constructivism—an epistemological position the author has adopted to inform the research investigation (Charmaz, 2006; Gilgun, 2005).

The singular ‘I’ is often frowned upon by some quantitative researchers, thesis committees and even conservative editors (Charmaz & Mitchell, 1996; Evans et al., 2011; Wolcott, 2009), who might consider it a ‘forbidden pool of knowledge’ (Fine as cited in Hertz, 1997, p. vii). However, some people (mainly qualitative researchers) believe (and
would defend) that the use of ‘I’ can make a thesis more readable and credible (Gilgun, 2005; Patton, 2015c). For example, Holloway (2005b) stated that ‘the use of “I” makes the write-up more lively and imaginative if used as a literary device, as well as credible and real’ (p. 280). He further added that ‘I’ can be used to amplify the voice of ‘the other’ (p. 280). That is, it can exemplify the ideas and beliefs of the researcher and participants (and other authors) without detracting from their own experience (Hertz, 1997). In contrast, Charmaz (2006) stated that ‘we can weave our points of view into the text and portray a sense of wonder, imagery, and drama’ (p. 174). Indeed, it is my intention to weave my voice throughout the thesis by asking questions, challenging ideas and assumptions, and integrating parts of my own lived experience. Hopefully, this will enable me to connect with readers and might stimulate further thinking from a ‘consumer’ perspective.

Regardless of the type of voice, the participants’ voices will take centre stage to share their views, beliefs and attitudes regarding the research topic (Holloway, 2005b). As is often the case, these marginalised women are rarely given the opportunity to express their lived experiences with mental health (Padgett, 2008). In fact, the principle of justice requires that we listen ‘to the voices of the minority and disadvantaged groups’ (Orb, Eisenhauer, & Wynaden, 2001, p. 96).

This thesis aims to introduce terms that are representative of, and acceptable to, people with eating disorders (Weissman et al., 2016). It is important for researchers to pay attention to language when referring to people with eating disorders to prevent further stigmatisation. Therefore, I will not use terms that would contribute to stigmatising people in the eating disorder community. Nor will I use terms such as ‘anorectic’ or ‘hard core’, which medicalise and pathologise women’s bodies (Boyle, 2019; Ramjan, 2004). Rather, I will use respectful language that is inclusive of and sensitive to the experiences of women with SE-AN (Weissman et al., 2016). After all, they are living with an illness and should be treated as
human beings rather than being defined by their illness (Holloway, 1997; Weissman et al., 2016). This sentiment was expressed by an author who had experienced mental illness herself: ‘we want our personhood to be recognised before our psychiatric diagnosis’ (Deegan, 1997, p. 12). It is hoped that readers of this thesis will respect my personhood.

The focus of this study is adult women; therefore, the thesis deliberately uses the pronouns of ‘she’ and ‘her’. Of course, this does not mean that males are not at risk of developing eating disorders (Crisp, 1995; Greenberg & Schoen, 2008; Mangweth-Matzek, Kummer, & Pope, 2016; Murray, Rieger, Karlov, & Touyz, 2013; Pope, Olivardia, Gruber, & Borowiecki, 1999; Wooldridge & Lytle, 2012).

Throughout the thesis, a number of terms are used interchangeably, such as ‘forced treatment’, ‘involuntary’, ‘inpatient care’ and ‘restrictive care’. Further, I have used several terms to describe the doctor–patient dyad, including ‘clinician’, ‘healthcare practitioner’ and ‘physician’, as well as ‘participant’, ‘patient’, ‘client’, ‘person’ and ‘individual’.

Of course, the terms ‘patient’ and ‘client’ have sociopolitical implications. It has been reported that such labels perpetuate stigmatising attitudes (Austin, Bergum, & Nuttgens, 2004; Crisp, 2005; McLaughlin, 2009; Ritchie, Hayes, & Ames, 2000). For example, patients are viewed as being ‘sick’, ‘weak’ and ‘mentally ill’, which automatically negates their ability to make informed decisions about their medical care (Lemma-Wright, 1994; Shattell, McAllister, Hogan, & Thomas, 2006).

As researchers, we need to move beyond these terms and others (i.e., ‘subject’) and develop language that is more inclusive (e.g., ‘people’) to describe people with serious mental issues (McLaughlin, 2009; Ritchie et al., 2000).

For clarity, the terms ‘patient’ and ‘person’ will be used (alternated with the term people) in this doctoral thesis because there are no acceptable alternatives. Further, the term
‘patient’ was frequently used in the interview transcripts; therefore, the term was retained for authenticity purposes (Boddy, Chenoweth, McLennan, & Daly, 2013).

On a final note, the qualitative studies that have been cited in this thesis, including my own study, consist of a small number of participants. This is acceptable and justified for social science research (Boddy 2016). Currently, there is no consensus as to what constitutes an objective measure of the sampling size in qualitative research, and there are no definitive studies on this topic (Bryman, 2012; Liamputtong, 2013; Thorne, 2008). Typically, though, qualitative studies involve small numbers, whereas quantitative studies use larger sampling sizes (Creswell, 1998; Hennink, Hutter, & Bailey, 2010; Onwuegbuzie & Leech, 2007). For researchers, this is a key concern because the generalisability and transferability of qualitative findings is a limited factor (Bryman, 2012).

Moreover, Morrow (2005) makes a valuable point by stating that ‘ultimately, what is far more important than sampling size are sampling procedures; quality, length, and depth of the interview data, and variety of evidence’ (p. 255).
Glossary

As part of the glossary of key terms provided to help the reader understand the research project, I have compiled a list of terms, including definitions, that will be used in this thesis.

**Advance directive:** An advance directive ‘enables a competent person to make decisions about future treatment, anticipating a time when they may become incompetent to make such decisions’ (Halpern & Szmukler, 1997, p. 323).

**Best interest:** This approach works from the maxim to act beneficently (what is thought to be in the best interest of the person) by making decisions (weighing the potential costs and benefits) that will protect their wellbeing (Buchanan & Brock, 1989; Carter, Detering, Silvester, & Sutton, 2015; Dresser, 1984c; Exworthy, 2004; Kapp, 2010).

**Capacity/competency:** This is predicated on the belief that a person has the ability to communicate choices, understand relevant information, appreciate the situation and its consequences, and manipulate information rationally (Appelbaum & Grisso, 1988).

**Compulsory treatment:** This refers to a person who has been force-fed (nasogastric feeding) against their will (Werth Jr, Wright, Archambault, & Bardash, 2003).

**Coercion:** This can be defined ‘as an individual’s perception or sense that her freedom has been violated’ (Matusek & Wright, 2010, p. 435).

**Countertransference:** Freud coined this psychodynamic term in 1910 to describe the unconscious reaction of the therapist to the patient’s transference (Corey, Corey, Corey, & Callanan, 2014).

**Dignity:** This can be defined as treating people as individual human beings by respecting their values, attitudes and feelings (Haddock, 1996).
**Egosyntonic:** This term describes a person’s mental state. People often believe that their behaviours fit with their sense of who they are (Beat Eating Disorders, 2017; Crisp, 1997).

**Feminism:** Feminism aims to reduce power differentials and androcentric patriarchal biases, work towards change and justice, overcome gender inequalities and oppression, and empower marginalised groups (Kushner & Morrow, 2003; Kvale, 1996; O’Leary, 2014).

**Heideggerian phenomenology:** This ‘phenomenology is the study of human experience and of the ways things presents themselves to us in and through such experience’ (Sokolowski, 2000, p. 2).

**Hermeneutics:** Hermeneutics ‘refers to the art, theory, and philosophy of interpreting the meaning of an object (a text, a work of art, social action, the utterances of another speaker, etc.)’ (Schwandt, 2014, p. 138).

**Iatrogenic:** Iatrogenic refers to negative outcomes (e.g., coercion) in treatment settings (e.g., hospitals) (Garner, 1985).

**The ‘inner voice’:** This is a nebulous concept in the literature with no clear definition apart from being described as an ‘inner critical voice’ with some parallels to psychotic hallucinatory experiences. However, there are few studies on this subject to support this claim (Noordenbos, Aliakbari, & Campbell, 2014; Pugh & Waller, 2017). This, of course, does not apply to all people with eating disorders, but rather it is an idiosyncratic experience that may have different meanings (both positive and negative aspects) for different people (Tierney & Fox, 2010). Some patients have conceptualised the inner voice as a different form of ‘self’ (Surgenor, Plumridge, & Horn, 2003).

**Involuntary treatment:** This refers to a person who has been placed in the care of state authorities (e.g., psychiatric hospital), sometimes detained under the *Mental Health Act*, to protect their safety and wellbeing (Werth Jr et al., 2003).
Maudsley Model for Treatment of Adults with Anorexia: This is a family based outpatient eating disorder program that targets specific symptoms, such as obsessional thinking, perfectionism and negative emotional avoidance. It is delivered using a cognitive–behavioural program in the treatment of the illness (Halmi, 2013).

Proxy: A proxy is ‘the person making a decision on the behalf of a person without decision-making capacity’ (Devettere, 2010, p. 489).

Serious mental illness: Individuals who experience episodic periods of a mental health crisis with periods of stability are defined as having a serious mental illness (Van Dorn, Scheyett, Swanson, & Swartz, 2010).

Severe and enduring anorexia nervosa: This term describes a person who has experienced anorexia nervosa for a protracted period of more than seven years (George, Thornton, Touyz, Waller, & Beamont, 2004; Hay, Touyz, & Sud, 2012; Wildes et al., 2016).

Substituted judgment: This doctrine allows a surrogate decision-maker (e.g., state, guardian, medical team or tribunal) to make a decision on behalf of an incompetent person—a decision that the person would have made if they were competent to do so (Appelbaum, 2007; Buchanan & Brock, 1989; Dresser, 1984c; Exworthy, 2004; Gillick, 2006; Ryan & Callaghan, 2014; Tan, Hope, & Stewart, 2003a).
Declaration of Position

Given that the qualitative researcher is considered the main research instrument (Avis, 2005; Creswell, 2013; Holloway, 1997, 2005b; Wimpenny & Gass, 2000), they must declare any biases, values, views (e.g., political and social), pre-existing knowledge and experiences that they bring to the research (Berger, 2015) because they could potentially influence the researcher’s interpretations and compromise the trustworthiness of the research findings (Creswell, 2013; Hennink, Hutter, & Bailey, 2010; Marshall & Rossman, 2010). This is known as ‘reflexivity’, whereby the researcher engages in a process of introspection and critical reflection regarding their position within the research project and their involvement with the research participants (Berger, 2015; Bryman, 2012; Hennink et al., 2010; Holloway, 2005a, 2005b, 2008; Janesick, 2003; Padgett, 2008; Patton, 2015c). Wolcott (2010) supported this position, stating that:

*Our readers have the right to know about us. And they do not want to know whether we play in the high school band. They want to know what prompts or interests us in the topics we investigate, to whom we are reporting, and what we personally stand to gain from our study.* (p. 36)

My exploration of this topic was prompted by my personal lived experience of severe and enduring anorexia nervosa (SE-AN). My lived experience has broadened my view of the mental health system and of the disparity in the quality of care between private and public healthcare providers. I have also gained a better depth of understanding of the psychopathology of SE-AN, both from a clinical and personal point of view.

I have not written this thesis with any ill feelings towards the medical profession, and this is not an attempt to undermine their profession or credibility. It is my sincere intent to write a balanced and well-informed analysis of the medico-legal debate by engaging with all stakeholders to ensure that an accurate and fair description is presented regarding the ethics of forced treatment among people with SE-AN. Thus, I do not favour one view over another (beneficence v. autonomy); rather, I see various shades of grey depending on a person’s
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circumstances. There is no intention to persuade readers to align themselves with a particular argument or agenda such as paternalism or feminism. Such a promotion would be superfluous given that this thesis is meant to present an unbiased account of the debate.

I must confess, though, that at the outset of the research, I was against any form of enforced treatment (stemming from my negative experience of hospitalisation) and supported the belief that hospitalisation has no role in the care of people with SE-AN. However, after listening to the participants’ stories and reflecting on my personal experience with anorexia, I came to realise that hospitalisation is necessary to facilitate a person’s recovery and, more importantly, it can be used as a ‘life-saving’ device (Melamed, Mester, Margolin, & Kalian, 2003, p. 625). I am living proof of this and am now more aware of my potential biases regarding the issue of forced hospitalisation. This could help to avoid contaminating the data.

On a personal level, a major part of my motivation for writing this thesis is to create social justice for people with SE-AN and to improve their quality of life. That is, I want to minimise the iatrogenic effects of hospitalisation by allowing them to actively participate in the decision-making process through the use of PADs. I have met a number of people with SE-AN who have expressed a need to be listened to because they felt disempowered by the mental health system. They often complained about the lack of fairness in the decision-making process regarding their care, which left them feeling disrespected, ignored and not valued.

This thesis has been written for those who have an interest in the phenomenon of SE-AN, but it is more specifically targeted to health professionals, policymakers and other researchers (Liamputtong, 2013a; Patton, 2015c). These groups can use the ethical model as an adjunct tool to guide clinical decision-making and enhance collaborative care for people with SE-AN (Papaioannou, Demetropoulos, & King, 2010). Further, they can incorporate aspects of the proposed model into clinical practice to improve the quality of mental
healthcare not just for those with SE-AN, but potentially for other people with severe disabilities—physical or otherwise (Liamputtong, 2013a). Researchers can test and modify the model for other clinical settings and patient groups (e.g., males or minors) to enhance the transferability of the findings.

I do not claim that the proposed model will completely eradicate coercion from our eating disorder hospitals, nor do I believe that such an *ideal*ist approach is possible given the nature of the illness. Rather, the rationale behind this model will promote awareness and contextual understanding of the ethical dimensions of decision-making when caring for patients with SE-AN (Warren & McGee, 2013).

I hope that this model will improve the social condition of women with SE-AN and assist in their emancipation by empowering them to tackle their chronic illness (Creswell, 1998; Kvale, 1996).
Chapter 1: The Research Problem

1.1 Introduction

This chapter will focus on the medico-legal debate between the ‘autonomy’ and ‘beneficence’ of compulsory treatment of people with anorexia nervosa (AN), the ethical considerations for professionals when enforcing treatment and the concept of advance directives (ADs) and its potential application in mental health services. It includes discussions of the following topics: research problem, significance of the study, study design, scope and aim of the research, and research questions.

1.2 Context of Study—The Ethical Dilemma

AN is a life-threatening condition with a high mortality rate. It is an illness that can affect anyone, often with devastating consequences (American Psychiatric Association [APA], 2013; Herpertz et al., 2011; Mitchison & Hay, 2014; Radu, Chirita, Untu, Ciubara, & Chirita, 2016; Royal Australian and New Zealand College of Psychiatrists [RANZCP], 2014; Tan, Hope, & Stewart, 2003a; Tiller, Schmidt, & Treasure, 1993).

It is confronting for both the patient’s family and health professionals to watch the patient starve themselves to the brink of death (Appelbaum & Rumpf, 1998; Hughes, 1997; Lemma-Wright, 1994; Melamed, Mester, Margolin, & Kalian, 2003). Parents and carers often feel overwhelmed by a sense of helplessness and blame themselves when a loved one is experiencing an eating disorder (Lackstrom & Woodside, 1998). Many carers go to great lengths to remedy the problem (Whitney et al., 2005), even to the point of committing their loved one to a hospital for treatment, specifically in countries where this practice is legalised (Dresser, 1984c; Giordano, 2010; Lewis, 1999; Yager, Carney, & Touyz, 2016).

In the literature on AN, involuntary treatment is justified under the ethical principle of beneficence—that is, the act of ‘doing good’ for the patient (Douzenis & Michopoulos, 2015; Golden, Corvea, Dang, Llorente, & Silverman, 2008; Guarda et al., 2007; Kjellin et al., 1993;
Vuckovich, 2003). Thus, when a patient refuses to eat, health professionals have a moral obligation (Hippocratic duty) to enforce treatment to prevent serious medical complications and ensure the patient’s safety and wellbeing (Carney, Wakefield, Tait, & Touyz, 2006; Douzenis & Michopoulos, 2015; Geller, Williams, & Srikameswaran, 2001; Guarda et al., 2007; O’Brien & Golding, 2003).

Although mental health practitioners have a duty of care to protect their clients from irreversible or preventable harm (beneficence), it can nevertheless be argued that they also have an ethical obligation to respect the values and interests of individuals (autonomy) with eating disorders (Breeze, 1998; Carney, Tait, Wakefield, Ingvarson, & Touyz, 2005; Giordano, 2005; Krieger, Moritz, Weil, & Nagel, 2018; MacDonald, 2002; Matusek & Wright, 2010; Tan, Hope, Stewart, & Fitzpatrick, 2006). The ethical dilemma of deciding whether to enforce involuntary treatment of people with anorexia or respect their right to refuse medical care is a controversial issue, and it remains a challenge not only for mental healthcare providers, but also for family members, carers and the community (Ayton, Keen, & Lask, 2009; Carney, Yager, Maguire, & Touyz, 2019; Faith, 2002; Feiring & Ugstad, 2014; Guarda et al., 2007; Swartz, Swanson, & Hannon, 2003; Tiller et al., 1993; Vandereycken, 1998).

More recently, international human rights bodies such as the World Health Organization (WHO) have voiced concerns about the application of involuntary care and the human rights violations of people with mental health issues:

*Often, people are admitted inappropriately and treated against their will. They lack access to legal processes and mechanisms to protect against abuses during involuntary treatment, and they do not have the possibility to appeal against decisions to involuntarily admit or treat them. Nor do they have access to complaints mechanisms should they wish to report human rights violations being committed against them. (World Health Organization and World Organization of Family Doctors, 2008, p. 37)*
This highlights a breach of the principle of non-maleficence—‘above all, do no harm’. It is paternalistic in preventing women from accessing legal aid and support mechanisms to enable them to exercise their basic legal rights—that is, their right to freedom of choice and action.

One possible way to solve this ethical dilemma, and to develop a more collaborative approach (e.g., clinicians, families and consumers) in the care of people with severe and enduring anorexia nervosa (SE-AN), is to explore the potential value of psychiatric advance directives (PADs) (Commonwealth of Australia, 2013; Elbogen, Swanson, Appelbaum et al., 2007; Exworthy, 2004; Gallagher, 1998; O’Connell & Stein, 2005; Srebnik & Fond, 1999). By definition, an AD ‘enables a competent person to make decisions about future treatment, anticipating a time when he or she may become incompetent to make such decisions’ (Halpern & Szmukler, 1997, p. 323).

PADs can be used as a social justice tool to increase the autonomy/empowerment of individuals with severe mental illnesses (SMIs) and thereby reduce the occurrence (or perception) of coercive practices such as involuntary treatment (Amering, Denk, Griengl, Sibitz, & Stastny, 1999; Amering & Schaffer, 2007; Bonnie, 2012; Henderson et al., 2008; Khazaal et al., 2014; O’Brien & Golding, 2003; Scheyett et al., 2008; Scheyett, 2007; Shields, Pathare, Van Der Ham, & Bunders, 2014; Swanson, Tepper, Backlar, & Swartz, 2000; Van Dorn, Scheyett, Swanson, & Swartz, 2010; Winick, 1994; Zelle, Kemp, & Bonnie, 2015).

These ideas are consistent with the ‘least restrictive principle’, which supports a harm minimisation approach that avoids (or at least minimises) the use of coercive practices in the least restrictive environment possible (Atkinson, 2007; Gallagher, 1998; O’Brien & Golding, 2003; RANZCP, 2014). It must be emphasised that coercion can occur in both voluntary and involuntary patients and, equally, not every person will experience coercion (Katsakou & Priebe, 2007; Khazaal et al., 2014; MacDonald, 2002; Matusek & Wright, 2010; Schreyer et
Acts of coercion can be categorised as either subtle or overt (Guarda et al., 2007; MacDonald, 2002); accordingly, people’s perceptions of coercion can vary widely (Guarda et al., 2007; Hoge et al., 1997; Kjellin & Wallsten, 2010; Matussek & Wright, 2010; Olofsson & Jacobsson, 2001; Tan, Stewart, Fitzpatrick, & Hope, 2010).

To better understand the ethics of coercion for adult women with SE-AN, a case study presented by Gans and Gunn Jr (2003) will form the framework of this discussion to highlight the key arguments of this medico-legal debate.

Mrs. Black (not her real name), a US resident, was a 44-year-old married female with two children, a son aged 20 and a daughter aged 17. Mrs. Black had a 25-year history of anorexia nervosa. At the time of the evaluation she suffered from anorexia nervosa and related medical complications. She was living in a hospice connected to the hospital at which she had received much of her treatment over the years, admitted by her physician who felt she might have less than 6 months to live. No further treatment for the anorexia nervosa was being administered.... She denied being actively suicidal and reiterated her wish to die should she need life supports. She had some insight into her illness, but continued to focus on food and weight without awareness of complex psychological issues. However, her husband strongly felt that, given her history and the family’s experience of Mrs. Black, that she was competent to make this decision and that a more complex approach to the question was needed. These evaluators, her husband and the ethics committee of the hospital agreed.... She only wanted to live if she could ‘feel good and comfortable’. She said: ‘it is better to die than to live with yourself ... I am trying to let myself die’ (pp. 678–688). She subsequently died.

Stories like that of Mrs Black may appear to be the exception rather than the norm. However, many anecdotal cases suggest the contrary (Applebaum & Rumpf 1998; Campbell & Aulisio, 2012; Coggon, 2014; Davies et al., 2012; Fost, 1984; Giordano, 2010; Hebert & Weingarten, 1991; Hodel et al., 2019; Maher & Rosedale, 1993; Melamed et al., 2003; O’Neill, Crowther, & Sampson, 1994; Selvini-Palazzoli, 1978; Tiller et al., 1993; Trachsel, et al., 2015; Wang, 2015).

The description of Mrs Black as a 44-year-old woman highlights that SE-AN is a debilitating illness with a duration of at least seven years (Hay, Touyz, & Sud, 2012; RANZCP, 2014; Stiles-Shields et al., 2013). It can dominate a person’s life and cause significant long-term social, physical and psychological sequelae (Bamford et al., 2015;
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It also highlights the fact that people with SE-AN are difficult to manage in a clinical setting, particularly those who have become resistant to therapy (Draper, 2000; Halmi, 2013; Kaplan & Strober, 2019; McIntosh et al., 2005), those whose values are different to those of others (e.g., pro-anorexia) (Dresser, 1984b; Giordano, 2005; Kendall & Hugman, 2014; Robertson, 1992), those who are not willing to give up their personal sense of identity (Hope, Tan, Stewart, & Fitzpatrick, 2011; Tan et al., 2003a; Tan et al., 2006) and those who wish to end their life (Campbell & Aulisio, 2012; Draper, 2000; Griffiths & Russell, 2000; Yager, 1992). In most cases (but not all), they succumb to the travails of their illness and lose hope of ever recovering, refusing all forms of medical assistance (Draper, 2000; Gans & Gunn Jr, 2003; Richmond, 2001; Russell, Mulvey, Bennett, Donnelly, & Frig, 2019; Selvini-Palazzoli, 1978; Yager et al., 2016).

This raises several ethical challenges for treating practitioners and illustrates the juxtaposition of the ethical principles of beneficence and autonomy (Beauchamp & Childress, 2001; Dyer & Bloch, 1987; Maher & Rosedale, 1993; Schreyer et al., 2016). In particular, it raises the question of whether involuntary treatment is the best course of action or even ‘morally’ acceptable in the care of people with SE-AN. It also questions whether patients have the right to refuse treatment (based on competency or otherwise), and, if so, what the implications are if they are not treated, whether traditional mental health services (curative treatments) are appropriate for people with SE-AN and how clinicians provide humane and dignified treatment without undermining the principle of respect for patient autonomy (Carney, Tait et al., 2006; Geppert, 2015; Kaplan & Strober, 2019; Knapp & Vandecreek,
In the literature, these questions have largely remained unanswered. There is a growing body of literature on the treatment of patients with SE-AN (Wonderlich et al., 2012), but there is no clear consensus on how to resolve the ethical dilemma of forced treatment (Bezance & Holliday, 2013; Matusek & Wright, 2010). Many authors consider involuntary treatment an ‘act of violation and compassion’, but one that is necessary to preserve human life (Vandereycken, 1998, p. 1). Yet there are those who argue that involuntary treatment is a breach of human rights and autonomy and should not be permitted (Griffiths & Russell, 2000; Yager, 1992). The following analysis will examine these and attempt to highlight the pros and cons of these ethical questions.

1.3 Arguments for Forced Treatment

A key argument in favour of compulsory treatment is that it can save lives (Draper, 2000; Griffiths & Russell, 2000; Mitrany & Melamed, 2005). To preserve Mrs Black’s life, advocates who support the use of forced treatment argue that coercion is necessary. They claim that the starvation effects of the disorder have affected her ability to make sound judgments (i.e., competency) and prevented her from understanding the full severity of her illness (Draper, 2000; Griffiths & Russell, 2000). Often, health professionals question whether a patient’s decision to refuse treatment is influenced by the disorder (cognitive impairment) or whether it is based on sound judgment (capacity) (Cutcliffe & Links, 2010; Draper, 2000; Holm, Brixen, Andries, Hørder, & Støving, 2012; Manley, Smye, & Srikameswaran, 2001; Mappes & Zembaty, 1981; Widdershoven & Berghmans, 2001). This is the main crux of the debate (Goldner, Birmingham, & Smye, 1997; Russell, 2001). This issue will be discussed in more detail in Section 5.1.8.
It has been theorised that the ego-syntonic features of the illness are a contributing factor to its psychopathology (Cutcliffe & Links, 2010; Draper, 2000; Fassino & Abbate-Daga, 2013; Mappes & Zembaty, 1981; Strober, 2004; Tan et al., 2003a; Widdershoven & Berghmans, 2001). People with AN cannot ‘see’ what other people can see—that is, an emaciated sick person who requires medical attention (Bruch, 1974; Dresser, 1984b; Starzomska, 2006; Treasure, 2002; Vandereycken & Beumont, 1998a; Vitousek, Watson, & Wilson, 1998). This is due to the distortion of thought (cognitive impairment) and being fixated by the belief that their condition is congruent to who they are—that is, the anorectic self (Fost, 1984; Turrell, Peterson-Badali, & Katzman, 2011; Williams & Reid, 2010). Mrs Black’s reluctance to accept medical help, and her ‘relentless pursuit of thinness’ (Bruch, 1979, p. 38), could be part of the ego-syntonic nature of the illness, which clouds her judgment and makes her think she is fat when in fact she is emaciated (Dresser, 1984b; Elbaky et al., 2014; Matusek & Wright, 2010; Westwood & Kendal, 2012).

This irrational belief is a common feature of anorexia and is considered an important feature in the diagnosis of the condition (APA, 2013; Draper, 2000). They often demonstrate a ‘lack of insight’ into their condition, thus placing themselves at risk of serious medical problems (Halmi et al., 2005). People with SE-AN usually lead precarious and unpredictable lives, that is—they ‘live on the edge’ of life—not understanding the risks associated with the illness (Westmoreland & Mehler, 2016, p. 316). That is, they die not because of their intentions, but because of a lack of awareness of the consequences of the illness (Draper, 2000; Goldner, 1989; Holm et al., 2012). Anaïs Nin’s proverb of ‘we don’t see things as they are; we see them as we are’ is true in this case (Nin, 1990, p. 124).

This ‘denial’ and ‘lack of insight’ is intrinsic to the illness (Anderson & Paulosky, 2004; Bruch, 1974; Crisp, Kalucy, Lacey, & Harding, 1977; Halmi, 2013; Stice, 2002). It is often accompanied by other comorbidities such as depression, low self-esteem, anxiety and
obsessive-compulsive disorder (Achamrah, Coëffier, & Déchelotte, 2016; APA, 2013; Herpertz et al., 2011; Jagielska & Kacperska, 2017; Manley et al., 2001; Steinhausen, 2002). These conditions can exacerbate the illness, leading to further weight loss, and are likely to cause a person to withdraw from their social support networks (Lacey & Sly, 2016). Given that Mrs Black has been suffering from the illness for a long time, it could be said that her morbid mood has prevented her from recovering. It is common for people with AN to lose hope in the face of adversity, and they question their ability to recover (Geller et al., 2001). Sometimes, these feelings can be fuelled by shame and guilt, which are caused by repeated hospital admissions (Dresser, 1984b; Geller et al., 2001; Goldner, 1989; Maier et al., 2014).

In extreme cases, people with AN may attempt to resolve the feeling of hopelessness through acts of suicide or self-harm. This is an increasing problem among people with SE-AN (Marzola & Abbate-Daga, 2019).

However, some people ‘see’ the condition and understand the nature of the illness but are unable to control it. Control is a central problem in AN and forms part of a person’s social psyche and identity (Crisp, 1995; Dresser, 1984b; Hope et al., 2011; Lewis, 1999; Tan, Hope, & Stewart, 2003b; Tan, Hope, Stewart et al., 2003). Some experts have argued that this is the main perpetuating factor sustaining the illness (Bell, 2003; Beumont & Vandereycken, 1998; Mitrany & Melamed, 2005; Murray et al., 2017; Rathner, 1998; Tan, Hope, Stewart, & Fitzpatrick, 2003).

People with AN are characterised by their extreme need to be in control, especially of their body weight and shape (Giordano, 2005; Hepworth, 1999; Murray et al., 2017; Tan, Hope, Stewart et al., 2003). They are not prepared to relinquish their control and will go to great lengths to avoid doing so (Goldner, 1989; Guarda & Heinberg, 2004). The principal motivating factor seems to be an intense fear of gaining weight (APA, 2013; Garner & Needleman, 1997; Stice, 2002). They will be in conflict (control) with health professionals
and loved ones (Beumont & Vandereycken, 1998; Faith, 2002; Geller et al., 2001; Goldner, 1989; Jarman, Smith, & Walsh, 1997; Melamed et al., 2003; Tan, Hope, Stewart, & Fitzpatrick, 2003; Woodside, 2002), pull out nasogastric fusion lines (Dresser & Boisaubin Jr, 1986; Gans & Gunn Jr, 2003), manipulate others and ‘eat their way out’ of hospital (Dresser, 1984b, p. 321), and relentlessly pursue weight loss through extreme measures (e.g., excessive use of laxatives) until they become medically unwell (Dresser, 1984b).

Mrs Black had reached the ‘end stage’ of her psychiatric illness (Campbell & Aulisio, 2012; Geppert, 2015; Selvini-Palazzoli, 1978; Westmoreland & Mehler, 2016; Woodside, Twose, & Olteanu, 2016). She had chosen not to surrender her control, but rather to maintain control to the point of death. Globally, among patients with chronic illnesses, the decision to withdraw from lifesaving treatment is common. For treating practitioners, this is increasingly becoming an ethical problem (Campbell & Aulisio, 2012; Draper, 2000; Dresser & Boisaubin Jr, 1986; Woodside et al., 2016).

However, in most cases, the ethical principle of beneficence outweighs autonomy (Fost, 1984; Maher & Rosedale, 1993). Often, but not always, involuntary treatment is dictated by ‘overzealous’ doctors who want to make the ‘final decision’ (Draper, 2000). Some have feelings of countertransference that overshadow their attempts to rescue sick patients (APA, 2006; Hebert & Weingarten, 1991), while others are morally bound out of ‘goodness and rightness’ to do the best for their patients (Giordano, 2005 p. 11), and a few remain indifferent but succumb to the pressures of ethical committees and are mandated to rescue dying patients (Maher & Rosedale, 1993). This strong adherence to these moral, legal and ethical codes shows that paternalism remains a threat to people’s autonomy (Hill, Glaser, & Harden, 1998; Kitchener, 1984; Murgic, Hébert, Sovic, & Pavlekovic, 2015; Rosenman, 1998; Werth Jr, Wright, Archambault, & Bardash, 2003).
A number of authors have suggested that Mrs Black’s problem could be related to her ‘inner anorexic voice’ (Noordenbos, Aliakbari, & Campbell, 2014, p. 338) telling her that she was not worthy of living, and as a result, she had lost hope of ever recovering from the insidious illness, and refused all offers of treatment (Fassino & Abbate-Daga, 2013; Tan, 2003; Tierney & Fox, 2010; Vialettes, Samuelian-Massat, Valero, & Béliard, 2006; Williams & Reid, 2010). An argument can be made that Mrs Black had lost her ‘authentic self’ and was consumed by the presence of this internal voice (Hope et al., 2011; Noordenbos et al., 2014). She was subjected to ongoing criticism about her weight and appearance and was convinced that life with AN was intolerable (Pugh & Waller, 2017).

Some patients actively seek help and want to be rescued, while others (a small group) remain ambivalent and live a life of despair with no hope of recovering (Crisp et al., 1977; Fairburn & Cooper, 2011; Strober, 2004; Vitousek et al., 1998; Woodside et al., 2016). These patients believe the illness is ‘impenetrable’, and they eventually hit ‘rock bottom’. Then, feeling ‘battle weary’ and ‘exhausted’, they simply give in, leaving them facing a continuing illness with severe mental and physical problems, possibly leading to death (Crisp, 1995; Dawson, Rhodes, & Touyz, 2014; Draper, 2000; Giordano, 2005; Kaplan & Strober, 2019). Mrs Black’s story exemplifies this point.

The above considerations have been identified as the main contributing factors in treatment refusal among patients with SE-AN. Forced treatment is therefore warranted (Carney, Tait, & Touyz, 2007; Mitran & Melamed, 2005; Tan et al., 2010); however, there are concerns about the legitimacy of the use and implications of involuntary treatment.

1.4 Arguments for Respecting Autonomy

Civil libertarians have argued that involuntary treatment is unacceptable, degrading and an infringement of the human right to justice and dignity. They believe that involuntary treatment is limited in its ability to help people with SE-AN, and it violates the fundamental
ethical principle of respect for persons (Feiring & Ugstad, 2014; Giordano, 2005; Kallert, Mezzich, & Monahan, 2011; Rathner, 1998; Roberts & Dyer, 2007; Silber, 2011; Tan, Hope, Stewart et al., 2003). Some commentators have criticised the use of coercion and have described it as an act of ‘humiliation’ (Feiring & Ugstad, 2014, p. 2), ‘punishment’ (Tan, Hope, Stewart et al., 2003, p. 640), ‘inhumane’ (Treasure, 2002, p. 342), ‘imprisonment’ (Chamberlin, 2005, p. 14) and ‘mistreatment’ (Treasure & Ramsay, 2002, p. 34), stating that it ‘contributes to stigma, trauma and [victimisation] criminalisation of the mentally ill’ (Swanson et al., 2008, p. 2). These all constitute abuse and cause irrevocable harm to the person, thereby further marginalising people with mental health issues (Austin, Bergum, & Nuttgens, 2004; Chamberlin, 2005; Douzenis & Michopoulos, 2015; Feiring & Ugstad, 2014; Holm et al., 2012; O’Brien & Golding, 2003; Tan, Hope, Stewart et al., 2003; Vandereycken, 1998).

Thus, the main arguments against involuntary treatment, which can be used as a defence for Mrs Black’s plight, include the following: it undermines and destroys trust and compromises the therapeutic alliance; it deter people from seeking future care; it violates and undermines a person’s autonomy and freedom of choice; it causes elevated rates of depression and suicide; it causes psychological trauma for those who have a past history of physical or sexual abuse; and there is no empirical research to support the view that compulsory treatment benefits people with SE-AN, especially in regard to force feeding (APA, 2013; Brewerton, 2007; Draper, 2000; Dresser, 1984b; Duker & Slade, 1988; Geller et al., 2001; Giordano, 2005; Goldner et al., 1997; Griffiths & Russell, 2000; Jacobsen, 2012; Kjellin & Wallsten, 2010; Lemma-Wright, 1994; Matusek & Wright, 2010; Melamed et al., 2003; Russell et al., 2019; Schreyer et al., 2016; Sjöstrand & Helgesson, 2008; Tan et al., 2003a; Tan, Hope, Stewart et al., 2003; Yager et al., 2016). In many cases, patients view involuntary treatment as being punitive (Russell et al., 2019).
The above analysis shows that there is no agreement among commentators regarding the ethics of coercion (Elzakkers, Danner, Hoek, Schmidt, & Elburg, 2014). The overarching question is whether clinicians will accept this ‘therapeutic nihilism’ and therefore respect Mrs Black’s autonomous self and dignity, thus jeopardising her safety and wellbeing, or whether they will independently intervene (e.g., invoke compulsory treatment), violate the patient’s rights (e.g., disrespect her autonomy and self-determination), subject her to aggressive treatments and thus prolong her suffering (Carney et al., 2019; Draper, 2000; Giordano, 2005; Goldner et al., 1997; Vandereycken & Beumont, 1998c; Yager, 1992).

These considerations raise a hypothetical question about the patient described by Gans and Gunn Jr (2003) in their vignette. If Mrs Black had been given an opportunity to receive PADs, it may have resulted in a different outcome regarding her suffering (coercion), longevity of illness, recovery and, more importantly, her quality of life while living with AN (Carney et al., 2019). This hypothetical question requires further evaluation and will form much of the discussion in the literature review (see Chapter 5).

1.5 Statement of the Problem

At present, the clinical practice guidelines of the National Institute of Health Care Excellence (NICE, 2017), the APA (2000) and the Clinical Practice Guidelines for the BC Eating Disorders (Geller, Goodrich, Chan, Cockell, & Srikameswaran, 2012) recommend restoring a person’s weight based on ‘operant conditioning’ with the primary objective of reversing malnutrition (Bakker et al., 2011; Golden et al., 2003; Mental Health First Aid Training & Research Program, 2008; Psychotherapy and Counselling Federation of Australia [PACFA], 2011; RANZCP, 2014; Treasure, 2004).

However, these clinical guidelines do not address the long-term effects of SE-AN (Boughtwood & Halse, 2010; Cost & Mehler, 2019; Dresser, 1984c; Geller et al., 2001; Guarda, 2008; Woodside et al., 2016; Yager et al., 2016). As a result, people with SE-AN
continue to exhibit significant eating disorder psychopathology’ (Scholtz, Hill, & Lacey, 2010, p. 396) and therefore experience frequent relapses (Fassino & Abbate-Daga, 2013; Guarda, 2008; Williams, Dobney, & Geller, 2010; Wonderlich et al., 2012). For a more detailed explanation, see Section 2.8.

In an attempt to redress this problem, this research project will develop a collaborative decision-making model (an intervention tool) that emphasises patient treatment preferences. Although there are only a few models in the professional literature on AN, none of them have been specifically designed to address or resolve the ethical concerns relating to the care of people with SE-AN when ADs have been used, and this represents a significant gap in the professional literature on anorexia (Tierney, 2008; Vandereycken & Beumont, 1998c).

### 1.6 Purpose and Significance of the Study

The purpose of this grounded theory (GT) study is to develop an ethical decision-making model, framed under the auspices of ADs, to enable people with SE-AN to nominate their own treatment preferences should they lose mental competency or experience a relapse.

The significance of this ethical decision-making model is that it will improve healthcare for people with SE-AN, provide clinical direction to clinicians in developing more collaborative ways to assist people in their recovery and health, give people more responsibility and ownership of their mental health issues, engender a culture of mutual respect and power balance, and empower marginalised people in their emancipation from psychiatric care. An important feature of this model is that it can be applied to a wide range of clinical settings and populations, including males and minors.

### 1.7 Scope

The scope of this study will be limited to adult women who have been formally diagnosed as having, or having had, SE-AN, and who have experienced inpatient psychiatric care. While the prevalence of eating disorders in males has increased in recent years, women
remain more highly represented (Garner & Garfinkel, 1997; Hepworth, 1994). For this reason, only women have been selected for this research.

1.8 Aim and Objectives of the Research

The overall aim of this study is to develop an ethical decision-making model based on the research data. This study has a number of objectives:

a. to give a ‘voice’ to patients who are experiencing from SE-AN

b. to encourage practitioners to think ethically and explore the ethical dimensions of decision-making processes when caring for women with SE-AN

c. to enhance the collaborative alliance between all key stakeholders (e.g., consumers and clinicians) using PADs

d. to examine the literature regarding the utility of PADs in reducing the effects of coercion

e. to identify the need to develop an ethical decision-making model.

1.9 Research Approach

The purpose of this study is to explore and understand the ‘lived experiences’ of adult women with SE-AN who had been admitted to hospital care (Creswell, 2013; Denzin & Lincoln, 2011). To better understand this phenomenon, a constructivist–interpretivist approach, underpinned by a symbolic interactionalist framework, will be applied to the research (Bryman, 2012; Crotty, 1998; Denzin & Lincoln, 2008; Patton, 2015).

In addition, GT will be used to analyse the data and inductively build a theoretical model (Bloomberg & Volpe, 2012; Corbin & Strauss, 2014; Whitman & Woszczynski, 2004). This research design aims to address the central research question and the stated aims and objectives of the study (Evans, Gruba, & Zobel, 2011; Oliver, 2013).
1.10 Formulation of Research Questions

According to Creswell (2013), qualitative researchers should have an overarching central question that will enable them to address the proposed research problem. Others suggest that the research question should be open-ended and broad (i.e., does not limit the views of participants) (Bluff, 2005; Bryman, 2012; Chenitz & Swanson, 1986a; Corbin & Strauss, 2014; Creswell, 2013; Holloway, 2008), clear and concise (avoid ambiguities) (Barker & Pistrang, 2015; Bloomberg & Volpe, 2008), enable the investigator to explore phenomena of interest with flexibility and depth (Bloomberg & Volpe, 2015; Charmaz, Thornberg, & Keane, 2017; Corbin & Strauss, 2014), and, more importantly, help guide the researcher to develop a substantial theory that is reflective of the participants’ perspectives (Corbin & Strauss, 2014; Holloway, 2008; O’Donoghue, 2006).

The research question of whether an ethical decision-making model that uses ADs can minimise the effects of coercion in psychiatric care for adult women ‘living’ with chronic AN will initially be broad, but it will undergo a refining process and become more focused during the course of the study (Barker & Pistrang, 2015; Bloomberg & Volpe, 2008; Carpenter & Suto, 2008; Charmaz, 2006, 2008a; Corbin & Strauss, 2014; Hennink, Hutter, & Bailey, 2010).

Maxwell (2012) explained that researchers tend to have sufficient theoretical knowledge about the research problem to formulate a provisional research question, but he argued that this knowledge (or source of concern) becomes clearer when a significant part of the research is completed—that is, the literature review. He encouraged researchers to interact with the literature and spend time with participants to obtain a feel for the research problem in order to design a research question that will provide clarity around the purpose and conceptual context of the research.
In addition to the principal research question, a number of sub-questions have been designed to explore further aspects of the phenomenon (Creswell, 2013). These include:

a. How do women construct knowledge about living with SE-AN through interactions with healthcare professionals?

b. How do women interpret their experiences of hospitalisation?

c. What is the relationship (social psychological process) between coercion and its effect on a patient’s autonomy?

d. What does decision-making mean to healthcare practitioners?

1.11 Overview of the Thesis

A key element in writing a well-structured thesis is to deliver a unified narrative (Evans et al., 2011; Holloway, 2008). This thesis comprises 10 interlinked chapters and is presented in a traditional monograph format and in chronological order. It consists of numbered headings and subheadings, as well as tables that present results and figures that illustrate concepts (Bloomberg & Volpe, 2008; Evans et al., 2011; Holloway, 2008; Morrow, 2005; Oliver, 2013). The layout of the thesis is outlined below.

Chapter 1 provides an overview of the ethical reasons for and against involuntary treatment, and it provides a brief description of the significance, purpose, statement problem, scope, objectives, design, and research questions of the study. Chapter 2 presents clinical background information regarding the history, aetiology, epidemiology, prevalence and definition of SE-AN, as well as the treatment modalities. Chapter 3 outlines the ethical principles and values that will form the framework of the thesis.

Chapter 4 and Chapter 5 are divided into two sections—the ethical debate and PADs. They explore the underpinnings of the philosophical debate and describe the different models of ADs and their utilisation and potential barriers. Chapter 6 explores the
philosophical underpinnings of constructivism, symbolic interactionism, reflexivity and phenomenology. It defines GT, justifies its use and identifies its strengths and limitations.

Chapter 7 outlines the ethical considerations, participant sample and recruitment process, data gathering strategies, and analysis and interpretation procedures. Chapter 8 presents the key findings (themes) of the thesis, while Chapter 9 discusses the interpretations of the findings. Finally, Chapter 10 presents the ethical model and explains the decision-making process and the model’s potential use as a collaborative tool to reduce the use of coercive measures. It also discusses whether the research aims have been met.

1.12 Conclusion

This chapter has provided an overview of the research problem and methodology, as well as a brief outline of the chapters presented in this thesis. This study proposes that PADs can resolve the ethical dilemma of treatment compulsion and thereby reduce the iatrogenic effects (coercion) of psychiatric care. This study can be considered a conduit to advance the principles of autonomy and beneficence within this discordant debate.
Chapter 2: Background

2.1 Introduction

The focus of this chapter is twofold. First, it explores the clinical characteristics of AN, including its history, definition, classification, epidemiology and aetiology. Second, it provides a general overview of the treatment modalities used to assist patients with SE-AN.

2.2 History of Anorexia Nervosa

AN has puzzled health professionals for many decades, and it remains an ‘enigmatic’ condition that is not fully understood by the scientific community (Bruch, 1974; Dresser, 1984b; Finelli, 2001; Schmidt & Treasure, 2006; Strober, 2004; Walsh, 2013). Even people with AN are bewildered, and they experience contradictory feelings about their illness (Bruch, 1974; Crisp, 1995; Fox, Ward, & O’Rourke, 2005; Geller et al., 2001; Giordano, 2005; Rance, Clarke, & Moller, 2017; Strober, 2004; Tan et al., 2003a).

Some theorists have attempted to unravel the complexities of the condition by offering a range of interventions, including cognitive behaviour therapy (CBT; Beck, 1976), psychodynamic therapy (PT; Freud, 1961) and interpersonal psychotherapy (IPT; Klerman, Weissman, Rounsaville, & Chevron, 1984), but there have been no significant breakthroughs apart from family therapy—Maudsley Model for Treatment of Adults with Anorexia—in the treatment of the illness (Finelli, 2001; Hsu, 1990; Tinker & Ramer, 1983; Walsh, 2013).

According to Silverman (1997), the word ‘anorexia’ first appeared in the medical literature in the seventeenth century, when Richard Morton (1689), an English physician, reported two cases of ‘Nervous Consumption’ (p. 3). Subsequent publications by Sir William Gull (1874) and Professor Ernest-Charles Lasègue (1873) reported similar findings (Finelli, 2001; Orbach, 1986; Selvini-Palazzoli, 1978; Silverman, 1997).

Gull published a paper in 1874 in which he described three cases of women who presented with unexplained weight loss symptoms and referred to their condition as ‘Apepsia
hysteria’ (Bruch, 1966, 1974; Gull, 1874; Hepworth, 1999; Hsu, 1990; Moncrieff-Boyd, 2016; Pearce, 2004; Selvini-Palazzoli, 1978; Walsh, 2013). Professor Ernest-Charles Lasègue also published a paper on the topic of anorexia, which described AN as ‘hysteria of the gastric centre’ (Lasègue, 1873; Striegel-Moore & Bulik, 2007, p. 182). Interestingly, both men regarded the illness as a ‘psychogenic affliction’ that predominately affected girls and young women (Hepworth, 1994).

Morton (1689), Lasègue (1873) and Gull (1874) were pioneers in identifying symptoms of AN—namely, constipation/diarrhoea, bradycardia/tachycardia, loss of appetite, emaciation, low body temperature, oedema and lanugo/hair loss—all of which are attributed to the starvation effects of the disorder and considered relevant in defining AN (APA, 2013).

Gull (1874) referred to the ‘mental perversity’ of individuals experiencing AN and suggested that the illness is characterised by a morbid mental state (Hepworth, 1999). He stated that ‘the want of appetite is, I believe, due to a morbid mental stage’ (Gull, as cited in Garner & Garfinkel, 1997, p. 5). Similarly, Morton described one of his patients with anorexia as ‘a skeleton only clad in skin’, who died from ‘a multitude of cares and passions of the mind’ (Morton, as cited in Lemma-Wright, 1994, p. 3). However, Hilde Bruch (1979), a German-born psychoanalyst, found that the pathological fear of obesity is pervasive among patients with eating disorders and is linked to body image distortion (Pearce, 2004; Striegel-Moore & Bulik, 2007).

These insights suggest that biological and psychological factors influence the illness. These early papers were influential in the twentieth century and were later used to define and categorise AN in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (Hepworth, 1999).
It is worth noting that Morton was the first physician to recognise AN in males (Bruch, 1974; Crisp & Burns, 1983; Dally, 1969; Lemma-Wright, 1994). AN was first recognised in Australia in the 1880s (Vandereycken & Beumont, 1990).

### 2.3 Diagnosis and Classification

According to Brewerton and Dennis (2016), ‘eating disorder (ED) diagnoses are fluid and exist on a continuum’ (p. 28). Thus, some authors have defined ‘anorexia’ based on the severity and chronicity of the illness (APA, 2013).

Some patients marginally develop the illness with few symptoms (single episode), and the illness subsequently resolves itself without ever being formally diagnosed (Andersen, 2007; Crisp, 1995; Melamed et al., 2003; Stuhldreher et al., 2012; Wildes et al., 2016). With other patients, it may be recurrent, lasting a few years (mild anorexia) and with frequent relapses (APA, 2013; Dresser, 1984b; Gans & Gunn Jr, 2003; Palmer & Treasure, 1999; Wildes et al., 2016). In some cases, SE-AN can be longstanding and can dominate a person’s life for decades, causing significant social morbidity, irreversible damage and even death (Campbell & Aulisio, 2012; Gans & Gunn Jr, 2003; Hay & Touyz, 2015; Hay et al., 2012; Palmer & Treasure, 1999; Werth Jr et al., 2003; Yager, 1992).

Despite these differences, the current classification system that is used to define AN is the DSM-5 (see Appendix I) (APA, 2013) and the International Classification of Diseases (ICD-10) (WHO, 2004), both of which describe the clinical presentations of disorders and their related signs and symptoms (Franko, Wonderlich, Little, & Herzog, 2004; Striegel-Moore & Bulik, 2007).

Although these classification systems are a standard diagnostic tool used to categorise eating disorder cases, there is heterogeneity in their presentations—for example, gender and cultural diversity, severity of illness, and idiosyncratic characteristics of patient groups (adult v. paediatric, dizygotic v. monozygotic twin populations)—therefore, they are not applicable
to each individual or subgroup (Anderson-Fye & Becker, 2004; Campbell & Peebles, 2014; Crisp et al., 1977; Eddy et al., 2008; Fairburn & Cooper, 2011; Melamed et al., 2003; Striegel-Moore & Bulik, 2007; Striegel-Moore & Smolak, 2002; Strober, 1980, 2004; Theander, 1985). Currently, DSM-5 offers no official recognition of SE-AN.

Further, a person’s eating disorder diagnosis may change over time. For instance, a person may have a primary diagnosis of AN but may later be diagnosed with binge eating disorder (BED) or vice versa (Achamrah et al., 2016; APA, 2013; Fichter, Quadflieg, & Hedlund, 2006; Hsu, 1990; Smith, Zuromski, & Dodd, 2018; Srinivasagam et al., 1995; Walsh & Garner, 1997; Wonderlich et al., 2012). A longitudinal study spanning seven years found that the majority of female participants (72.73%) experienced some form of diagnostic crossover (Eddy et al., 2008). This has important therapeutic implications for clinicians in that they may find it difficult to predict treatment outcomes and benefits, select appropriate patient treatments and conduct positive diagnoses (Dresser, 1984b; Goldner et al., 1997; Hsu, 1990; Kirkpatrick et al., 2019; Radu et al., 2016). To mitigate these concerns and ensure an accurate diagnosis and proper treatment, the APA recommends diagnosing a person’s eating disorder based on their current symptoms.

2.4 Aetiology of Anorexia Nervosa

There is a considerable amount of literature on the causes and effects of anorexia, and scholars have offered convincing theories and evidence to support their claims (Steinhausen, 2009; Striegel-Moore & Bulik, 2007). Most scholars have broadly conceptualised SE-AN within the ‘general’ AN population because the clinical features between the two groups are similar (Striegel-Moore & Smolak, 2002). However, the following analysis regarding the aetiology of SE-AN has been extracted from the general eating disorder literature.

The general consensus within the medical and psychiatric literature is that there is no single factor or event that causes an eating disorder; rather, it is a multifactorial problem
comprising sociocultural, biological and psychological factors (Andersen, 2007; Cooper, 1995; Finelli, 2001; Hsu, 1990; Khalafzai, 2009; MacDonald, 2002; Nevonen & Broberg, 2000; Phillipou, Musić, & Lee Rossell, 2019; RANZCP, 2014; Striegel-Moore & Smolak, 2002; Weigel et al., 2015).

2.4.1 Physical consequences of severe and enduring anorexia nervosa

The APA (2013) defined AN as a physical and a psychiatric condition. Therefore, the aetiology of eating disorders consists of a number of biological and psychosocial factors, as shown in Table 2.1 (Fassino & Abbate-Daga, 2013; Redenbach & Lawler, 2003; Steinhausen, 2002; Uher et al., 2003). However, these factors may not be applicable to all patients.

Table 2.1

<table>
<thead>
<tr>
<th>Psychological</th>
<th>Physiological</th>
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<tbody>
<tr>
<td>Anxiety</td>
<td>Amenorrhoea</td>
</tr>
<tr>
<td>Depression</td>
<td>Dry skin</td>
</tr>
<tr>
<td>Mood swings</td>
<td>Lanugo (fine hair growth)</td>
</tr>
<tr>
<td>Irritability</td>
<td>Polyuria (excessive passage of urine)</td>
</tr>
<tr>
<td>Social withdrawal</td>
<td>Fatigue (exhaustion and tiredness)</td>
</tr>
<tr>
<td>Food preoccupation</td>
<td>Paraesthesia (pins and needles)</td>
</tr>
<tr>
<td>Poor concentration</td>
<td>Hypotension (low blood pressure)</td>
</tr>
<tr>
<td>Hypersensitivity to noise</td>
<td>Sinus bradycardia (slow heart rate)</td>
</tr>
<tr>
<td>Obsessional thinking and increasing</td>
<td>Reduced gastric mobility (decrease in</td>
</tr>
<tr>
<td>perfectionism</td>
<td>intestinal motility)</td>
</tr>
</tbody>
</table>


Collectively, these symptoms demonstrate that AN is a life-threatening illness and can affect patients’ quality of life (Campbell & Aulisio, 2012; Cost & Mehler, 2019; Herpertz et al., 2011).

NICE (2017) stated that these specific medical markers may indicate medical instability, thereby providing a framework to make clinical ‘decision-making for people with
eating disorders (in particular when deciding whether to admit someone, whether to use compulsory care and how to provide nutrition)’ (p. 39).

People with SE-AN routinely engage in a variety of self-harming behaviours such as restricted food intake, abuse of laxatives, self-inflicted vomiting and excessive exercising (APA, 2013; Bruch, 1979; Draper, 2000; Matusek & Wright, 2010; Mental Health First Aid Training & Research Program, 2008; Stice, 2001; Striegel-Moore & Smolak, 2001). These self-harming behaviours can lead to cardiac arrhythmia, electrolyte imbalance, sudden organ failure and osteoporosis—and in some cases, infections (e.g., bronchial pneumonia and sepsis) can result in premature death (Dresser, 1984b; Geppert, 2015; Giordano, 2010; Hay et al., 2012; Redston et al., 2014; Walsh, 2013; Werth Jr et al., 2003; Zipfel, Löwe, Reas, Deter, & Herzog, 2000). These symptoms can impair a person’s cognitive functioning as a result of prolonged periods of starvation, causing significant neuropsychiatric disturbances (Garner & Garfinkel, 1997; Holm et al., 2012; Silber, 2011; Sjöstrand & Helgesson, 2008; Treasure & Russell, 2011; Woolsey, 2002).

Keys, Brožek, Henschel, Mickelsen and Taylor (1950) conducted a research experiment during World War II involving 32 young, healthy men for a period of six months. They found an association between a decrease in body mass index (BMI) and a change in physical, psychological and social functioning, and these symptoms are consistent with those found in eating disorders (Fedyszyn & Sullivan, 2007; Walsh, 2013). The symptoms include a preoccupation with food, obsessional ruminations, lack of concentration, decreased sexual libido, irritability, social withdrawal, low mood, depression and anxiety (APA, 2000; Carney, Tait et al., 2006; Garner & Garfinkel, 1997; Ogburn, 1951).

Those who have experienced anorexia for a protracted period of time are susceptible to serious long-term medical complications. These include, but are not limited to, damage to internal organs (e.g., liver), deterioration of teeth and gums, osteoporosis (particularly for
women), chronic renal dysfunction, hair and skin changes (e.g., loss of scalp hair or growth of hair), changes to the composition of the brain (i.e., reduced brain size) and long-term sleeping difficulties (Calugi, El Ghoch, & Dalle Grave, 2017; Dally, 1969; Gans & Gunn Jr, 2003; Orbach, 1986; Redston et al., 2014; Touyz & Beumont, 1985; Treasure, Cardi, Leppanen, & Turton, 2015; Zipfel et al., 2000).

Early intervention can reduce the effects of these long-term medical complications, reduce mortality, reduce the duration of the illness and improve the prognosis and treatment outcomes (Agras et al., 2004; Campbell & Peebles, 2014; Elzakkers et al., 2014; Natt, 2018; NICE, 2017; Steinhausen, 2002; Turrell et al., 2011; Walsh, 2013).

It is important for health professionals to arrange a ‘medical risk assessment’ at regular intervals during the course of treatment to determine the severity of the patient’s physical and psychological states (Andersen, 1992; Strober, 2004; Woodside, 2002). The patient should attend weekly check-ups with their general practitioner (GP), or preferably a psychiatrist, along with a follow-up appointment to monitor their general progress and weight—namely, BMI weight [kg]/height [m]$^2$ (APA, 2013; Andersen, 1992; RANZCP, 2014; Steinhausen, 2002). If there are any ethical or legal concerns about a patient’s health and welfare, clinicians should consult their relevant national guidelines (APA, 2006; NEDC, 2010; NICE, 2017; PACFA, 2011; RANZCP, 2014).

2.4.2 Psychological consequences of severe and enduring anorexia nervosa

People with chronic anorexia fit the well-known saying ‘revolving door syndrome’, which describes a person who has frequent hospital admissions and continues to experience chronic symptoms for years without relief (Gallagher, 1998; Guarda & Heinberg, 2004; Wonderlich et al., 2012). To illustrate this notion, SE-AN people typically experience an earlier onset of the illness, are admitted to hospital more often, are at higher risk of self-harm and suicide, have a higher rate of comorbid conditions, struggle to maintain social
relationships, and have issues with self-esteem and perfectionism (Ayton et al., 2009; Burrows, Beumont, & Casper, 1987; Lacey & Sly, 2016; Noordenbos, Jacobs, & Hertzberger, 1998; Ramsay, Ward, Treasure, & Russell, 1999).

This section will focus on these psychological factors. Although some factors will be discussed in more detail than others, this does not mean that they are less important. According to Moons, Royston, Vergouwe, Grobbee and Altman (2009), identifying prognostic factors can help in understanding the illness—particularly in relation to diagnosis, treatment decision-making, therapeutic outcomes and predicting risk factors in specific individuals. Thus, this section will provide the necessary background information on the risk factors so that health professionals can develop an understanding of SE-AN and therefore conceptualise the aetiology of the disorder.

Although there is little empirical data to support the following claims (Bastiani, Rao, Weltzin, & Kaye, 1995; Kirkpatrick et al., 2019; Stice, 2002), they continue to be of interest to investigators seeking to understand the nature of eating disorders (Errichiello, Iodice, Bruzzone, Gherghi, & Senatore, 2016; Mitchison & Hay, 2014; Pike et al., 2008; Stice, 2002). Each factor will now be considered in turn.

2.4.2.1 Social adjustment

Treasure et al. (2015) reported that people with SE-AN experience pervasive interpersonal difficulties, which means that they struggle to maintain a reasonable quality of life. Many of them quit their job or educational pursuits and become dependent on government benefits (APA, 2013; Calugi et al., 2017; Carney et al., 2019; Hay et al., 2012; RANZCP, 2014; Redston et al., 2014; Theander, 1985; Touyz et al., 2013; Zipfel et al., 2000). They often rely on carers and loved ones (e.g., parents, siblings and spouse) to support and take care of them during periods of severe illness (Treasure et al., 2001). However, they have difficulty in maintaining trusting relationships, and their relationships are often strained.
and result in a loss of friends and partners (Crisp, 2005; Halmi, 2013; Lacey & Sly, 2016). Some people with SE-AN do not have immediate family or friends and are completely reliant on the mental health system. They experience isolation and loneliness, express unhappiness and have problems with social integration (APA, 2013; Button & Warren, 2001; Conti, Rhodes, & Adams, 2016; Finelli, 2001; Fox & Diab, 2015; Gans & Gunn Jr, 2003; Löwe et al., 2001; Noordenbos et al., 2002; Ratnasuriya, Eisler, Szmukler, & Russell, 1991; Theander, 1985).

In rare cases, some people with SE-AN remain reclusive, estranged from family and friends, and simply wither away and die in their home (Holm et al., 2012; Lemma-Wright, 1994; RANZCP, 2014). One epidemiological study reported that up to 50% of these patients were undetected in the medical system (Keski-Rahkonen et al., 2007).

There is some evidence to support the proposition that people with SE-AN have greater severity of social impairment. For example, Tchanturia et al. (2013) found that social impairment was significantly greater among patients with SE-AN when compared with a healthy control group. A psychometric instrument (Work and Social Adjustment Scale) was used to measure patients’ perceptions of social impairment. In all measured variables, ‘social leisure’ registered the highest score (mean score = 6.26/8), while ‘home management’ was rated the lowest (mean score = 3.53/8) in people with AN. These results confirmed that people with AN experience greater severity of social impairment (fewer social contacts and social outings such as parties and social/community clubs) than people without mental health problems. The study also established that an increase in the severity of the eating disorder symptoms is a predictor of increased social morbidity. Put differently, increased severity of symptoms is correlated with a decrease in social functioning. This suggests that patients with SE-AN struggle to maintain ‘basic occupational and functioning’.
A similar finding was reported by Robinson, Kukucska, Guidetti and Leavey (2015), who interviewed eight participants with SE-AN, with illness duration between 20 and 40 years. They discovered that all participants experienced difficulty in sustaining employment, either on a short or long-term basis. The study identified three important factors that were responsible for lack of employment: psychological problems, poor working relationships and regular hospitalisation. The authors concluded that SE-AN is a chronic illness that requires ‘constant attention’ (i.e., concentrating on thinness), which interferes with patients’ day-to-day functioning, including work and social commitments.

Conversely, Russell et al. (2019) found that a prolonged duration of SE-AN does not necessarily mean that a person does not have the ability to function on a day-to-day basis. Some people have the capacity to work or go to university while maintaining their professional career without too much disruption. This is despite the fact that they have ‘poor self-care’ and a ‘narrow focus’ to their life (Russell et al., 2019, p. 5). That is, people can function and maintain a ‘normal’ life at a relatively low BMI for many years without encountering serious medical complications. This is in contrast with the results reported by Bamford and Sly (2010), which showed that severity of illness (low BMI) among patients with eating disorders (N = 156) is a predictor of poor quality of life, but duration of illness is not associated with a lower quality of life.

These studies show that there is variability in people’s ability to cope with the illness; thus, professionals should refrain from making statements that could potentially stigmatise people as being inherently ‘sick’ and having no capacity for self-management (Skårderud, 2007). In short, severity and duration of the illness does not necessarily cause ‘social functional limitation or disablement’ (Peters, 2015, p. 1); rather, the association is arbitrary.

The above findings are consistent with the ‘functional consequences of anorexia nervosa’ found in DSM-5 (APA, 2013).
2.4.2.2 Substance abuse and comorbidities

Social adjustment problems have also been identified as a predictive variable in higher rates of substance abuse, depression and mortality among people with SE-AN (Franko et al., 2013). People with SE-AN often experience long-term depression and/or anxiety, along with periods of alcohol or drug dependency, which can reduce their quality of life (Agras et al., 2004; Cole, 2015; Garner & Garfinkel, 1997; Goldbloom, 1993; Hannon, Eunson, & Munro, 2017; Steinhausen, 2002; Werth Jr et al., 2003; Wilson, 2002).

Symptoms of depression can vary from mild to severe and mainly consist of mood swings, social withdrawal and irritability (APA, 2013). Substance abuse can exacerbate eating disorder symptomology and prolong the course of the illness (Lacey & Sly, 2016; Wolfe & Maisto, 2000). In some cases, severe depression can lead to suicidal thoughts (Franko & Keel, 2006; Franko, Keel et al., 2004).

A retrospective chart analysis was conducted with eating disorder patients to compare differences between substance users (SUs, n = 122) and non-substance users (NSUs, n = 81) (Kirkpatrick et al., 2019). SUs showed significant differences in most examined variables. They were female (96%), regular drug users (60%), diagnosed with purging behaviours (33.4%), at risk of self-harming (57%) and more likely to drop out of treatment (41.4%).

Overall, these results suggest that women with eating disorders and substance abuse issues are less likely to respond to treatment and therefore more likely to drop out of ongoing treatment. Particular emphasis should focus on ‘emotional dysregulation’ and ‘impulsivity’ with regard to mitigating the effects of substance abuse but also to enhance treatment adherence.

The findings of a small qualitative research study involving (N = 5) patients with SE-AN found a positive correlation between SE-AN and comorbidities. Of the five patients, four had significant comorbidities, including mood and personality disorders, with reported rates
from ‘deterioration to improvement’ (Hannon et al., 2017). Although the sample was small, it highlighted that people with SE-AN are vulnerable to other forms of mental disorders, which can contribute to high rates of morbidity.

Kaye et al. (2004) investigated the relationship between comorbidities and eating disorders. Approximately two-thirds of the participants experienced one or more forms of comorbid anxiety disorder, with most participants suffering from obsessive compulsive disorder (OCD). Thompson-Brenner et al. (2008) reported a higher rate of substance abuse among females with an eating disorder when compared with the general population. A recent meta-analysis of 43 studies estimated that lifetime prevalence rates of comorbid substance abuse among patients with eating disorders have increased from 7.7% to 21.9%, with alcohol being the most commonly used drug (Bahji et al., 2019). It has been suggested that individuals with SE-AN who also have substance abuse problems often experience being ‘out of control’ (Lacey & Sly, 2016, p. 207)—‘control’ being the operative word—and is synonymous with the SE-AN identity (Tan, Hope, Stewart, & Fitzpatrick, 2003). These figures reflect global concerns regarding the relationship between mental health issues and the rise of substance abuse, which has been attributed to people’s way of coping with the negative emotional aspects of living with the illness—for example, drinking to ‘numb difficult emotions’ (Bahji et al., 2019; Geller et al., 2012; Pike, Devlin, & Loeb, 2004; Wilson, 2002).

Interestingly, Bahji et al. (2019) found that substance abuse among people with bulimia nervosa (BN) and purging behaviours is significantly higher for females than males. This finding is not consistent with the literature (Kinasz, Accurso, Kass, & Le Grange, 2016), because the data are mixed and there are no definitive conclusions.

Some studies have identified substance abuse—especially alcohol use—as a major contributing factor towards the mortality of people with eating disorders (APA, 2000; Franko et al., 2013; Kask et al., 2016; Keel et al., 2003; Mann, Erford, & Minnich, 2018; Russell et
al., 2019). However, these symptoms may be secondary to the main cause of the illness—namely, starvation (Campbell & Aulisio, 2012; Crisp, 1995; Gans & Gunn Jr, 2003; Lacey & Sly, 2016; Touyz & Beumont, 1985; Werth Jr et al., 2003).

Evidence suggests that clinicians should screen for potential substance abuse in patients with eating disorders (or for differential diagnosis purposes) to assist with care management (APA, 2013; Geller et al., 2012; Keel et al., 2003; Wilson, 2002). In addition, a suicide risk assessment should be part of the screening process, because substance abuse and comorbidities can lead to suicidal ideation in people with eating disorders (Franko & Keel, 2006; Keski-Rahkonen & Mustelin, 2016; Milos, Spindler, Hepp, & Schnyder, 2004).

Further, a referral to a substance abuse program may be warranted to address alcohol and drug dependency issues (Russell et al., 2019).

2.4.2.3 Suicide and self-harm

Suicide is a manifestation of a person’s attempt to be in control of their life (Bruch, 1974). Thus, it is a misconception that people with SE-AN want to end their life by means of suicide or self-harm (Bruch, 1974; Carney, 2009; Fost, 1984; Geppert, 2015; Giordano, 2010; Melamed et al., 2003; Rathner, 1998; Selvini-Palazzoli, 1978; Tiller et al., 1993). Rather, their harming behaviours (e.g., overdosing, laxative abuse and cutting) are responsible for their death (Melamed et al., 2003; Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006; Starzomska, 2006; Tan, Hope, Stewart, & Fitzpatrick, 2006; Werth Jr et al., 2003; Yager et al., 2016). The nature of SE-AN means that it can be a form of ‘passive’ suicide because of the effects of starvation (Milos et al., 2004; Nordbø et al., 2006; Radu et al., 2016; Robertson, 1992).

Suicide is one of the main causes of SE-AN mortality, with lifetime prevalence estimates ranging from 30% to 60%, and it can be either a conscious or unconscious act (Agras et al., 2004; APA, 2013; Ayton et al., 2009; Bulik et al., 2008; Lilenfeld, 2016; Radu
et al., 2016; Selvini-Palazzoli, 1978; Steinhausen, 2002). More often than not, individuals—particularly those with chronic AN—die as a result of medical complications of the illness such as low potassium levels and sudden cardiac arrhythmia; thus, an unconscious act (APA, 2013; Goldner, 1989; Löwe et al., 2001; Mann et al., 2018; Mehler & Andersen, 1999; Palmer & Treasure, 1999; Rathner, 1998; Ratnasuriya et al., 1991; Starzomska, 2006; Vandereycken & Beumont, 1998c; Ward, Ramsay, Russell, & Treasure, 2015). In contrast, some individuals actively attempt suicide and use lethal means, such as an intentional overdose, in a conscious act (Ayton et al., 2009; Bulik et al., 2008; Lacey & Sly, 2016; Manley & Leichner, 2003; Radu et al., 2016; Smith et al., 2018).

A meta-analysis of previously published research (spanning 1966–2010) on the risk of suicide found that patients with SE-AN were 18 times more likely to die from suicide than young women aged 15–34 in the general population (Keshaviah et al., 2014). A similar finding was reported by Smith et al. (2018), who found that suicide in SE-AN patients was 18 times higher when compared with individuals with BN, who were seven times more likely to die from suicide. Keel et al. (2003) reported a higher crude mortality rate of suicide in patients with AN compared with patients with BN (7.4% v. 0.9%).

In comparison, a small study involving five cases of people with AN revealed that suicide was not a contributing factor. Rather, these deaths (n = 4) resulted from the severity of illness (10-year duration of illness), psychiatric comorbidity and early hospital discharge (Holm et al., 2012). These results were consistent with a previous report by Favaro and Santonastaso (1997), who reported higher rates of suicide among AN patients who were older, had a long duration of the illness and had previous failed treatments when compared with non-attempters. In a meta-analysis, Arcelus, Mitchell, Wales and Nielsen (2011) reported that major depression was a contributing factor to suicide among people with anorexia, with an overall estimated ratio of 20% of deaths. These studies demonstrate that
there are psychological and social factors—not just physical factors—that contribute to suicide rates.

It has been reported that self-injurious behaviours (SIBs) are common among people with SE-AN, and they are often carried out as a means to regulate their emotions (Brewerton & Dennis, 2016; Lacey & Sly, 2016; Smithuis et al., 2018). SIB can involve shallow or deep cutting, scratching, bruising, hair pulling, biting, burning and swallowing batteries (not a common occurrence), with cutting being the most reported behaviour (Brewerton & Dennis, 2016; Lacey & Sly, 2016; Smithuis et al., 2018).

Smithuis et al.’s (2018) recent quantitative study of eating disorder patients with a diagnosis of SE-AN or an eating disorder not otherwise specified (EDNOS) ($N = 136$, mainly females 96%) reported high rates of SIBs. Of those, 41% reported an SIB at a one-month prevalence rate, while 83% had a long history of outpatient psychiatric treatment, 55% had some type of psychiatric diagnosis and, interestingly, 31% lived alone. Fifty-nine per cent of patients reported ‘cutting’ as their preferred type of SIB. In all subcategories, the most frequently cited reasons for SIBs were ‘to avoid negative feelings’, ‘to punish myself’ and ‘to get attention from others’. Based on these findings, it can be concluded that female patients who have an anorexia diagnosis, a history of psychiatric care and a comorbidity diagnosis are at greater risk of SIBs when compared with patients without SIBs. Eating disorder clinicians should undertake a detailed examination of SIBs with an aim of reducing the emotional distress associated with them. It is important to have conversations with patients to identify potential triggers of SIBs, be better informed and understand the consequences (Smithuis et al., 2018). This, in turn, might help to reduce the severity of eating disorder symptoms.

Shame has been linked with both SIBs and eating disorders (Crisp, 2005; Skårderud, 2007). A qualitative study by Skårderud (2007) explored the role of shame and its effects on the lives of 13 women aged 16–19 who were diagnosed with anorexia. The study identified
two subcategories—‘loss of control’ and ‘self-destructive behavior’—that were interlinked with the category of shame. Two participants expressed their shame through acts of non-suicidal behaviours such as cutting and alcohol abuse. These theoretical constructs were linked to the core theme of lack of control, whereby all participants felt unable to manage their illness and self-destructive behaviours, and as a result, they experienced guilt and self-blame. Similarly, a recent phenomenological study by Verschueren et al. (2015) found that SIBs were associated with patients’ eating disorders, which contributed to their shame. The overarching theme of the study was that participants felt a ‘lack of control’. Recently, thematic analysis was conducted on semi-structured interviews with 12 women (11 formally diagnosed) with anorexia who considered themselves recovered or in recovery (Rance, Clarke et al., 2017). The results of the study generated three major themes: shame, solitude and salvation. Shame was defined by participants as self-disgust, self-hatred and inadequacy, and it was described as having a negative effect on their recovery. A key finding from the study was that participants felt that their shame was being controlled by others rather than being in control of their SE-AN. This sense of a lack of control perpetuated negative feelings such as ‘confusion’ and ‘hopelessness’, which exacerbated their eating disorder, and they believed that they had failed to manage their SE-AN. Similarly, Hannon et al. (2017) reported that longer duration of treatment failure was associated with an increase in hopelessness.

Several predictors were associated with suicide and self-harm, including comorbid psychiatric diagnoses such as depression and substance abuse (Agras et al., 2004; Bulik et al., 2008; Keel et al., 2003; Keshaviah et al., 2014; Lilenfeld, 2016; Milos et al., 2004; Smith et al., 2018; Strober, 2010), history of physical and/or childhood sexual trauma (APA, 2000; Beumont, 2013; Bulik et al., 2008; Favaro & Santonastaso, 1997; Franko & Keel, 2006), history of suicide attempts (Bulik et al., 2008; Milos et al., 2004), experienced shame (Crisp, 2005; Rance, Clarke et al., 2017; Skårderud, 2007; Verschueren et al., 2015), previous failed
attempts at treatment (Favaro & Santonastaso, 1997), chronic disease (Lilenfeld, 2016; Radu et al., 2016) and being female (Keel et al., 2003).

As a result, and given the nature of the illness, AN has one of the highest mortality and morbidity rates among Western psychiatric conditions (Garner & Garfinkel, 1997; Keshaviah et al., 2014; Steinhausen, 2002; Strober, 2004; Strober, 2010; Tan et al., 2003a; Thiels, 2008; Werth Jr et al., 2003). For this reason, eating disorder clinicians should conduct regular suicide risk assessments to determine the degree of severity, intent to die, current and prior suicide attempts, and the patient’s state of mind—that is, they should identify signs of depression and hopelessness (APA, 2013; Appelbaum & Rumpf, 1998; Bulik et al., 2008; Goldner et al., 1997; Lilenfeld, 2016; Smith et al., 2018; Strober, 2010; Westmoreland & Mehler, 2016).

2.4.2.4 Sociocultural factors

Dresser (1984b) stated that sociocultural explanations challenge the common assumption that anorexia is a mental disorder that is primarily caused by biological or behavioural factors. One large study tested this theory by examining the views of health clinicians (dentists n = 4,282) to determine its validity. It found that both psychological (92%) and sociocultural factors (75%) were perceived to be the main causes of the illness, whereas hereditary and biological factors (9% and 8%) were the least probable causes (Johansson, Nohlert, Johansson, Norring, & Tegelberg, 2009). These results confirm and support previous reports showing that anorexia is not a biological disorder; rather, it is determined by sociocultural factors (APA, 2000; Harvey & Robinson, 2003; Levine & Harrison, 2004; Mitchell & Eckert, 1987; Murray, Rieger, Karlov, & Touyz, 2013; Schwartz, Thompson, & Johnson, 1982; Striegel-Moore & Smolak, 2002). This suggests that attitudes could be modified and, in turn, could reduce the prevalence of eating disorders (Mitchell & Eckert, 1987).
It is becoming increasingly evident, especially in Western societies, that sociocultural models (e.g., family, peers and media such as television and social media) that promote the ‘thin ideal’ can markedly influence social norms regarding body shape and image. Specifically, they can change how people perceive ‘beauty ideals’ and can, particularly with adolescents (Kirkpatrick et al., 2019), profoundly affect their attitudes (APA, 2013; Andersen, 2007; Bruch, 1966; Crisp, 2005; Garner & Garfinkel, 1997; Kirkpatrick et al., 2019; Knauss & Schofield, 2009; Lawrence, 1979; Lemma-Wright, 1994; Midlarsky & Nitzburg, 2008; Stice, 2002; Striegel-Moore & Bulik, 2007; Thompson, 2004).

For example, the beauty ideal for men is a strong, muscular, lean physique (Harvey & Robinson, 2003; Murray et al., 2013; Weltzin, 2016), whereas women are objectified (sexualised) with an emphasis on being thin (Garner, 1997; Giordano, 2005; Hepworth, 1999; Maine, 1985; Orbach, 1986; Striegel-Moore & Smolak, 2002; Zanetti, 2013). These gender-specific attitudes are internalised through a process of socialisation from early childhood and adolescence and are carried through to adulthood, and they can lead to significant body dissatisfaction (Hepworth, 1999; Keel & Forney, 2013; Keski-Rahkonen & Mustelin, 2016; Levine & Harrison, 2004; Stice, 2002; Striegel-Moore & Bulik, 2007). These attitudes were confirmed by a qualitative study that used a non-probabilistic sample of \( n = 9 \) females and \( n = 1 \) males. The study found that all of the females wanted to be ‘thin’, whereas the male wanted to be ‘muscular’ (Tierney, 2008). This finding has been verified by larger quantitative studies (Furnham, Badmin, & Sneade, 2002; Kinasz et al., 2016; Radwan et al., 2019).

The pressure to be thin can lead not only to eating disorders (Midlarsky & Nitzburg, 2008), but to other forms of body image problems such as body dysmorphic disorder (BDD) (Grant & Phillips, 2004; Mitchison & Mond, 2015; Olivardia, 2004; Phillipou, Castle, & Rossell, 2019; Wooldridge & Lytle, 2012). One study reported that BDD can exacerbate the
severity of the illness, contribute to earlier onset of the disorder, increase the risk of suicide attempts and lead to more frequent hospital admissions (Grant & Phillips, 2004).

In recent times, pro-anorexia websites such as ‘pro-ana’ and ‘pro-mia’ are becoming increasingly popular forms of online advertisements for the maintenance (perpetuating factors) of eating disorders, and, in some cases, promoting unrealistic body ideals (Bardone-Cone & Cass, 2007; Brewerton & Dennis, 2016; Fairburn & Brownell, 2005; Golden et al., 2003; Orbach, 1986; Smahelova, Drtilova, Smahel, & Cervilicek, 2019; Williams & Reid, 2010). Indeed, these websites are the antithesis of the medical approach of preserving an individual’s life and health (Fox et al., 2005).

Although there is a strong association between sociocultural models and the development of eating disorders, a contention remains: Why do some females develop anorexia while others remain unaffected, even though they are exposed to the same environmental risk factors (Lemma-Wright, 1994)? A similar argument can be made for males, people from different cultures and athletes such as gymnasts and dancers (Garner, 1997; Mitchison & Hay, 2014; Pike et al., 2008; RANZCP, 2014; Striegel-Moore & Smolak, 2002).

One possible explanation for this difference is genetic disposition (APA, 2013; Marzola & Abbate-Daga, 2019; Mitchell & Eckert, 1987; Wade, Bulik, Neale, & Kendler, 2000). Dresser (1984c) added that labelling a person with a ‘mental illness’ automatically assumes that there is an innate predisposition. Therefore, this negates the idea that social pressure is a determining factor that causes the illness. From a biopsychosocial perspective, there has been a lack of research into the ‘biological underpinnings of the condition [AN]’ (Phillipou, Musić et al., 2019, p. 1) to confirm or refute this hypothesis—nature v. nurture—and it remains a controversial debate with no clear consensus (Hannon et al., 2017). It has also been postulated that personality traits such as low self-esteem and perfectionism may
contribute to explaining this difference (Anderluh, Tchanturia, Rabe-Hesketh, & Treasure, 2003; Button, 1993; Keel & Forney, 2013; Kring & Davison, 2007; Marzola & Abbate-Daga, 2019; Wolfe & Maisto, 2000). These theories will now be explored.

2.4.2.5 Self-esteem

Susie Orbach (1986), a psychoanalyst and expert on anorexia, stated that self-esteem is ‘chronically absent’ in people with anorexia (p. 105). The social construct of self-esteem has been broadly defined ‘as a positive or negative attitude towards oneself’ (Adamson, Ozenc, Baillie, & Tchanturia, 2019, p. 1).

In the context of AN, a lack of self-esteem is considered a precipitating factor of the illness and is associated with weight concerns; therefore, it significantly interferes with a person’s treatment and recovery (Adamson et al., 2019; APA, 2013; Bamford, Mountford, & Geller, 2016; Button & Warren, 2001; Frank, 2016; Garner, 1997; Golden et al., 2003; Gowers, Weetman, Shore, Hassain, & Elvins, 2000; Hay & Cho, 2013; Kearney-Cooke & Striegel-Moore, 1997). Further, self-esteem has been identified as a possible risk factor in the development of AN, but there is no solid evidence to support this claim (Adamson et al., 2019).

A person’s perception of their body shape and weight can determine their level of self-esteem (Garner, Vitousek, & Pike, 1997; Higbed & Fox, 2010; Kashubeck-West, Mintz, & Saunders, 2001; Pike et al., 2004). For example, low body weight has been associated with a higher level of self-esteem compared with the perception (or overvaluation of size) of higher body weight (APA, 2013; Pike et al., 2004). That is, ‘a pursuit of thinness is the pursuit of enhanced self-esteem’ (Pike et al., 2004, p. 133).

Body image concerns such as heavy thighs, large abdomen or buttocks, and feeling oversized contribute to determining a person’s level of self-esteem (APA, 2013; Crisp, 1995).
In turn, these concerns could induce feelings of self-loathing, insecurity and depression, thereby increasing the risk of relapse (Crisp, 1995; Hsu, 1990; Pike et al., 2004).

One study found that focusing solely on a patient’s self-esteem resulted in reducing their depression and improving their self-esteem and eating attitude (Newns, Bell, & Thomas, 2003). Over a 20-month period, the authors conducted a number of support groups with adult patients (mean age = 29 years) with a diagnosis of AN (n = 3), BN (n = 17), BED (n = 14) and EDNOS (n = 9). The result of the study supports the hypothesis that too much emphasis on people’s eating behaviours could, in fact, be counterproductive. A number of studies have confirmed this finding and noted that AN is a multifactorial problem and not solely a ‘physical’ problem (Andersen, Bowers, & Evans, 1997; Beumont & Vandereycken, 1998; Courbasson, Shapira, & Fonzo, 2011; NICE, 2017; RANZCP, 2014; Touyz & Beumont, 1985). A major drawback of Newns et al.’s (2003) study was that the groups were heterogeneous regarding the type of eating disorder; therefore, the results are less generalisable to patients with AN.

Several authors have noted that low self-esteem and perfectionism are important perpetuating factors of SE-AN and are often interrelated to explain the natural course of the illness (Anderluh et al., 2003; Brewerton & Dennis, 2016; Fairburn, Cooper, Doll, & Welch, 1999; Federici & Kaplan, 2008; Hepworth, 1999).

2.4.2.6 Perfectionism

Perfectionism is classified as a personality trait that is characteristic of self-imposed high standards in which one strives for flawless achievements despite the potential adverse consequences (APA, 2013; Bastiani et al., 1995; Damiano, 2012; Egan et al., 2017; Keel & Forney, 2013; Lacey & Sly, 2016; Larsson, Lloyd, Westwood, & Tchanturia, 2018; Stice, 2002). Perfectionism is considered a risk factor in the development and maintenance of AN and is a negative prognostic factor for treatment outcomes (Bastiani et al., 1995; Egan et al.,
For example, the results of a study involving 322 females with different subtypes of AN used a Multidimensional Perfectionism Scale and found that perfectionism was associated with decreased motivation to change ($r = 0.23$, $df = 319$, $p < 0.01$), and this was correlated with lower body weight ($r = -0.20$, $df = 319$, $p < 0.01$) (Halmi et al., 2000). The report identified that greater severity of eating disorder symptoms resulted in an increase in perfectionism.

For some individuals, perfectionism may have an adaptive value such as gaining satisfaction from achieving goals without the fear of failure or setbacks. However, for others, it may become maladaptive (Norris, Gleaves, & Hutchinson, 2019). Giordano (2005) explained that perfectionism is a maladaptive coping strategy for women with eating disorders. She posited that they attempt to control their ‘chaotic body’ through the ‘ethic of perfectionism’ by adopting morals and values (e.g., self-control, intellectual achievement, responsibility and denying pleasure) that would enable them to maintain pride and discipline in an effort to control their body weight.

Several authors have connected perfectionism with inflexible, rigid and obsessional thinking, and setting unrealistic standards. It often occurs in those who have introverted personalities (APA, 2013; Anderluh et al., 2003; Bastiani et al., 1995; Srinivasagam et al., 1995; Tan et al., 2006). Perfectionism is typically related to weight and body shape but can manifest in other domains such as work, school and exercise (Egan et al., 2017; Giordano, 2005; Schmidt & Treasure, 2006). Symptoms can vary in severity from mild to severe, and it can present in one or more of the following ways: obsession, symmetry, exactness, ordering, arranging and repeating (Anderluh et al., 2003; Srinivasagam et al., 1995).
There is a strong correlation between perfectionism and comorbidities such as OCD, depression and anxiety, which can exacerbate the illness and impede a person’s recovery (Anderluh et al., 2003; Halmi, 2013; Norris et al., 2019; Strober, 1980; Wonderlich, 1995). In the case of those experiencing AN, this could lead to starvation by death. Stice (2002) stated that perfectionism promotes a relentless pursuit of the ‘thin ideal’ in people with eating disorders.

Several studies have reported that perfectionism persists even after a person’s recovery, suggesting that a person might be susceptible to relapses—hence the term ‘chronic’ anorexia (Bastiani et al., 1995; Ratnasuriya et al., 1991; Srinivasagam et al., 1995; Wonderlich, 1995).

2.5 Definition of Severe and Enduring Anorexia Nervosa

Since its inception, the term ‘chronic’ anorexia has had several name changes. The terms ‘Critical, Refractory, Prolonged, Treatment-refractory, Treatment-resistant and Persistent [Long-standing]’ (Broomfield, Stedal, Touyz, & Rhodes, 2017, p. 617) were previously used interchangeably to describe the condition, but they were not well defined and were open to misconception (Ciao, Accurso, & Wonderlich, 2016; Noordenbos, Jacobs et al., 1998; Theander, 1992). These labels have evolved and changed over time as new evidence has emerged. Thus, there is now a consensus that chronic anorexia should be ‘SE-AN’ because it is a more ‘inclusive’ and ‘hopeful’ term (Lacey & Sly, 2016, p. 203).

A number of authors have endorsed and conceptualised SE-AN as a patient who has lived with the illness for a period of more than seven years (Conti et al., 2016; Dru, Mosley, & Esad, 2014; Robinson et al., 2015; Touyz & Hay, 2015; Treasure et al., 2015). Previously, there was no consensus regarding how long a person must have the illness to warrant a diagnosis of SE-AN (Bamford et al., 2015; Ciao et al., 2016; Hannon et al., 2017; Hay & Touyz, 2015; Lacey & Sly, 2016; Raykos, Erceg-Hurn, McEvoy, Fursland, & Waller, 2018;
Robinson et al., 2015; Strober, 2004; Wonderlich et al., 2012). For example, some (as cited in Wildes et al., 2016, p. 2) have estimated a protracted period of five years (Andries, Frystyk, Flyvbjerg, & Støving, 2014), six years (Fox & Diab, 2015), seven years (Dawson et al., 2014) or 10 years (Arkell & Robinson, 2008), but these were subjective estimates with no objective measurements. Further, it was not clear whether SE-AN was characterised as having no periods of remission (Goode, 2012), or more specifically, whether it had to ‘display an “absence of change” along some key clinical dimensions before being considered chronic’ (Wonderlich et al., 2012, p. 471).

However, a more recent study offered a set criterion and identified six prognostic markers in making a diagnosis of SE-AN (Lacey & Sly, 2016). Namely, a person must have experienced ‘a pursuit of thinness combined with a hatred of the body’, an ‘irrational phobia of “normal” body weight’, a ‘persistent illness with possible periods of remission’ and ‘resistance to treatment’, and they must ‘have had the illness for a period of 7 years’ and ‘failed to respond to a broad spectrum of therapies’ (p. 203). Geller et al. (2001) held a similar view and defined SE-AN as having a ‘lengthy illness duration, a history of unsuccessful treatment attempts, and low expressed interest in recovery’ (p. 366).

In contrast, Tierney and Fox (2009) conducted a Delphi study of 53 professionals who worked in the field of eating disorders but were from different clinical backgrounds. They found that there was no consensus on the ‘mean duration of the illness’ or the ‘number of treatment attempts’ to define chronic AN; rather, these were considered arbitrary. Instead, the authors found that a ‘lack of motivation’ was the key feature used to define chronic AN. Overall, the results indicated that SE-AN can be defined as a ‘lack of readiness to change thoughts and behaviours, and maintenance of a low BMI’ (p. 66).

However, these studies offer no clarity as to what constitutes the ‘severity’ of the illness (Ciao et al., 2016). For example, a number of patients may present with the same
illness, but the severity may differ greatly. The APA (2013) defined the severity of AN based on BMI criteria: ‘mild (≥17.0 BMI), moderate (16–16.99 BMI), severe (15–15.99), and extreme (< 15 BMI)’ (p. 339). However, these estimates do not distinguish between age, clinical impairment and symptom presentation (Ciao et al., 2016; Raykos et al., 2018); therefore, they may not be applicable to people with SE-AN (Ciao et al., 2016).

To clarify, Wonderlich et al. (2012) presented a case study of a 42-year-old AN patient with a 10-year history of the disorder and a 22-year-old AN patient with an equivalent 10-year history. The scenario raised two questions: Are there any differences (heterogeneity) in the severity and chronicity between these individuals (e.g., one could have significant medical and social impediment problems)? Are they both considered chronic?

Labelling and defining subgroups within research has important implications. In a recent study by Raykos et al. (2018), the label ‘SE-AN’ was found to be problematic. The authors found that there is a growing body of evidence against non-evidence-based treatments in which clinicians may justify, and therefore recommend, non-evidence-based treatments to people with SE-AN. Not only does this risk further stigmatising people with SE-AN, but it also limits their recovery and treatment options (Raykos et al., 2018). A similar concern was expressed by Wonderlich et al. (2012), who found that clinicians might be biased in their treatment recommendations based on their preconceived notions (‘labelling terms’) about people with SE-AN.

Unless there are clear parameters around the definition of diagnoses of SE-AN, this raises concerns about the reliability of the data (Broomfield et al., 2017; Wonderlich et al., 2012). Tierney and Fox (2009) advocated for a unified definition of SE-AN. Setting clear parameters as to what constitutes SE-AN can help in better understanding the condition (e.g., prognostic and predictive factors), recommending suitable treatments and providing a
standardised approach for defining, evaluating and reporting results—all of which can provide a focus for future studies.

The combined data from these studies demonstrate several key points regarding the definition of SE-AN, including length of duration of the illness of >7 years, greater severity of symptoms, maintenance of low BMI of < 15, history of multiple relapses and lack of motivation to change. In addition, others have suggested that history of mood and personality disorders and poor adaptive functioning are contributing factors in the development of SE-AN (Broomfield et al., 2017; Guarda, 2008; Hay & Touyz, 2015; Werth Jr et al., 2003; Wonderlich et al., 2012). Further research is required for these patients, specifically in relation to the psychological, physical and behavioural symptoms, and more recently, the quality of life aspects of the illness (Adair et al., 2007; Dawson et al., 2014; Geppert, 2015; Marzola & Abbate-Daga, 2019; Tierney & Fox, 2009; Wildes et al., 2016).

2.6 Recovery from Severe and Enduring Anorexia Nervosa

Recently, there has been increasing interest in exploring the multidimensional aspects underlying the phenomenon of SE-AN, especially in understanding people’s experiences of recovery (Dawson et al., 2014; Touyz & Strober, 2016). Dawson et al. (2014) used a narrative inquiry approach to explore the process of recovery of people who were fully recovered from SE-AN (n = 8 females, aged 31–64, SD 1, mean duration of illness = 15.4 years, mean duration of recovery = 13 years).

The results revealed that recovery was a ‘long and complex process’ and was understood and expressed as four distinctive phases: ‘unready and/or unable to change’, ‘the tipping point of change’, ‘active pursuit of recovery’ and ‘reflections and rehabilitation’ (Dawson et al., 2014, p. 495). A common thread between these themes was that people have a desire to recover (albeit exponentially), and recovery was largely attributed to people’s ‘self-determined motivation’. The importance of having ‘internal and external’ support during the
recovery process was identified as a factor in overcoming eating disorder symptoms, whereas ‘hopelessness’ was identified as a major obstacle preventing people from recovery. Other factors that were identified as assisting with a person’s recovery were the devaluation of AN, the externalisation of AN, an increase in insight and the feeling of being understood by and connected to others.

Another qualitative study conducted semi-structured interviews with five participants with SE-AN with a duration of illness ranging 4–11 years and reported mixed responses regarding the issue of recovery (Hannon et al., 2017). More than half of the participants (n = 3) reported feelings from ‘self-deprivation to self-satisfaction, from self-criticism to self-acceptance, from isolation to connectedness, from perfectionistic over-control to flexibility, and from unmet needs to met needs’ (p. 294). The authors of the study identified a two-stage approach: ‘readiness to change’ and ‘achieving change’. Similar to the previous study, the two major factors identified in the recovery process were receiving professional support and making a commitment to change. The authors postulated that recovery from SE-AN is possible. Interestingly, both studies showed similarities in the attitudinal and behavioural change of its participants and in accordance with the Transtheoretical Model of Change (TTM) (Prochaska & DiClemente, 1982).

While these studies have illustrated that a small percentage of people with anorexia recover, it is important to note that people are susceptible to relapses after periods of full remission (Berends et al., 2018; Garner & Garfinkel, 1997; Löwe et al., 2001; Melamed et al., 2003). In an earlier study, Guarda (2008) estimated that 30–50% of relapses occur among people with AN. According to one longitudinal study, some patients experience indefinite repeated cycles of relapses (Strober, Freeman, & Morrell, 1997). Identifying the causes of relapses—particularly among patients with SE-AN—remains an area for future research (Phillipou, Musić et al., 2019). To date, no studies have explored this phenomenon (Dawson
et al., 2014). One study of long-term outcomes demonstrated that full recovery decreases with duration of illness; up to 20% do not recover, but continue to experience chronic symptoms (Steinhausen, 2002). Similarly, a 20-year follow-up study by Ratnasuriya et al. (1991) found that recovery decreases to 7% 15 years after of the onset of the illness.

To date, there is mixed evidence of what constitutes recovery in the literature on eating disorders; therefore, it remains an ill-defined concept with no existing ‘shared definition’ (Bardone-Cone et al., 2010; Couturier & Lock, 2006; Dawson et al., 2014; Dresser, 1984b; Higbed & Fox, 2010; Marzola & Abbate-Daga, 2019). This is largely a result of a number of methodological issues when interpreting data, specifically relating to the length of time of recovery until the absence of symptomology (Couturier & Lock, 2006; Lock et al., 2013; Strober et al., 1997). Further, there are few long-term clinical-based outcome studies that accurately measure recovery predictors for patients with AN (Espindola & Blay, 2013; Lock et al., 2013; Strober et al., 1997; Uher et al., 2003). It is notoriously difficult to conduct follow-up studies because of high attrition rates among people with SE-AN (Elbaky et al., 2014; Halmi et al., 2005; Steinhausen, 2002). This has been attributed to two factors: AN symptoms and people’s reluctance/ambivalence to seek and accept treatment (Agras et al., 2004). Three studies have reported that people with AN often feel a profound sense of shame and guilt about their ‘treatment failure’ and ‘duration of illness’ and are therefore less likely to participate in clinical trials (Bamford et al., 2016; Dresser, 1984b; Maier et al., 2014).

Turton et al.’s (2011) study on recovery attempts to clarify this ambiguous term. From a medical perspective, the authors stated that ‘recovery’ occurs when a person has been cured (the term ‘cure’ is an elusive concept—see Lemma-Wright’s, 1994, p. 60, thoughts on this subject) and when no symptoms affect a person’s normal functioning. The authors noted that the concept of recovery has many aspects because people view recovery differently. For
example, it can refer to restoring a person’s autonomy through treatments, preserving a sense of self-hood and control, or reclaiming personal identity on a physical, spiritual, emotional or cultural level; thus, it should not be limited to symptom reduction (Turton et al., 2011).

In contrast to the previous view, Jacobson and Greenley (2001) argued that recovery ‘is not synonymous with cure’; rather, it is a process of healing in which the person is striving to recover a sense of ‘self’ and ‘control’ in managing their symptoms of mental illness (p. 484). Similarly, a mixed-method study using qualitative and quantitative measures found that ‘recovery was not an endpoint, but rather an ongoing process, and a graded subjective experience’ (Pettersen & Rosenvinge, 2002, p. 68).

Despite these different definitions, an emphasis on the quality of life aspects of the illness is a prerequisite, especially for those with a longstanding illness, and should be included as part of a broader definition of recovery (Marzola & Abbate-Daga, 2019).

The trajectory of a person’s recovery depends on mediating factors such as motivation to change (Darcy et al., 2010; Fassino & Abbate-Daga, 2013; Federici & Kaplan, 2008; Hsu, Crisp, & Callender, 1992; Maine, 1985; Marzola, Albini, Delsedime, Fassino, & Abbate-Daga, 2019; Stockford, 2014), readiness to engage in treatment services—that is, reaching a ‘tipping point’ (Ayton et al., 2009; Colton & Pistrang, 2004; Dawson et al., 2014; Dresser, 1984c; Espindola & Blay, 2013; Guarda, 2008; Serfaty & McCluskey, 1998; Vitousek et al., 1998)—existing support (both formal and informal) (Cockell, Zaitsoff, & Geller, 2004; Dawson et al., 2014; Espindola & Blay, 2013; Federici & Kaplan, 2008; Russell, 2004; Spinelli, 1994; Turton et al., 2011), severity and duration of illness and comorbidities (e.g., major depressive disorder) (Franko et al., 2018; Keski-Rahkonen et al., 2007), age and diagnosis (Dresser, 1984b; Lemma-Wright, 1994; Spinelli, 1994), the person’s temperament and resilience (Espindola & Blay, 2009; Liu, 2007; Lock et al., 2013; Schmidt & Treasure, 2006; Strober, 2004), and family and self-acceptance (Cockell et al., 2004; Maine, 1985).
addition, Crisp et al. (1977) claimed that patients with AN need to surrender their sense of control of the illness to recover. Another study reported that the desire to have children is a motivating factor to recover (Darcy et al., 2010). This result is reflective of the findings in the present study, in which one patient reported a similar wish. Creative endeavours such as art therapy and writing a book about one’s lived experience have been identified as possible ‘turning points’ for people and their recovery (Russell et al., 2019). It could be hypothesised that ‘new interests and meaningful life activities’ (a theme that emerged in Hay & Cho, 2013, p. 738) could be catalysts for change (William, 1993).

Overall, recovery rates suggest that most people fully recover within five years (Mann et al., 2018), but there are cases in which a person may have intermittent periods of recovery; therefore, it is not dictated by time (Cockell et al., 2004; Matoff & Matoff, 2001; Melamed et al., 2003; Radu et al., 2016; Steinhausen, 2002). This notion has been supported by other authors, who have advocated that recovery is a long and drawn-out process characterised by frequent relapses (Dresser, 1984b; Lackstrom & Woodside, 1998; Radu et al., 2016).

It is reasonable to assume that those who have a longer duration of illness will take longer to recover (Bamford et al., 2015; Birmingham, Su, Hlynsky, Goldner, & Gao, 2005; Dresser, 1984b; Kaplan & Strober, 2019; Noordenbos et al., 2002; Robinson et al., 2015; Strober, 2004). For example, Crisp (1995) stated that ‘the longer the person has been ill e.g. 12 years compared with four years, the more difficult it is to recover and the less likely’ (p. 155). Those with a shorter period of illness—that is, the period between illness onset and the time of receiving treatment—have a higher success rate of recovery (Agras et al., 2004; Geller et al., 2012).

Further, it would be wrong to assume that because people have gained weight, they have recovered (Eddy et al., 2017; Leichner, 1991; Russell, Mulvey, Bennett, Donnelly, & Frig, 2019). Conversely, it would be ill-advised to think that people who are of normal weight
or overweight cannot have an eating disorder (Noordenbos et al., 2002). In his review of chronic anorexia, Button and Warren (2001) suggested that a person may experience social adjustment problems post-recovery, specifically relating to mood disturbances, problems with relationships and low self-esteem. Similarly, Russell (2004) stated that some patients recover relatively quickly with minimal support, but for others, the journey to recovery can be marked with ongoing anxiety, frustration, impotence and despair, particularly in the absence of tertiary support and treatment. Couturier and Lock (2006, p. 551) claimed that patients who no longer meet the diagnostic criteria for anorexia will experience ‘weight-related psychopathology’ relating to their eating disorder—that is, they will experience ongoing ‘anorectic-like symptoms’ (Tierney, 2008, p. 368).

Interestingly, in scattered anecdotal case studies in the literature of AN, there are no obvious reasons to explain why a person has recovered. Instead, the illness has simply ‘run its course’ or the person has ‘spontaneously’ or ‘miraculously’ recovered—an unexplained anomaly (Bruch, 1974; Crisp et al., 1977; Dally, 1969; Dresser, 1984b; Melamed et al., 2003; Woodside et al., 2016). To give credence to this point, Hsu et al. (1992) offered a case study in which a 39-year-old woman who was diagnosed with anorexia at the age of 15 suddenly decided to end her long battle with the illness, stating ‘that’s it, I have had enough of this’ (p. 345). Similarly, in another reported case, a patient stated that, ‘after eight years of going in and out of hospital, I decided I was sick of it. I was sick of yo-yoing in and out of hospitals. “That’s it”! I thought’ (Dawson et al., 2014, p. 501). Obviously, there was a shift in the patients’ thinking—perhaps a turning point in the trajectory of the illness, but with no clear pattern as to why this occurs—an area of research that warrants attention (Russell et al., 2019).

It has even been suggested by some researchers that people with AN can recover in the absence of therapy (Ramjan, 2004; William, 1993). This begs the question: Why do some
patients recover spontaneously over time, while others require long-term intensive treatments and therapies, but with no meaningful changes to their overall recovery? This topic requires further exploration to help improve the understanding of recovery and the mechanisms behind this phenomenon. Indeed, it might clarify some of the ambiguities pertaining to the definition of recovery regarding SE-AN. Couturier and Lock (2006) argued that a consistent definition of recovery is needed in the literature to guide and facilitate future researchers when investigating the psychological and physical effects of recovery for this cohort of patients.

Of course, there are those who never recover and eventually die (Atkinson, 2010; Tan et al., 2003a). As mentioned earlier, AN has a high rate of mortality among psychiatric disorders (Hsu et al., 1992; Tan et al., 2003a). The mortality rate for people diagnosed with anorexia is 5% per decade, resulting from suicide, medical complications (e.g., electrolyte imbalance) and starvation–dehydration (APA, 2013; Campbell & Peebles, 2014; Crisp et al., 1977; Mann et al., 2018; Wegner & James, 2012). Further, a longer duration of anorexia is associated with a greater risk of mortality (Franko et al., 2013; Mann et al., 2018; Ratnasuriya et al., 1991).

Lock et al. (2013) concluded that it may not be helpful to define and impose limitations on recovery for people with SE-AN; rather, there should be a focus on harm minimisation, improvements to quality of life and reductions in high-risk behaviour. The assertion here is that adopting such an approach would be more conducive to people’s overall care and recovery than offering standardised therapeutic interventions.

It must be acknowledged that early diagnosis and access to specialised eating disorder services for all eating disorders can significantly reduce the severity of the illness, increase early recovery rates and reduce overall mortality rates (Errichiello et al., 2016; Garner, 1985; Hay & Cho, 2013; Holm et al., 2012; Lähteenmäki et al., 2014; Li, Noll, Bensman,
However, the authors of a recent article disagreed, stating that ‘there is no foundation … that early intervention can prevent the development of a chronic course of illness’ (Kaplan & Strober, 2019, p. 2). They argued that it is difficult to pinpoint exactly what contributes to a person’s recovery. It can depend on factors such as the type of ‘intervention’, ‘early experience in the illness’, ‘qualities of the practitioner’, ‘clinical acumen’, ‘shifts in attitudes or motivation’ and a person’s ‘life experiences’ (p. 2). One or more of these factors may be identified as a predictor of long-term recovery from SE-AN, but there is no definitive data to suggest that these factors play a role. One factor that cannot be refuted—indeed, it is supported by empirical data—is that prevalence rates of AN (and likely SE-AN) are rising.

2.7 Epidemiology and Prevalence of Severe and Enduring Anorexia Nervosa

Several decades ago, AN was erroneously defined as ‘morbid, untreatable; creates resistant patients, a disorder of the pre-pubescent girl, affecting girls from upper-middle-class families, shown up in high achievers, and a flight from full genital sexuality’ (Orbach, 1986, p. 1). A growing body of evidence supports the view that AN can affect anyone, regardless of gender, age, ethnicity or economic status; more importantly, it can be treated (Carney, Tait et al., 2006; Franko, Wonderlich et al., 2004; Garner & Garfinkel, 1997; RANZCP, 2014; Vandereycken & Beumont, 1998c; Wills & Olivier, 1998; Zanetti, 2013). In fact, this study debunks the view that anorexia only affects adolescent girls from upper-middle-class families. All participants in this study were older women (the youngest was 27 years of age) and all were receiving sickness benefits (Knight, Sophia, & Jackson, 2019).

Thus, epidemiological data suggest that prevalence rates are rising in both males and females—specifically, there has been an increase in adolescent females aged 15–19, as well
as younger males (Hoek, 2016; Midlarsky & Nitzburg, 2008; Pike, Hoek, & Dunne, 2014; Radu et al., 2016; RANZCP, 2014; Wooldridge & Lytle, 2012).

Although many studies have examined the prevalence and incidence rates in eating disorder populations, some have identified a number of methodological issues when reporting their findings (Pike et al., 2008). These include: variability of the selection of samples in terms of age onset (i.e., peak onset v. late onset), ethnicity and geographical location, which mainly comprise subgroups of populations (e.g., community-based studies v. clinical) rather than a whole population sample; variability of classification systems, most notably the DSM and ICD; and variability of methods—that is, researchers use different criteria (e.g., self-reporting and structured interviewing) to interpret their findings (Hoek, 2016; Hoek & Van Hoeken, 2003; Keski-Rahkonen et al., 2007; Keski-Rahkonen & Mustelin, 2016; Kimura, Tonoike, Muroya, Yoshida, & Ozaki, 2007; Lähteenmäki et al., 2014; Mitchison & Hay, 2014; Mitchison & Mond, 2015; Pike et al., 2008; Preti et al., 2009; Schmidt & Treasure, 2006; Smink, Van Hoeken, & Hoek, 2012; Stice, Marti, Shaw, & Jaconis, 2009; Striegel-Moore & Bulik, 2007; Zanetti, 2013). Overall, these methodological differences raise concerns about the reliability and validity of these studies in reporting the prevalence and incidence rates of eating disorders (Mohler-Kuo, Schnyder, Dermota, Wei, & Milos, 2016).

A recent epidemiological review conducted by Mohler-Kuo et al. (2016) reported that average prevalence rates among women with eating disorders were:

- 0.3% (-0.1%) for anorexia nervosa (AN), 1.0% (0.2-2.0%) for bulimia nervosa (BN) (Bijl, Ravelli, & van Zessen, 1998; Garfinkel, Lin, Goering, & Spegg, 1995; Hoek & Van Hoeken, 2003; Hudson, Hiripi, Pope, & Kessler, 2007; Kessler et al., 2013; Preti et al., 2009; Smink et al., 2012), and 1.4% (0.2-2.6%) for binge eating disorder (BED) (Hudson et al., 2007; Kessler et al., 2013; Preti et al., 2009; Smink et al., 2012).
Although there are no specific epidemiological data available relating to prevalence rates (or even international trends) for people with SE-AN (Bamford & Mountford, 2012), the DSM estimates that the 12-month prevalence rate for women with ‘general anorexia’ (AN) is 0.4% (APA, 2013).

Several epidemiological studies have concluded that incidence rates for Caucasian women with AN in Western countries have generally ‘remained stable’ over the past decade, but rates among adolescent girls aged 15–19 years have increased (Currin, Schmidt, Treasure, & Jick, 2005; Hoek & Van Hoeken, 2003; Pike et al., 2014; Smink et al., 2012; Zanetti, 2013). The factors that may help to explain this ‘stability’ rate include improved diagnostic skills among clinicians, social media influence (in particular, web-based treatment programs such as the Recovery Record mobile app, which enables consumers and therapists to share treatment information), a change in public attitudes and perceptions towards eating disorders (i.e., eating disorders can affect anyone—even males and older women), an increase in the reporting of incidents (Dresser, 1984b) and the availability of more mental health services (Hepworth, 1994; Hoek, 2016; Kazdin, Fitzsimmons-Craft, & Wilfley, 2017; Keski-Rahkonen & Mustelin, 2016; Linville, Benton, O’Neil, & Sturm, 2010; Melamed et al., 2003; Preti et al., 2009; Van Son, Van Hoeken, Bartelds, Van Furth, & Hoek, 2006).

However, Giordano (2005) made a valid point by stating that there are ‘silent sufferers who will never seek help, and who will never declare they have a problem with food’ (p. 19). That is, many individuals lack insight, experience shame and secrecy, fear being stigmatised as having a mental health disorder, deny their illness and therefore avoid seeking professional help (Crisp, 2005; Crisp et al., 1977; Geller et al., 2012; Lilienfeld, 2016; Mitchison & Mond, 2015; Noordenbos et al., 2002; Redston et al., 2014; Rosling, 2013; Smink et al., 2012; Zanetti, 2013). This statement suggests that these silent individuals are not included in the overall epidemiological data (Keski-Rahkonen et al., 2007; Mitchison & Hay, 2014; Palmer
& Treasure, 1999; Striegel-Moore & Bulik, 2007). Thus, these factors limit researchers’ capacity to generate reliable empirical data that reflect the true magnitude of the social epidemic problem of eating disorders (Palmer & Treasure, 1999).

This problem is further compounded by the suggestion that primary care physicians (PCPs) are best suited to providing early intervention care, particularly in the screening of patients with eating disorders (Geller et al., 2012). However, evidence shows that PCPs may not have adequate training (e.g., knowledge, experience and skills) to detect cases of eating disorders; therefore, many of these cases may be overlooked or even misdiagnosed and treated within a general medical ward (Jarman et al., 1997; Joughin, Crisp, Gowers, & Bhat, 1991; Linville et al., 2010; Mehler & Andersen, 1999; Mitchison & Mond, 2015; Murray, Crawford, McKenzie, & Murray, 2011; Noordenbos et al., 2002; RANZCP, 2014; Tan, Doll, Fitzpatrick, Stewart, & Hope, 2008; Tierney, 2008).

Noordenbos et al. (2002) found that more than half of the respondents who were diagnosed with an eating disorder reported that their doctor had a problem in diagnosing their eating disorder. Another study reported that 43% of respondents (currently ill or recovered) said that their first or subsequent consultation with their GP was ‘unhelpful’ (Newton, Robinson, & Hartley, 1993). Ninety-two per cent of frontline workers (consisting mainly of general/specialist practitioners and nurses) believed they had ‘missed’ an eating disorder diagnosis (Linville et al., 2010). Johansson et al. (2009) reported that only about half of their respondents (dentists) believed that the patient or a relative should be informed of a suspected diagnosis of an eating disorder. Overall, these problems prevent reliable reporting of incidence and prevalence rates and affect the accuracy of epidemiological data relating to eating disorders.
2.8 Treatment Models and Severe and Enduring Anorexia Nervosa

Currently, there is a paucity of literature relating to the treatment and care of SE-AN patients (Byrne et al., 2017; Carney et al., 2019; Geller et al., 2012; Kaplan & Strober, 2019), as well as a lack of empirical studies that assess the long-term effects of treatment outcomes (George, Thornton, Touyz, Waller, & Beamont, 2004; Hay et al., 2012; Long, Fitzgerald, & Hollin, 2012; Mander, Teufel, Keifenheim, Zipfel, & Giel, 2013; McIntosh et al., 2010; Noordenbos et al., 2002; Steinhausen, 2009; Stiles-Shields et al., 2013; Tierney & Fox, 2009; Wonderlich et al., 2012). Further, there is no ‘golden standard’ of treatment and no agreement as to what constitutes ‘good care’ for this group of people (Ciao et al., 2016; Dresser, 1984b; Lacey & Sly, 2016; Marzola & Abbate-Daga, 2019; NICE, 2017; RANZCP, 2014; Tierney & Fox, 2009; Treasure et al., 2015).

2.8.1 General therapeutic modalities

Despite this, there are many well-established therapeutic modalities (e.g., psychodynamic therapy, family therapy and intrapersonal therapy) that encourage active behavioural and attitude changes to treat SE-AN (Woodside, 2002). Although these modalities have their own therapeutic merits and outcomes, and although they are to some degree beneficial (e.g., reduction of eating disorder symptoms/relapses), they are nonetheless limited in their scope to treat those with SE-AN (Guarda, 2008; Guarda et al., 2007; Long et al., 2012; Noordenbos & Vandereycken, 1998). Even family based treatments such as the Maudsley approach are limited in helping individuals with SE-AN who have a late onset and longer duration of the illness compared with adolescents with a recent onset who are less critically ill (Dare & Eisler, 1997; Fairburn & Brownell, 2005; Finelli, 2001; Guarda, 2008; Russell, Szmukler, Dare, & Eisler, 1987; Stiles-Shields et al., 2013; Strober, 2010; Treasure & Russell, 2011; Walsh, 2013).
These proscriptive psychotherapies are limited in their efficacy because of the following characteristics of many adults with SE-AN, which include the egosyntonic features of the illness (Linville et al., 2010; Preti et al., 2009; Vandereycken & Beumont, 1998c; Wade, Bergin, Tiggemann, Bulik, & Fairburn, 2006; Winkler et al., 2017), high levels of suicide ideation (Noordenbos et al., 2002; Warren & McGee, 2013), greater treatment ambivalence and resistance (Goldner, 1989; Guarda et al., 2007; Mander et al., 2013; Newton et al., 1993; Page, Sutherby, & Treasure, 2002; RANZCP, 2014; Richmond, 2001; Schreyer et al., 2016), cognitive distortions such as an ‘overvalued idea’ about being thin (Beumont & Carney, 2003; Fox & Diab, 2015; Guarda et al., 2007; Long et al., 2012; Tierney & Fox, 2009; Treasure, 2002), maintaining a low BMI (Strober, 2004; Winkler et al., 2017), often presenting with multiple comorbidities and personality disorders (Guarda, 2008; Scholtz et al., 2010), and not responding to standard treatments (Bulik & Kendler, 2000; Geppert, 2015; le Grange & Lock, 2005).

Bruch (1979) and Mitchell and Eckert (1987) suggested that therapeutic interventions can be useful, but only when starvation symptoms have been adequately addressed. That is, it is difficult to offer meaningful and tangible therapy to a patient who is medically underweight, psychologically impaired and ambivalent about accepting treatment (Dresser, 1984b; Steinhausen, 2002). To address this problem, a number of authors have advocated that the delivery of treatment services should include both psychological and physical care (Bell, 2003; Button & Warren, 2001; Cockell et al., 2004; Colton & Pistrang, 2004; Dresser, 1984b; Escobar-Koch et al., 2010; Federici & Kaplan, 2008; Palmer & Treasure, 1999; Ramjan & Fogarty, 2019; Rance, Clarke et al., 2017; Scholtz et al., 2010; Williams & Reid, 2010). This recommended treatment was first recognised in 1969, when Dally (1969) stated that ‘it is essential to remember that anorexia nervosa involves psychological and physical factors and that to treat one and neglect the other is illogical’ (p. 47).
However, in some cases, when a ‘critically unwell’ or ‘treatment-resistant’ person is not responding to these conventional therapeutic modalities, which have failed to provide meaningful outcomes, compulsory treatment is often used as a last resort (APA, 2006; Bonnie, 2012; Giordano, 2005; Kendall, 2014; Yager et al., 2016).

2.8.2 Medical model of care—‘compulsory treatment’

The medical model that is based on the principle of ‘primum non nocere’—above all, do no harm—adopts a curative approach to address the concern about underweight AN patients (Beauchamp & Childress, 2001; Carney, Tait et al., 2006; Goldner, 1989; Knapp & Vandecreek, 2007; Richmond, 2001; Scolan et al., 2013; Silber, 2011). Typically, it is designed for patients with a chronic illness who have experienced repeated treatment failures, have more comorbidities than younger patients with a short duration of illness and are usually detained under a Mental Health Act (Bamford et al., 2016; Carney et al., 2019; Russell et al., 2019; Tan, Hope, Stewart et al., 2003; Westmoreland & Mehler, 2016). However, this is gradually changing. Patients are now requesting voluntary admission to assist with their recovery or to shorten their hospital admission (Beumont & Vandereycken, 1998; Russell et al., 2019). It is a structured program with designated meal times, group sessions (i.e., counselling/family therapy), regular medical check-ups and psychoeducation (i.e., dietary), all of which are supervised in a safe and supportive environment (Vandereycken, 2003). It is overseen by a multidisciplinary team of health professionals, including a psychiatrist, and it involves a process of collaborative clinical decision-making about the treatment and care of AN patients (Andersen et al., 1997; Guarda & Heinberg, 2004; Hay et al., 2019; Hepworth, 1999; NEDC, 2010).

The approach recognises that SE-AN is a life-threatening illness and often requires medical intervention based on behaviour modification, psychopharmacological and psychotherapy treatments (Goldner, 1989; Guarda, 2008; Hay et al., 2019; Lacey & Sly,
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2016; Mitchell & Eckert, 1987; RANZCP, 2014). The overriding treatment goal is to medically stabilise the patient by restoring their weight to an acceptable BMI level (Bakker et al., 2011; Golden et al., 2003; Mental Health First Aid Training & Research Program, 2008; PACFA, 2011; RANZCP, 2014; Treasure, 2004; Turrell et al., 2011). Another goal is to support the patient’s transition from involuntary to voluntary care for subsequent hospital admissions (Dresser, 1984c; Kjellin & Nilstun, 1993). Part of the program upon discharge is to provide follow-up appointments to monitor the patient’s weight and safety risk (particularly regarding suicide) (Franko & Keel, 2006; Russell et al., 2019).

There is little empirical evidence to support and evaluate the efficacy of compulsory treatment for people with SE-AN (Goldner, 1989; Guarda & Heinberg, 2004; Hay et al., 2012; Vandereycken & Beumont, 1998c). To date, due to ethical concerns, there has only been one randomised controlled trial (RCT) (Guarda & Heinberg, 2004; Lacey & Sly, 2016).

Commentators generally agree that forced treatment does not ‘cure’ AN or produce significant long-term outcomes; rather, it offers short-term relief of symptoms. Compulsory treatment is often viewed as both ‘lifesaving’ and the ‘last chance’ to keep the patient alive until they gain sufficient body weight to enable them to engage in therapy and start recovering (Bamford et al., 2016; Draper, 2000; Dresser, 1984b; Goldner et al., 1997; Holm et al., 2012; Lackstrom & Woodside, 1998; Lopez, Yager, & Feinstein, 2010; Westmoreland & Mehler, 2016; Yager et al., 2016).

2.9 Modified Treatments—‘A Different Paradigm of Management’

Given that there is little empirical evidence to guide practitioners in the care of SE-AN patients, and because there is insufficient data to support the use of traditional models of care, there appears to be a growing trend in the use of a recovery approach model (Calugi et al., 2017; Robinson et al., 2015; Stockford et al., 2018; Tierney & Fox, 2009; Touyz & Hay, 2015). In this model, symptom reduction is not the goal (Holm et al., 2012; Raykos et al.,
2018), but rather a focus on increasing the quality life for people with SE-AN (APA, 2000; Bamford et al., 2016; Bamford & Mountford, 2012; Conti et al., 2016; Lock et al., 2013; Russell et al., 2019; Wonderlich et al., 2012). It is about restoring a person’s general health and function instead of preserving life (Russell, 2001; Tierney & Fox, 2009; Touyz & Hay, 2015). Indeed, the rehabilitation model of care has proven to be helpful in treating other psychiatric conditions such as schizophrenia. It is therefore recommended that this approach be adopted for patients with SE-AN (Carney et al., 2019; Russell et al., 2019).

Goldner (1989) noted that ‘individuals who develop chronic anorexia nervosa may warrant a treatment approach different from those who have had a shorter duration of the illness’ (p. 304). Similarly, Tierney and Fox (2009) suggested that working with SE-AN patients may require a ‘particular type of practitioner’ who has a unique set of skills to effectively engage and cope with the chronicity of the disorder (p. 67). Based on these observations, researchers have proposed a number of modified treatment approaches in the care of people with SE-AN. Strober (2004) referred to these as ‘a different paradigm of management’ (p. 251). These approaches are designed to offer flexibility in the provision of services and promote collaboration between the patient and physician by giving more control to the patient in the decision-making process—a fundamental tenet of the rehabilitation model of care (Alharbi, Carlström, Ekman, Jarneborn, & Olsson, 2014; Amering et al., 1999; Coulter, Parsons, Askham, & WHO, 2008; Hannon et al., 2017; Waterworth & Luker, 1990; William, 1993).

2.9.1 Specialist supportive clinical management

The specialist supportive clinical management (SSCM-SE) model provides both clinical management and supportive psychotherapy in the context of outpatient treatment and is specifically suited for adult patients with SE-AN (Hay, McIntosh, & Bulik, 2016; Paxton & Hay, 2009; Tierney & Fox, 2009; Touyz et al., 2013; Wonderlich et al., 2012). SSCM-SE is a
A therapeutic structured program that consists of three phases. The first phase focuses on the orientation to SSCM-SE, psychodynamic formulation and agreement on target symptoms. The second phase involves reviewing the symptoms of the illness, the patient’s goals and weight considerations. The last phase focuses on closure in the therapeutic relationship and examines future goals (Hay et al., 2016; McIntosh et al., 2010). In all three phases, a person-centred and collaborative approach to care is emphasised (McIntosh et al., 2010; Stiles-Shields et al., 2013).

Unlike the medical model, this model does not principally focus on weight restoration or enforced change; rather, it aims to improve people’s quality of life (Elbaky et al., 2014; Grilo & Mitchell, 2011; Hay et al., 2016; Hay et al., 2012; Stiles-Shields et al., 2013). This can be achieved through a supportive milieu that consists of psychoeducation (e.g., nutrition counselling, the effect of starvation and advice about anorexia), care and support (e.g., empathic attunement and attendance), and fostering a strong therapeutic alliance with the patient (Cockell et al., 2004; Hay et al., 2016; Hay et al., 2012; Lacey & Sly, 2016; McIntosh et al., 2010; NICE, 2017; Paxton & Hay, 2009; Strober, 2004). The other important components of this model of care are the use of ‘praise, advice and reassurances’ (Stiles-Shields et al., 2013 p. 785), along with ‘centring on developing patient’s skills and assets’ (Tierney, 2008, p. 66) during the course of treatment. For example, patients are encouraged to make lifestyle changes (e.g., develop and maintain social support networks, engage in hobbies and social activities) to improve their overall wellbeing and quality of life (Cockell et al., 2004; Strober, 2004; Tierney & Fox, 2009; Trachsel, Wild, Biller-Andorno, & Krones, 2015). However, to date, the long-term efficacy of the SSCM-SE approach is unknown, mainly because there is a lack of empirical studies involving SE-AN patients (Hannon et al., 2017; Hay & Touyz, 2015).
2.9.2 Cognitive behaviour therapy

Cognitive behavioural therapy—anorexia nervosa (CBT-AN) is an empirically validated treatment for eating disorders (Garner & Bemis, 1982; Hay et al., 2019). The aim of CBT-AN is to ‘examine and modify their negative thinking, dysfunctional assumptions, and overwhelming feelings of inadequacy’ (Halmi et al., 2005, p. 777). This approach is recommended by a number of eating disorder guidelines and is the preferred treatment for adults and adolescents with SE-AN (Hay et al., 2012; NEDC, 2010; NICE, 2017; RANZCP, 2014).

However, there have been few studies about the effects of CBT-AN on people with SE-AN (McIntosh et al., 2005; Pike, Walsh, Vitousek, Wilson, & Bauer, 2003). One study demonstrated that CBT-AN was effective in reducing eating disorder symptoms among patients with SE-AN (Touyz et al., 2013). However, subsequent analysis revealed higher rates of attrition in some cases (Touyz et al., 2013).

An RCT evaluated the efficacy of CBT-AN and SSCM therapies with promising results (Touyz et al., 2013). A total of 63 patients with a clinical diagnosis of SE-AN were randomly assigned into two therapy groups: CBT-AN (n = 31) and SSCM (n = 32). Baseline characteristics did not significantly differ between the groups. At follow-ups, a total of 45 participants (71.3%) (OR = 22 CBT-AN, 23 SSCM) and 50 participants (79.4%) (OR = 24 CBT-AN, 26 SSCM) completed follow-up assessments respectively. Completion rates did not differ, but overall improvements were observed in primary and secondary outcomes for both groups. However, CBT-AN outscored SSCM in three outcome measures: at follow-up, CBT-AN participants improved in the ‘Weissman Social Adjustment Scale (WSAS) \((p = 0.038)\), and at 12 months, improvements were also seen in Eating disorder examination (EDE) \((p = 0.004)\), and higher readiness for recovery \((p = 0.013)\), compared to SSCM’ (Touyz et al., 2013, p. 2501).
These figures indicate that the application of the CBT-AN treatment model, which is more structured in nature, was effective in increasing quality of life, reducing eating disorder symptoms and improving recovery rates for SE-AN participants. While these figures are encouraging, further research is needed to strengthen these findings because there are no comparable studies. In fact, this is the only published article of its type involving SE-AN patients. Remarkably, this study had a retention rate of 85%, which is considered very good, because high attrition rates are not unusual in trials involving people with AN (Elbaky et al., 2014; Touyz & Hay, 2015). The results of this study suggest that there is a higher acceptance rate for modified psychological therapies when there is less emphasis on weight gain and more emphasis on psychological interventions to improve the quality of life of people with SE-AN (Hay & Touyz, 2015; Stiles-Shields et al., 2013).

Interestingly, a group of researchers carried out a secondary data analysis based on the previous research results (Touyz et al., 2013). The aim of the study was to investigate factors that may affect attrition rates. In multivariate analysis, a longer duration of illness (characterised by AN-purging subtype and poor eating disorder quality of life) was associated with higher attrition rates irrespective of the treatment group. This finding suggests that these patients might require a different type of treatment regime or a longer period of treatment to achieve a higher rate of treatment adherence (Hay & Touyz, 2015).

Raykos et al. (2018) found that evidence-based treatment such as enhanced cognitive behaviour therapy (CBT-E) was effective for those with a greater duration or severity of illness. The study involved 134 formally diagnosed AN patients aged 18–25 (median age = 22 years, 97% female) with a mean duration of illness of five years. Three predictor outcome measures (illness duration, pre-treatment disorder symptom severity and pre-treatment BMI) were used to determine whether poor treatment outcomes were associated with evidence-based CBT-E. Only two predictor variables (duration/severity and treatment outcome) were
positively associated with the continuation and completion of CBT-E treatment; therefore, it did not affect treatment outcomes. The results also showed that patients with a low BMI can effectively engage in evidence-based treatments, thereby providing hope for improved clinical outcomes for people with SE-AN. A limitation of the study was the mean duration of the illness of five years; thus, the results may not be applicable to those with a longer duration of illness. Overall, the treatments were effective in reducing eating disorder symptomology, and this was largely attributed to their collaborative nature (Bamford et al., 2016). Table 2.2 illustrates the differences and similarities between CBT and SSCM-SE.

Table 2.2

*Similarities and Differences between CBT and SSCM-SE*

<table>
<thead>
<tr>
<th>CBT</th>
<th>SSCM-SE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients receive motivational therapy strategies to improve motivation and readiness for change.</td>
<td>Psychoeducational material is given and discussed to increase patient motivation.</td>
</tr>
<tr>
<td>Treatment and sessions are highly structured and largely therapist-directed.</td>
<td>Treatment and sessions are less structured and are based on what the patient brings to the session.</td>
</tr>
<tr>
<td>Eating behaviour is directly challenged through the use of behavioural experiments and cognitive strategies.</td>
<td>Changes to eating behaviours are encouraged using advice and education around nutrition rather than specific strategies.</td>
</tr>
<tr>
<td>Patients are given homework in each session that relates to session content and is always followed up in the next session.</td>
<td>No homework is ever given. Patients may be sent away with educational material, but it is not necessarily raised in the next meeting.</td>
</tr>
</tbody>
</table>

*Note.* Touyz et al. (2013, p. 2504).

**2.9.3 Internet-based interventions**

It is increasingly recognised that inpatient care in the treatment of AN is an expensive enterprise (Vandereycken, 2003) and requires more resources and labour than outpatient and other forms of care. Hospitals are under enormous financial pressure to meet budget targets, and they have limited resources to deliver even adequate services. Resources such as specialised hospital staff (e.g., nurses, psychiatrists and dietitians), equipment, psychoeducational material, medications and lengthy hospital admissions can contribute to
the overall expenses of providing hospital care, thereby exceeding budget and time estimates (Stuhldreher et al. 2012).

This problem is further compounded by the fact that health insurance companies may not cover the full costs or may even refuse to provide medical coverage (Andersen, 1998; Escobar-Koch et al., 2010; Guarda & Heinberg, 2004; Vandereycken, 2003). This is attributed to the chronic nature of the illness, which is both an expensive and time-consuming illness to treat, particularly for patients who have repeated hospital admissions (Guarda & Heinberg, 2004; Noordenbos et al., 2002; Strober, 2004).

An argument that health insurers could use to defend their position, and one that holds some truth, is that patients with SE-AN do not respond to standard empirically validated treatments (Bulik & Kendler, 2000; Geppert, 2015; le Grange & Lock, 2005). Of course, this further limits women’s treatment options and creates a potential barrier to receiving health care, especially for those who are in the early stages of the illness (Silber, 1994; Touyz et al., 2013). As a result, hospitals are pressured to discharge patients early, which may compromise their health (Andersen et al., 1997; Guarda & Heinberg, 2004; Vandereycken, 2003). One study reported that an episode of anorexia is the second most expensive common condition to treat in private healthcare (NEDC, 2012). The average cost of restoring a person’s weight is estimated to be up to US$321,300 per patient through the inpatient care system (Guarda et al., 2017).

To counteract this, there is growing interest in internet-based intervention programs that offer a solution to these economic problems (Deng, Chen, & Li, 2017). A number of online digital tools (e.g., webchats, videos, blogs, Facebook, Google, Instagram and Twitter) are cost-effective and offer availability and accessibility, efficiency and anonymity, privacy and confidentiality, and flexibility (Winzelberg, Luce, & Abascal, 2004). Further, they give more control to consumers, who determine when and how they engage with these online
platforms. In addition, these platforms can facilitate cross-cultural communication, promote collaboration and enhance the understanding of different cultural perspectives (Deng et al., 2017, p. 2).

A systematic review concluded that internet-based interventions that used CBT principles, aimed at eating disorders, were effective in reducing eating disorder symptoms (e.g., purging and bingeing behaviours) and could potentially overcome the social stigma and barriers to accessibility and cost (Dölemeyer, Tietjen, Kersting, & Wagner, 2013). The review consisted of eight control studies involving 609 participants, of which 97% were female patients aged 24–45 with ‘serious eating issues’ or ‘diagnosed eating disorders’. A key limitation of the study was the use of a heterogeneous sample size. The results may not be applicable to one or all patient groups: with or without a formal diagnosis, to patients aged younger than 24 or older than 45, or to males with eating disorders.

There are both advantages and disadvantages to using online forums. A recent qualitative study identified two main factors that motivated online users (Smahelova et al., 2019). One was to seek out support from different social media platforms to maintain their motivation to be thin. The second involved recovery support, in which participants used online social networks to maintain their motivation to recover.

Despite the above, the data from the study suggest that internet-based interventions could become an adjunct, or in some instances be an alternative to conventional forms of treatment, with a focus on prevention. Failing to integrate internet-based interventions into clinical practice could otherwise limit service delivery, particularly for those who may not otherwise have access to, or choose not to seek, traditional forms of care (Dölemeyer et al., 2013; Winzelberg et al., 2004).
2.9.4 Palliative care

Another philosophical dimension of this ethical debate, and one that has gained increasing research interest, is the issue of ‘palliative care’ and ‘passive euthanasia’ in the treatment of SE-AN patients—especially for those who do not respond to curative treatment and are competent to refuse treatment (Calugi et al., 2017; Draper, 1998; Geppert, 2015; Giordano, 2010; Kaplan & Strober, 2019; Maher, 1993; Manley et al., 2001; Ramsay & Treasure, 1996; Starzomska, 2006; Vandereycken, 1998; Vandereycken & Beumont, 1998c; Williams, Pieri, & Sims, 1998).

The WHO has framed the issue of palliative care within the context of human rights, whereby a person has the right to access healthcare, hospice and palliative care to prevent and reduce their suffering or to end their life in accordance with their personal values or beliefs (Elzakkers et al., 2014; Gallagher, 1998; Guarda, 2008; McIlfatrick et al., 2013; Melamed et al., 2003; Starzomska, 2006; Thiels, 2008). The global aim of palliative care is to increase the quality of life of a patient and their family by providing them with comfort and dignity when alternative measures have failed (Al-Mahrezi & Al-Mandhari, 2016; Kaplan & Miles, 2016; Kaplan & Strober, 2019; McIlfatrick et al., 2013; Westmoreland & Mehler, 2016; Woods, Willison, Kington, & Gavin, 2008).

Several authors have suggested that palliative care (an alternative to the medical model) could yield better results (because it is less burdensome for patients and doctors) and provide a much more humane approach in the treatment of people with SE-AN (Beumont & Vandereycken, 1998; Draper, 2000; Elzakkers et al., 2014; Lopez et al., 2010; Ramsay & Treasure, 1996; Yager et al., 2016). Commentators have observed that a small percentage of SE-AN patients have an ‘intractable’ illness (beyond a seven-year duration) for which they have tried various therapies to treat and manage their illness, but to no avail (Draper, 2000; Kaplan & Strober, 2019; O’Neill et al., 1994; Schreyer et al., 2016; Starzomska, 2006;
Vandereycken & Beumont, 1998a). Rebecca Dresser (1984b), a civil libertarian, argued that repeatedly imposing coercion not only violates a person’s dignity and autonomy, but also undermines their quality of life. She stated that ‘it condemns her to a life of continued suffering’ (p. 360). Yager et al. (2016) similarly observed that there is no point in continually ‘flogging’ a person who has attempted and exhausted all treatments and whose prognosis for recovery is modest at the very least. In some cases, palliative care may be the last resort when other humane options have failed (Geppert, 2015; Lopez et al., 2010).

However, this approach has legal and ethical shortcomings. A counter-argument exists that anorexia should not be considered a ‘terminal illness’, ‘incurable’ or a ‘degenerative illness’, but rather a treatable illness (Draper, 1998; Gans & Gunn Jr, 2003; Giordano, 2010; Melamed et al., 2003; Noordenbos, Jacobs et al., 1998; Scolan et al., 2013; Tan et al., 2003a; Tan et al., 2010; Vialettes et al., 2006). Therefore, it would be superfluous to offer palliative treatment where death is ‘avoidable’ and indeed ‘reversible’ (APA, 2013; Dresser, 1984b; Feighner et al., 1972; Giordano, 2003; Melamed et al., 2003). There is evidence to support the view that recovery is possible for patients with a longstanding illness (Eckert, Halmi, Marchi, Grove, & Crosby, 1995; Noordenbos, Jacobs et al., 1998; Noordenbos et al., 2002; Ratnasuriya et al., 1991; Steinhausen, 2009; Theander, 1992; Tiller et al., 1993), and this adds weight to the counter-argument that palliative care should not be used in the care of SE-AN patients (Draper, 1998; McIlfatrick et al., 2013; Noordenbos, Jacobs et al., 1998; Vialettes et al., 2006; Williams et al., 1998).

A recent Australian study of psychiatrists’ views about PADs demonstrated a lack of support for the use of palliative care as part of a person’s PAD. Three respondents disclosed that they were ‘unsure’ whether palliative care was a suitable method of treatment (Sellars et al., 2016). This finding was comparable to a recent study involving the views of Swiss psychiatrists (N = 457) on the issue of assisted suicide for people with mental illnesses—a
form of palliative care. The survey questions were based on three case vignettes. Overall, the results showed that most psychiatrists were neutral (n = 29%) in supporting a person’s request for assisted suicide. However, the results differed slightly between case vignettes. Thirty-five participants supported a person with AN’s request, 31% supported patients with schizophrenia and 32% supported those with depression (Hodel et al., 2019).

Factors such as ambivalence (or even resistance) between respecting a person’s autonomy and upholding a clinician’s duty of care (Henderson et al., 2008; Sellars et al., 2016), being influenced by counter-transferential feelings (Strober, 2004; Zerbe, 1998) and harbouring doubts about whether a person has the capacity to make life and death decisions (Kaplan & Miles, 2016) could further explain the above results.

In addition, clinicians who support this approach might be seen as abandoning ethical values (e.g., Hippocratic Oath) and even committing a legal offence, particularly in countries such as Australia, the United Kingdom (UK) and Canada, where active euthanasia is outlawed (in certain states, territories, countries and provinces) (Giordano, 2003; Vandereycken & Beumont, 1998c). On this basis, clinicians cannot lawfully accept or respect a severely ill person’s consent to withdraw from treatment (Giordano, 2003; Starzomska, 2006).

Adopting this attitude could be seen as colluding with the patient’s pathological denial of nihilism (eating disorder) (Draper, 2000; Giordano, 2010; Lackstrom & Woodside, 1998; Russell, 1995), perceived as ‘giving up’ on the patient (Draper, 1998, p. 5) or misconstrued as supporting ‘pro-anorexic’ attitudes (Starzomska, 2006, p. 93) or even being ‘complicit’ (Campbell & Aulisio, 2012, p. 629).

Indeed, some quarters of the medical profession, where the focus is on curative interventions to preserve and prolong life, doubt the efficacy of the use of palliative care (Al-Mahrezi & Al-Mandhari, 2016; Draper, 1998). This has been corroborated by the Royal Australian and New Zealand clinical practice guidelines for the treatment of AN, which state...
that ‘prompt recognition and treatment is likely to improve the prognosis, but recovery is yet possible, even after many years of illness. It is never too late to apply vigorous treatment’ (RANZCP, 2009, p. 619).

Despite these differences in opinions, a question that concerns everyone on a personal or professional level is: When is the cut-off point to withdraw treatment that is having no effect and that has profoundly affected a person’s quality of life, which has been depleted of meaning to the point that living is simply too unbearable? One way to answer this question is to establish whether PADs have any value in the lives of people with SE-AN who are medically or psychologically unwell, and whether they could minimise a person’s suffering and improve their overall quality of life (Atkinson, 2010; Halpern & Szmukler, 1997). These questions will be further discussed in the findings section, where the participants of this study share their views.

Although palliative care has been suggested as an option for people with SE-AN—particularly those at the ‘end stage’ of their psychiatric illness—it remains a controversial issue with few empirical or theoretical studies to support its use, and it is an area that requires further research (Lindblad, Helgesson, & Sjöstrand, 2019; Westmoreland & Mehler, 2016).

2.9.5 Good practice principles

This review has demonstrated that there is little empirical or theoretical data to support any one specific counselling modality, and there are no comparative data to prove that one method is superior to another in the treatment of SE-AN (Byrne et al., 2017; Dresser, 1984b; Finelli, 2001; Guarda, 2008; Lacey & Sly, 2016; Madder, 1997; Mann et al., 2018; Matoff & Matoff, 2001; McIntosh et al., 2010; McIntosh et al., 2005; Strober, 2010; Touyz et al., 2013).

However, this is not to say that these ascribed models cannot be integrated to form a number of ‘good practice principles’ in the provision of care for SE-AN patients (Garner & Needleman, 1997; Golan, 2013). These include: avoiding using the label ‘chronic anorexia’,...
which could lead to a ‘self-fulfilling prophecy’ (labelling theory), resulting in poor recovery and stigmatising of the individual (Broomfield et al., 2017; Dresser, 1984b; Ramjan, 2004; Theander, 1985; Tierney & Fox, 2009); providing ongoing psychoeducation (both written and verbal) about the illness (Carney, Tait et al., 2006; Connan & Treasure, 2000; Garner, 1997; McIntosh et al., 2010); early referral for intensive care, particularly in acute cases (Tierney & Fox, 2009); supporting patients to maintain and build supportive relationships (Bakker et al., 2011; Tierney & Fox, 2009); and establishing a collaborative alliance with the patient, the patient’s family and carers (Bell, 2003; Carney, Tait et al., 2006; McIntosh et al., 2010; Rathner, 1998; Wonderlich et al., 2012).

Further, establishing a strong therapeutic relationship with a focus on improving the quality of life of people with SE-AN (Bamford et al., 2015; Bamford & Sly, 2010; Bamford & Mountford, 2012; Bulik & Kendler, 2000; Calugi et al., 2017; Robinson et al., 2015; Touyz et al., 2013; Winick, 1994; Wonderlich et al., 2012), as well as being respectful of a person’s dignity and autonomy (Ciao et al., 2016; Connan & Treasure, 2000; RANZCP, 2014; Wonderlich et al., 2012), can reduce the severity and longevity of the illness and predictably improve a person’s recovery (Carney, Tait et al., 2006; Garner & Garfinkel, 1997; RANZCP, 2009; Shattell, McAllister, Hogan, & Thomas, 2006; Stiles-Shields et al., 2013; Tierney, 2008; Werth Jr et al., 2003).

2.10 Conclusion

In summary, this chapter has identified that the incidence and prevalence rates of people with AN have continued to increase, especially among teenage girls living in Western countries. Emerging data have revealed that eating disorders have increased in non-Western countries, particularly over the past decade. It appears to be a growing social problem that has been previously reported but acknowledged by few studies. A growing body of data derived from surveys suggests that health professionals—mainly community doctors and nurses—do
not have adequate training to detect signs and symptoms of eating disorders. In addition, this chapter has provided an overview of the types of treatment models that are currently or have previously been used to assist patients with SE-AN in managing their chronic symptoms. This analysis highlights two important points. First, these patients have complex needs that have been overlooked by the traditional medical model, which has proved to be largely ineffective in reducing the risk of relapse. Second, a number of modified eating disorder therapies have been proposed that place less emphasis on weight and more emphasis on harm minimisation, and these are showing promising results for the treatment of SE-AN. These targeted therapies reflect a growing trend to provide individualised care that will meet the needs of people with SE-AN. However, further research is required to determine their efficacy in ensuring that appropriate care is being provided to reduce the chronicity of the illness.

As indicated earlier, patients with SE-AN are often medically underweight, psychologically impaired and refractory in nature. This poses a number of ethical issues when providing healthcare services for these patients. The next chapter will explore the application of the core ethical principles and values to guide and navigate clinicians in their treatment decisions.
Chapter 3: Ethical Principles and Values

In our culture we hold ingrained and asserted beliefs that all men [and women] are endowed with certain unalienable rights ... among these are life, liberty and the pursuit of happiness. (Backlar, 2004, p. 84)

3.1 Introduction

The purpose of this chapter is to provide an overview of the ethical principles and values underpinning the medico-legal debate involving the care of females with SE-AN. Further, it is designed to act as a reference point to help the reader navigate the claims and counter-claims of the debate and interpret their meaning.

3.2 Ethical Principles—Principlism

Ethics and values are inexorably linked to healthcare and eating disorders. They play an important role in decision-making—especially in cases of treatment refusal—and reconciling competing values (Fry & Johnstone, 2008; Geller et al., 2012; MacDonald, 2002; Matusek & Wright, 2010; Norvoll et al., 2017; Roberts & Dyer, 2007; Silber, 2011; Sjöstrand et al., 2015; Werth Jr et al., 2003).

At present, there are limited guidelines to give clinicians direction in the care of adults with SE-AN, particularly relating to the ethical considerations of involuntary treatment (APA, 2000; Carney et al., 2019; Knapp & Vandecreek, 2007; NICE, 2017; Noordenbos et al., 2002; RANZCP, 2014; Woodside et al., 2016; Yager et al., 2016).

Beauchamp and Childress (2001) proposed that the normative ethical principles of autonomy, beneficence, nonmaleficence and justice can guide clinicians and therefore provide a standard framework for ethical decision-making—that is, to critically evaluate and resolve ethical issues—a concept known as principlism (Austin, 2008; Barker, 2010b; Beauchamp & Childress, 2001; Bergum & Dossetor, 2005; Burnor & Raley, 2011; Davis, 1997; Haughey & Watson, 2015; Johnstone, 2009; Jonsen, Siegler, & Winslade, 2010; Kitchener, 1984; Patel &
Bloch, 2009; Robertson, Ryan, & Walter, 2007; Rosenman, 1998; Sellers, 2009; Werth Jr et al., 2003; Yager et al., 2016).

These principles are considered the ‘dominant paradigm in Western medical ethics’ (Robertson et al., 2007, p. 281) and are applied using a rational analytical approach (Buchanan & Brock, 1989; Davis, 1997; Fry & Johnstone, 2008; Jonsen, Veatch, & Walters, 1999b). Further, they can be applied in different cultural, social and economic contexts (Roberts & Dyer, 2007) and are in no way inferior or less valuable than each other (Carter, 2002; Haughey & Watson, 2015). In addition, one or more principles can simultaneously be used to guide clinical decision-making (Carter, 2002; Gampel, 2006; Werth Jr et al., 2003). Of course, there is no ‘right’ answer to ethical decision-making, because people’s values and beliefs may vary in different situations and at different times (Buchanan & Brock, 1989; Charles, Gafni, & Whelan, 1997; Forester-Miller & Davis, 1995; Fry & Johnstone, 2008; Hill et al., 1998). Further, rights are not ‘absolute’ but are relative to people’s circumstances; accordingly, they can be upheld or taken away (Beauchamp & Childress, 2001; Loewy, 2004; Peel, 2005). For example, if an incompetent person threatens to self-harm or harm others, clinicians are not bound to honour the principle of respect for autonomy. This is predicated on the belief that it is in the best interest (safety) of the individual and for the protection of society—a concept known as social paternalism (Bogdanoski, 2009; Dresser, 1984a; Høyer et al., 2002; Kjellin & Nilstun, 1993; McLachlan & Mulder, 1999; Roberts & Dyer, 2007; Tort-Herrando, Van Lier, Olive-Albitzur, Hulsbos, & Muro-Alvarez, 2016; Vogelstein, 2016).

Ultimately, the goal of decision-making is to find a ‘balance’ between competing principles that is made in the ‘best interest’ of all parties, that is based on the ‘least restrictive principle’ and that is ‘collaborative’ in nature (Haughey & Watson, 2015). These moral principles will form the basis of the proposed ethical decision-making model in this study (see Section 10.3).
According to Beauchamp and Childress (2001) to gain insights into and clarity about ethical conflicts, it is ‘only by examining moral principles and determining how they apply to cases, and how they conflict, can we bring some order and coherence to the discussion of these problems’ (p. vii). These principles are each outlined below.

3.2.1 Autonomy: ‘respect for persons’

The term ‘autonomy’ is derived from the Greek auto (‘self’) and nomos (‘law’)―that is, having one’s own laws (Breeze, 1998; Carter, 2002; Giordano, 2005; Grace, 2013; Mitchell & Lovat, 1991; Thomasma, 1983).


This means that a person has freedom of action, or ‘the freedom to do what one wants to do with one’s own life as long it does not interfere with similar freedoms of others’ (Kitchener, 1984, p. 46), and freedom of choice, or making autonomous decisions about their life based on their preferences, desires, plans, values and goals (even if they are not obvious) without any direct or indirect interference or coercion (e.g., familial, social or cultural), even though others may disagree or consider them foolish, irrational or unreasonable (Austin, 2008; Bersoff & Koeppel, 1993; Draper, 2000; Giordano, 2003; Johnstone, 2009; Jonsen, Veatch, & Walters, 1999a; Kitchener, 1984; Oshana, 1998; Roberts & Dyer, 2007; Van Deurzen & Adams, 2010; Vogelstein, 2016; Winick, 1996).
For this reason, it has been argued that autonomy (individualism) plays an important role in people’s lives because it gives them a sense of control and independence and is generally considered by society a fundamental right to liberty—that is, a ‘sacrosanct principle’ that cannot be denied or compromised (Austin, 2008; Backlar, 1999; Dresser, 1984c; High, 1990; Ho, 2008; Loewy, 2004; O’Brien & Golding, 2003; Varelius, 2006).

3.2.1.1 Concept of competency—a brief overview

The principle of autonomy works from the presumption that a person has the ability to make competent and rational decisions until proven otherwise, notwithstanding their diagnosis or condition (Beauchamp & Childress, 2001; Campbell & Aulisio, 2012; Faith, 2002; Haughey & Watson, 2015; Johnstone, 2009; Kitchener, 1984; Lepping, 2011; Olsen, 2003; Roberts & Dyer, 2007). However, the notion of competency has many philosophical and ethical dimensions and remains a moot point in the bioethical literature in terms of determining a person’s level of competency (Appelbaum, 2007; Appelbaum & Grisso, 1988; Beauchamp & Childress, 2001; Lepping, 2011). Subsequent sections (see Section 5.1.8) will expand on this concept.

3.2.2 Beneficence: ‘promoting well-being’

Beneficence can be defined as ‘active well-doing’, ‘altruism’, ‘conduct aimed at the good and well-being of others’ (Mitchell & Lovat, 1991, p. 79) or actions that ‘contribute to their welfare’ (Beauchamp & Childress, 2001, p. 165).

This ethical principle is contentious in the medico-legal debate because it can, at times, conflict with the ethical principle of autonomy (Breeze, 1998; Dworkin, 1993; Hill et al., 1998; Kitchener, 1984; Roberts & Dyer, 2007; Werth Jr et al., 2003). For example, what constitutes ‘doing good’ from a clinician’s perspective may not necessarily be consistent with the patient’s wishes or views; therefore, the clinician may risk violating the patient’s right to liberty (Gans & Gunn Jr, 2003; Rathner, 1998; Varelius, 2006). The main concern here lies
with the ethical challenge of balancing these core principles (see Section 1.2 for an example) (Faith, 2002; Mappes & Zembaty, 1981; Varelius, 2006).

3.2.3 Nonmaleficence: ‘above all, do no harm’

Nonmaleficence has its roots in Latin and is derived from the term ‘maleficent’, from maleficus (‘wicked’ or ‘prone to evil’), from malum (‘evil’) and male (‘ill’) (Johnstone, 2009, p. 40). To capture the essence of this ethical principle, one such dictum has been cited—‘one ought to prevent evil or harm’ (Beauchamp & Childress, 2001, p. 151).

Thus, nonmaleficence is considered a cardinal ethical principle in which health professionals are bound to the Hippocratic Oath of ‘above all, do no harm’ (Bersoff & Koeppl, 1993; Grace, 2013; Johnstone, 2009; Mohanti, 2009). Specifically, the Hippocratic Oath states: ‘the regimen I adopt will be for the benefit of my patients according to my ability and judgment’ (Campbell & Gillett as cited in McLachlan & Mulder, 1999, p. 729).

However, this moral principle provides little guidance to help clinicians determine whether their actions (or decisions) could result in potential harm to others; equally, it is difficult to determine what actually constitutes ‘harm’ (Capron, 1991; Hill et al., 1998; Jonsen et al., 1999b; Kitchener, 1984; Varelius, 2006). According to Kitchener (1984), care providers have a stringent obligation of ‘not inflicting intentional harm nor engaging in actions which risk potential harm to others’ (p. 47). Beauchamp and Childress (2001) defined harm in a physical, emotional and financial sense and recommended that clinicians consider the possible effects on their patients.

To minimise potential harm, most clinicians apply the utilitarian approach of weighing up the ‘benefit–risk ratio’ (expressed as the principle of proportionality) when making ethical decisions (Danis et al., 1991; Goldner et al., 1997; Jonsen et al., 2010; Quill, Dresser, & Brock, 1997; Roberts & Dyer, 2007; Rosenson & Kasten, 1991). This involves weighing up the pros and cons of each option (i.e., treating v. not treating) and then choosing the option
that carries the most weight (Beauchamp & Childress, 2001; Rosenson & Kasten, 1991; Varelius, 2006). Using this ‘logical reasoning’ approach enables the treating practitioner to consider the implications of each option and, in theory, should minimise the risk of potential harm to others or have the least restrictive effect (see Section 5.1.7) (Bersoff & Koepppl, 1993; Bond, 2009; Charles et al., 1997).

3.2.4 Justice: ‘act in a fair and equitable manner’

Justice is an ethical principle that fits into the human rights and social justice framework in which people have the right to access service ‘goods’ such as healthcare services to meet their individual or cultural needs (Chase, 2004; Daniels, 1991; Jacobson & Greenley, 2001; Peel, 2005; Roberts & Dyer, 2007). Therefore, the principle of justice can act as a vehicle to protect and safeguard the wellbeing of disadvantaged and vulnerable people by ensuring that all resources are equally distributed and that the provision of treatment (standard of care) is not biased and does not discriminate on the basis of mental health status, age, gender, cultural background or disability (Huycke, 2000; Johnstone, 2009; Kitchener, 1984; PACFA, 2011; Vogelstein, 2016). This is consistent with Beauchamp and Childress’s (2001) definition of ‘a wrongful act or omission that denies people benefits to which they have a right or distributes benefits unfairly’ (p. 226).

A major catalyst for the principle of justice is to combat and therefore reduce people’s experience of stigma, prejudice and discrimination within the mental health system (Deegan, 1997; Jacobson & Greenley, 2001; Pozón, 2015). There is overwhelming evidence to support the assertion that people’s experiences of these factors can negatively influence their engagement and treatment in mental health services and therefore affect their recovery (Chamberlin, 2005; Johnstone, 2009; Winick, 1994).

The principle of justice recognises and upholds the inalienable ‘rights’ and ‘dignity’ of every person (Barker, 2010b; Jacobson & Greenley, 2001; National Health and Medical
Research Council [NHMRC], 2007; Rosenman, 1998). It also empowers individuals and groups by allowing them to exercise their fundamental rights to make quality of life choices that are consistent with their values and beliefs.

### 3.3 Moral Values

Moral values are the foundation of human interactions and are designed to guide human behaviour in resolving moral problems (Bersoff & Koeppl, 1993; Deegan, 1997; Fry & Johnstone, 2008; Johnstone, 2009; Mappes & Zembaty, 1981). To help this process, Beauchamp and Childress (2001) identified four values: veracity, fidelity, privacy and confidentiality. These values are all likely to influence each other, they are all underpinned by the doctrine of informed consent and they all support a person’s wellbeing and self-determination (Barker, 2010b; Buchanan & Brock, 1989; Dyer & Bloch, 1987; Sellers, 2009).

#### 3.3.1 Veracity

Veracity is the principle of ‘truth-telling’, and it involves acting in a moral manner by not telling lies or deceiving others (Dyer & Bloch, 1987; Fry & Johnstone, 2008; Pergert & Lützén, 2012; Roberts & Dyer, 2007). Veracity requires healthcare workers to provide ‘accurate, comprehensive and objective information’ (i.e., duty of disclosure) to the patient and their family (Beauchamp & Childress, 2001, p. 289), and it should be delivered in a culturally sensitive and respectful manner (Fry & Johnstone, 2008; Pergert & Lützén, 2012; Roberts & Dyer, 2007). Further, healthcare workers have an obligation to ensure that the patient comprehends the medical and psychological information (i.e., costs, benefits and risks) so they can make an informed decision to accept or reject treatment (Bergum & Dossetor, 2005; Dyer & Bloch, 1987; Huycke, 2000; Jonsen et al., 2010; Jonsen et al., 1999b; Rathner, 1998; Roberts & Dyer, 2007; Vialettes et al., 2006).
3.3.2 Fidelity

Fidelity is defined as an ‘obligation to act in good faith to keep vows and promises, fulfill agreements, maintain relationships, and discharge fiduciary responsibilities’ (Beauchamp & Childress, 2001, p. 312). This principle can be best understood within the context of maintaining a person’s privacy and confidentiality (Bersoff & Koeppl, 1993; Dyer & Bloch, 1987).

3.3.3 Privacy and confidentiality

People with mental health disorders have the right to privacy and confidentiality (Barker, 2010b; Dworkin, 1993; Husted & Husted, 1991). Respecting a person’s privacy and confidentiality recognises that the person has control over their personal information. They determine to whom, when and under what circumstances to disclose and provide access to their personal details (Berglund, 2001).

Privacy is defined as ‘a state or condition of limited access’ (Beauchamp & Childress, 2001, p. 296) or denying a person’s access to information about their medical care. Confidentiality is an important value in a patient–doctor relationship, especially when honouring a person’s trust (Beauchamp & Childress, 2001; Grace, 2013; Kitchener, 1984; Peel, 2005). The clinician has a duty to protect (or conceal) a patient’s information (e.g., medical records), which cannot be disclosed to a third party without their explicit consent (Barker, 2010b; Beauchamp & Childress, 2001; Mappes & Zembaty, 1981). Respecting a person’s confidentiality also respects their dignity as a worthy human being (Kunyk & Austin, 2012; NHMRC, 2007; PACFA, 2011).

3.4 Conclusion

In summary, these moral values and normative ethical principles provide a framework for decision-making to guide health professionals in resolving ethical dilemmas in healthcare settings. They are an integral component of the doctor–patient relationship because they can
act as a platform from which to promote collaboration, and they safeguard people’s rights.

This is an essential component of the development of PADs and will be discussed in the next chapter.
Chapter 4: Part One: ‘Advance Care Planning’ Literature Review

4.1 Introduction

This chapter will explore advance care planning, and Chapter 5 will examine the ethical considerations of people with SE-AN. The two chapters aim to draw parallels between the two topics to examine how they interrelate, and thereby provide justification for the development of an ethical decision-making model. Australian and international studies are used in this study to illustrate key issues about PADs. End-of-life and general PAD literature were used because of their social contextual factors, namely competency, healthcare preferences and quality of life values.

4.2 History of Psychiatric Advance Directives—Models of Care

Thomas Szasz, a well-known United States (US) psychiatrist, stated:

*Competent American adults should have a recognized right to reject involuntary psychiatric interventions that they may be deemed to require in the future, when they are not competent to make decisions concerning their own welfare.* (Szasz, 1982, p. 766)

Traditionally, the ‘medical model’ was based on the idea that a mental illness ‘is a brain disease with a genetic or biochemical origin’ (Chamberlin, 2005, p. 12) that renders a person incapable of autonomous decision-making—that is, they do not have the capacity to understand their need for treatment (Høyer et al., 2002; Olofsson & Jacobsson, 2001). However, there are no data to support this claim (Wand, 2015). By default, consumers were viewed as ‘passive recipients’ in their medical care, in which their civil and human rights were abrogated and they were treated in an infantile manner (Alharbi et al., 2014; Ambrosini & Crocker, 2007; Charles et al., 1997; Dyer & Bloch, 1987; Ho, 2008; McQueen, 2000; Miller, 1998; NEDC, 2012; Polgar & Thomas, 2008; Pozón, 2015; Waterworth & Luker, 1990; Weller, 2010; Winick, 1994).
Further, it was common practice for doctors to adopt the role of a surrogate decision-maker (i.e., determining the benefits and risks of proposed treatments), thus excluding the patient’s views and support (e.g., friends and significant others) from the medical decision-making process (Battin, Francis, & Landesman, 2007; Brown, 2003; Gampel, 2006; High, 1990; Lally & Tullo, 2012; Levinsky, 1984; McLachlan & Mulder, 1999; Rich, 1998; Wand, 2015). Clearly, this approach is paternalistic and undermines the person’s autonomy.

In contrast, the consumer-focused model encourages consumer participation in the mental health system (Alharbi et al., 2014; Amering et al., 1999; Coulter et al., 2008; Waterworth & Luker, 1990). For example, in Victoria, Australia, the Victorian Government developed a set of guiding principles called ‘The Framework for Recovery-Oriented Practice’ to help health workers promote recovery among people living with a mental illness and to enhance collaboration between health professionals and people with mental health issues and their significant others through supported decision-making (Commonwealth of Australia, 2013; Department of Health & Human Services, 2011; Jacobson & Greenley, 2001; Loewy, 2004; RANZCP, 2014; William, 1993; Wyder, Bland, & Crompton, 2013). One of the principal goals is to develop partnerships and meaningful engagement: ‘Mental health services work to promote people’s mental health, wellbeing, and recovery by establishing and sustaining collaborative partnerships with people’ (Department of Health & Human Services, 2011, p. 11).

This model of care neither assumes nor subscribes to the view that a person with a mental illness is a passive recipient who lacks the capacity to make decisions; rather, it considers them an active decision-maker in their medical care (Andersen et al., 1997). Mental illness per se does not necessarily render a person incompetent—that is, they have the ability to engage in the process of reasoning and formulating an argument (Breeze, 1998; Brock,
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To support this new model of patient care, PADs have been promoted to enhance a person’s autonomy and control in the decision-making process (Atkinson, 2007, 2010; Atkinson, Garner, Stuart, & Patrick, 2003). This is consistent with the recommendations of the national framework for recovery-oriented health services (Commonwealth of Australia, 2013).

4.3 Benefits and Value of Psychiatric Advance Directives

PADs are a new ‘paradigm for management’ of people with SMIs. They aim to give a voice to people who were or are currently receiving psychiatric care (Srebnik, Russo, Sage, Peto, & Zick, 2003). PADs are designed to improve patients’ health outcomes by giving them control and autonomy in decision-making (i.e., refuse or accept treatment) and by nominating a proxy in the event of losing competency (Bogdanoski, 2009; Collier, Coyne, & Sullivan, 2005; Johnstone, 2009; Perkins, 2000; Shields et al., 2014; Srebnik et al., 2003; Swanson et al., 2003; Swanson et al., 2000; Van Dorn et al., 2010; Vollm & Nedopil, 2016).

There is a considerable body of literature on the potential benefits of PADs, which include improving continuity of care and guiding treatment decisions (Geller, 2000; Sherman, 1998; Swanson, Van McCrary, Swartz, Van Dorn, & Elbogen, 2007), fewer and shorter hospital admissions (Backlar & McFarland, 1998; Bogdanoski, 2009; Gallagher, 1998; Geller, 2000), promoting the patient’s autonomy and empowerment (Backlar & McFarland, 1998; Bogdanoski, 2009; Farrelly et al., 2014; Gallagher, 1998; O’Connell & Stein, 2005; Scheyett et al., 2008), increasing trust and satisfaction in the physician–patient relationship (Bogdanoski, 2009; Page et al., 2002; Srebnik & Russo, 2008; Srebnik et al., 2005), improving treatment participation and adherence (Bogdanoski, 2009; Srebnik et al., 2005; Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006; Van Dorn et al., 2010; Winick, 1994).
decreasing perceived coercion (Gallagher, 1998; La Fond & Srebnik, 2002; Srebnik & Russo, 2008; Swanson et al., 2000; Weller, 2010; Zelle et al., 2015), enabling the patient to take more control and responsibility for their illness (Atkinson et al., 2003; Davidson & Birmingham, 2003; La Fond & Srebnik, 2002; Ritchie, Sklar, & Steiner, 1998; Swanson et al., 2000), strengthening the therapeutic alliance and communication (Papageorgiou, King, Janmohamed, Davidson, & Dawson, 2002; Sutherby et al., 1999), maintaining the patient’s sense of dignity and self-worth (Miller, 1998; Morrissey, 2010; Olsen, 2016; Scheyett, Kim, Swanson, & Swartz, 2007; Swanson et al., 2000), and improving the patient’s quality of life (Backlar, 1995; Miller et al., 2019).

Despite these benefits, research has shown that PADs are not widely used among patients with SMIs, which is indicative of their low completion rates and is a problem that has been reported in many countries (Lemon, De Ridder, & Khadra, 2019; White et al., 2014).

The next section outlines a number of barriers that have contributed to this problem (Elbogen, Swanson, Appelbaum et al., 2007; Foti, 2003; Scheyett et al., 2007; Sherman, 1998; Swanson, Swartz, Ferron et al., 2006; Swanson et al., 2003; White et al., 2014).

### 4.4 Barriers to Completing Advance Directives

The literature review identified a number of potential barriers that prevent people with SMIs from completing PADs, thereby reducing their uptake. These include patient-reported barriers, clinician-reported barriers and system barriers (Anselm et al., 2005; Boddy, Chenoweth, McLennan, & Daly, 2013; Miller et al., 2019; Ramsaroop, Reid, & Adelman, 2007; Shields et al., 2014; Spoelhof & Elliott, 2012; Sulmasy, Song, Marx, & Mitchell, 1996; Van Dorn et al., 2010; Zelle et al., 2015). Common to all three categories is a lack of communication and knowledge about PADs, particularly in the context of information sharing between all stakeholders (Anselm et al., 2005; Backlar & McFarland, 1996; Boddy et al., 2013; Golden et al., 2008; Henderson, Jackson, Slade, Young, & Strauss, 2010; Jezewski,
4.4.1 Patient-reported barriers

It is a fallacy to believe that people with SMIs are not interested in, or capable of, participating in discussions about PADs. Rather, researchers have concluded that they have limited or no knowledge of their existence, they lack an understanding of how they work, or they receive limited or no assistance in notarising a document (Bogdanoski, 2009; Elbogen, Swanson, Appelbaum et al., 2007; Foti, 2003; McLennan, Boddy, Daly, & Chenoweth, 2015; Srebnik & Fond, 1999).

Recently, promising results have shown that when patients are offered assistance to create a PAD, this in turn increases their interest in PADs and improves the therapeutic alliance. A study that examined the views of psychiatric outpatients (N = 1,011) across five US cities (n = 200 at each site) reported that fewer than 13% of individuals with SMIs had completed a PAD. Most respondents (66–77%) indicated that they would be interested in having a PAD if they were given support to fill it out (Swanson, Swartz, Ferron et al., 2006). This interest was strongly correlated with those who had experienced a higher degree of coercion, had experienced negative police involvement, had a past history of suicide or self-harm, or were non-white females with limited autonomy.

A trial of (N = 469) participants demonstrated a strong correlation between the uptake rate of PADs and the use of facilitators (Swanson, Swartz, Elbogen et al., 2006). The intervention group received written information about PADs and referral resources. As a result, 61% of the participants from the intervention group had completed an AD or used an authorised proxy decision-maker, whereas fewer than 3% of control participants had written a PAD. At one-month post-treatment, participants in the facilitated group reported having a
stronger working relationship with their healthcare providers and felt that their needs were being met. In another study, evidence showed ‘overwhelming endorsement of the usefulness of and the need for the F-PAD (facilitated PAD intervention) intervention’ (Elbogen, Swanson, Swartz et al., 2007, p. 9). Almost all (94%) of the 125 participants indicated that they would not have completed a PAD without the help of a facilitator. At the one-year follow-up, 78% of the respondents reported that they were satisfied with their PAD.

A study involving adults with an SMI ($N = 303$) found that 53% of the respondents expressed an interest in creating a PAD (Srebnik et al., 2003). Among the many reasons offered, 27% said that their case manager had suggested a PAD, 36% believed that a PAD would be helpful and 22% did not want to be subjected to repeated negative treatment experiences.

A recent qualitative study that involved general nurses helping patients to fill out an advance care plan (ACP) showed that patients ‘value the opportunity to speak about issues that are important to them’ (Miller et al., 2019, p. 1). Six major themes were identified from the interviews. There was a general consensus that ACP could help with ‘working through their ideas’, ‘improving the therapeutic alliance with nurses’, ‘learning to exercise personal autonomy’, ‘benefiting their families by reducing uncertainty, burden, and conflict’, ‘protecting them from unwanted life-sustaining procedures’ and ‘challenges of family communication’. Thus, this study confirmed that participants benefitted from facilitated ACPs and supported their general usage.

An Australian study in Melbourne found that 30% of non-English-speaking elderly Italian and Greek patients used interpreters, and this was associated with an increase in ADs ($p < 0.005$) (Detering et al., 2015).

Other studies have reported similar findings and shown that patients would like to be given the opportunity to have a PAD; however, this was contingent on clinicians’ knowledge
of PADs and their support in implementing and honouring patients’ preferences (Backlar, 1999; Backlar & McFarland, 1996; Backlar, McFarland, Swanson, & Mahler, 2001; Kim et al., 2007; Srebnik et al., 2003; Swanson, Swartz, Elbogen et al., 2006).

4.4.1.1 Honour a person’s psychiatric advance directive and the law

A common theme that emerged from a number of studies was that not ‘honouring’ a person’s AD was considered a major disincentive for those wishing to complete an AD (Backlar, 2004; Henderson et al., 2008; Kim et al., 2007; Scheyett et al., 2007; Sellars et al., 2016; Srebnik & Fond, 1999; Swanson et al., 2000).

In fact, there has been some conjecture about the legal validity of ADs in the mental health system (Atkinson, 2007; Bogdanoski, 2009; Hope, 1996). Some commentators have raised a concern that if psychiatrists and the law (i.e., Mental Health Act) can override a patient’s wishes, then this defeats the purpose of having a PAD. Indeed, completing a PAD can give patients a ‘false sense of security’, make them feel further ‘marginalised and betrayed’ and, as a consequence, undermine ‘consumer confidence’ in the mental health system (Atkinson, 2007; Backlar & McFarland, 1998; Barker, 2010a; Bogdanoski, 2009; Exworthy, 2004; Swanson et al., 2000). This concern is reinforced by the fact that a PAD can be overruled by an involuntary admission in both Australia and the US (Bogdanoski, 2009; RANZCP, 2014; Shields et al., 2014). In some cases, ADs are simply ignored or not respected by health professionals (Backlar, 1995; Danis et al., 1991; Gilbert, 1995; Johnson, Singer, Masso, Sellars, & Silvester, 2015; La Fond & Srebnik, 2002).

In Victoria, Australia, section 73 (2) of the Mental Health Act 2014 states that a person’s advance statement can be overridden by a psychiatrist based on the following criteria:

1. An authorised psychiatrist may make a treatment decision under section 71(3) for a patient that is not in accordance with that patient’s advance statement, if the authorised psychiatrist is satisfied that the preferred treatment specified by the
patient in the advance statement—(a) is not clinically appropriate; or (b) is not a treatment ordinarily provided by the designated mental health service.

This raises a question of whether PADs are promoted as having a legitimate role in assisting people with SMIs or whether they are merely an attempt to acquiesce patients into believing that they have legal rights, guised under the ethical principle of autonomy, but with no real value (Kapp, 1989; Swanson et al., 2000). PADs are not legally binding documents in Australia (Commonwealth of Australia, 2013; Ouliaris & Kealy-Bateman, 2017), and there is no standard legislation about ADs. Rather, ADs in Australia are legally recognised through common law or statute law; therefore, they vary in their degree of legal enforceability in different states and territories (Atkinson, 2010; Atkinson, 2007; Boddy et al., 2013; Farrelly et al., 2014; Henderson et al., 2008; Miller et al., 2019; Ouliaris & Kealy-Bateman, 2017; Rhee, Zwar, & Kemp, 2012; Weller, 2010). An Australian study found different prevalence rates between states and territories in the uptake of ADs. These differences partly resulted from the different laws and policies governing ADs (White et al., 2014).

This poses a significant problem to consumers and clinicians. For example, continuity of care becomes a problem for consumers who frequently travel from one state to another in which their PAD may not be recognised or may even be illegal (Brown & Jarrad, 2008; Carter, Detering, Silvester, & Sutton, 2015). This may also mean that a person’s proxy (family member or advocate) may not be legally recognised (Farrelly et al., 2014). Health practitioners may feel overwhelmed by the complexities of legislation in different jurisdictions (Brown & Jarrad, 2008), and this may dissuade them from engaging in discussions about PADs with their patients.

This paternalistic legislation undermines the very essence of a person’s liberty and autonomy (see Section 3.2.1), and it acts as a barrier to prevent people with SMIs from using PADs (Ambrosini & Crocker, 2007; Backlar, 2004). An example of this is seen in the recent
changes to Victoria’s *Voluntary Assisted Dying Act 2017*, which came into effect on Wednesday 19 June 2019. The Better Health Channel website stated that:

*A person cannot request voluntary assisted dying in an advance care directive. It was decided that people requesting voluntary assisted dying need to have decision-making ability throughout the entire process to make sure their decision remains voluntary and consistent.* (Department of Health and Human Services, 2019)

This statement is contradictory given that ADs are promoted as a social justice tool for increasing the autonomy and empowerment of individuals with serious or terminal health conditions (Amering et al., 1999; Amering & Schaffer, 2007; Bonnie, 2012; Henderson et al., 2008; Khazaal et al., 2014; O’Brien & Golding, 2003; Scheyett et al., 2008; Scheyett, 2007; Shields et al., 2014; Swanson et al., 2000; Van Dorn et al., 2010; Winick, 1994; Zelle et al., 2015).

In addition, PADs can be overridden by other factors, such as their illegality, conflicts with standard treatments, exigencies of emergency treatment, incompetency issues, availability of services requested, the *Mental Health Act* and the patient’s refusal of lifesaving medical treatment (Atkinson, 2010; Bogdanoski, 2009; Exworthy, 2004; Loewy, 2004; Scheyett et al., 2008; Srebnik & Brodoff, 2003; Swanson et al., 2007). The last point is the most contentious because accepting this course of action may lead to a slippery slope whereby the patient’s wellbeing and safety are compromised while contravening the doctor’s duty of care to protect the patient’s health (Westmoreland & Mehler, 2016). As mentioned in Chapter 1, it is common for doctors to override a patient’s request to refuse treatment in order to save their life or reduce the burden of the illness (Appelbaum, 2007).

However, a number of studies have refuted the suggestion that PADs are used as a prescriptive tool to refuse lifesaving treatment (Ambrosini & Crocker, 2007; Scheyett, 2007; Swartz, Swanson, Van Dorn, Elbogen, & Shumway, 2006). For example, a group of researchers in Oregon conducted a study to elicit the views of people with SMIs regarding
PADs (Backlar et al., 2001). A convenience sample of 40 participants with SMIs were recruited from two psychiatric facilities. Most participants had a chart diagnosis of schizophrenia. The results showed that 75% of the respondents had completed a PAD and 73% had nominated a surrogate decision-maker (of which 63% elected a close family member). An important finding of the study was that none of the respondents indicated that they would use their PAD to refuse treatment.

Swartz et al. (2006) found that patients who wanted to create a PAD were strongly correlated with the recommendations (prescriptive preferences) of their doctors, whereas those who wanted to avoid unwanted treatment (proscriptive preferences) were the least valued by patients. This finding strengthens the evidence that patients do not create a PAD for the sole purpose of avoiding unwanted treatment.

Multiple studies have shown that PADs have not been used to refuse treatments or to exclude family members or doctors from being involved in the patient’s treatment (Amering, Stastny, & Hopper, 2005; Appelbaum, 2004; Backlar et al., 2001; Elbogen, Swanson, Appelbaum et al., 2007; Kim et al., 2007; Page et al., 2002; Peto, Srebnik, Zick, & Russo, 2004; Sherman, 1998; Swanson et al., 2000).

Other barriers that have been identified as preventing the uptake of PADs include the patient’s lack of trust and confidence in their care provider and the mental health system (Atkinson et al., 2003; High, 1990; Ritchie et al., 1998; Rosenson & Kasten, 1991; Swanson et al., 2003; Swartz et al., 2006; Varekamp, 2004; West & Hollis, 2012), the patient’s belief that PADs will not make a difference to their overall care and treatment (Atkinson, 2007; Backlar et al., 2001; McLennan et al., 2015; Srebnik et al., 2003; Swartz et al., 2006), a lack of information and resources to enable the patient to complete, notarise and submit the document (Kim et al., 2007; Ramsaroop et al., 2007; Ratnam, Rudra, Chatterjee, & Das, 2015; Rolnick, Asch, & Halpern, 2017; Scheyett, 2008; Srebnik & Fond, 1999; Van Buskirk,
1977; Vuckovich, 2003), and locating an appropriate person to serve as a proxy (Rhee et al., 2012; Swanson et al., 2000; Van Dorn et al., 2010; West & Hollis, 2012). In addition, the NICE (2017) guidelines for eating disorders do not recognise PADs, and this is a further barrier in the implementation of PADs.

Collectively, these findings suggest that a clinician’s lack of knowledge, lack of willingness to engage in discussions, lack of logistical support and lack of endorsement (honouring) of ADs are significant barriers that prevent people with SMIs from drafting and completing PADs (Golden et al., 2008; Jezewski et al., 2005; Kapp, 1989; Srebnik et al., 2003; Tulsky, 2005).

4.4.2 Clinician-reported barriers

To date, studies have found that health professionals have mixed attitudes regarding whether they would support the use of PADs for people with SMIs (Boddy et al., 2013; Gravel, Légaré, & Graham, 2006; Jezewski, Meeker, & Schrader, 2003; Shields et al., 2014; Van Dorn et al., 2010; Varekamp, 2004).

Elbogen et al. (2006) conducted a survey and found that clinicians were in favour of PADs as a beneficial tool for helping patients with SMIs. They interviewed 597 clinicians, including social workers, psychiatrists and psychologists, to determine whether they endorsed ADs. Forty-seven per cent of the respondents reported that they supported PADs as a therapeutic device, and 57% approved the use of a healthcare agent. This result was influenced by the fact that clinicians are not legally bound to follow a directive concerning a patient’s treatment refusal. Thus, most participants (61%) would honour a PAD to refuse treatment, and this was influenced by knowledge of the law, family opinions regarding treatment and respecting the patient’s autonomy. This result suggests that the clinicians’ legal knowledge was a deciding factor in whether they would support a directive for the refusal of
treatment. The authors concluded that this factor alone could affect the implementation of PADs.

In contrast, a recent survey was conducted to examine whether Australian psychiatrists (N = 143) would support an individual’s request for a PAD (Sellars et al., 2016). The study concluded that fewer than 30% of psychiatrists would support a person’s request for a PAD. Thematic analysis revealed that respect for the patient’s autonomy was the main theme for those who supported a patient’s request for a PAD, whereas ‘patient risk’ was considered an important theme when rejecting a person’s request for a PAD.

A similar pattern of results was reported in a survey involving 164 psychiatrists (Swanson et al., 2007). A total of 47% of the interviewed participants indicated that they would override a patient’s PAD if it contained a treatment preference to refuse hospitalisation and medication (OR = 3.37, p < .05).

Surveys of Norwegian and Swedish psychiatrists’ views about compulsory treatment have shown similar results (Diseth, Bøgwald, & Høglend, 2011; Kullgren, Jacobsson, Lynöe, Kohn, & Levav, 1996). The emerging theme from these studies suggests that the psychiatrists would not respect a person’s treatment preference to refuse involuntary treatment. Two factors influenced the psychiatrists’ clinical decision-making: the severity of the illness and the patient’s family, who usually pressure doctors to hospitalise their loved one.

A two-year prospective study was conducted with 126 competent patients and 49 family members of incompetent patients at a nursing home (Danis et al., 1991). Interviews were conducted to explore treatment preferences based on eight emergency medical scenarios. These preferences were recorded and placed together with the patient’s medical record to enable staff to better assist with their care. In most cases (75%), treatment preferences were consistent with the patients’ expressed wishes; however, this result was not influenced by the presence of an AD. In these cases, the principle of ‘beneficence and proportionality’
outweighed the patient’s autonomy. This suggests that ADs were ineffective as a standalone measure.

Overall, these conflicting findings support either the patient’s autonomy or the clinician’s ethical and legal obligations to protect the patient’s wellbeing and safety. This difference determines whether PADs are supported and implemented by health professionals (Elbogen et al., 2006; Rhee et al., 2012; Sellars et al., 2016; Swanson et al., 2007; Van Dorn et al., 2010; Weller, 2010).

4.4.2.1 Lack of knowledge and training

Several studies have identified that practitioners’ lack of knowledge and training regarding PADs were significant barriers in preventing their uptake and implementation (Boddy et al., 2013; Foti, Bartels, Merriman, Fletcher, & Van Citters, 2005; O’Connell & Stein, 2005; Rhee et al., 2012; Scheyett et al., 2008; Shields et al., 2014).

Scheyett et al. (2008) conducted an exploratory survey of social workers (N = 193) to determine their familiarity with Health Care Power of Attorneys (HCPAs) and advance instructions (AIs). Responses were rated on a four-point scale (not at all, a little, somewhat and very). Only 5% (n = 10) of the participants were very familiar with AIs, whereas 15% indicated that they were very familiar with HCPAs. These results indicate that the participants had little experience in helping clients with AIs, thus limiting their uptake.

A comparable result was found by O’Connell and Stein (2005), who investigated the views of different professional groups in relation to PADs. Of the 272 participants, 55% had never heard of PADs (legal/law: n = 48; general healthcare: n = 33; clergy: n = 29; mental health professional: n = 19, mental health consumer: n = 13; family members: n = 5), while a small number (11%) claimed to be ‘very familiar’. The univariate results indicated that a higher level of familiarity was associated with those who had frequent contact with consumers with mental health issues, who had earned the highest degree in their professions,
and females were more likely to know about PADs than their male counterparts. Similar to the previous study, a lack of knowledge of PADs could be a barrier in their implementation and uptake.

A qualitative study involving in-depth interviews with 26 community members found that a ‘lack of knowledge’ of advance care planning was a major contributing factor in preventing its uptake (McLennan, Boddy, Daly, & Chenoweth, 2015 p. 529). In addition, participants emphasised that ACPs were inaccessible and complex, they expressed fear and mistrust that their ACP would not be followed, they had concerns over control (particularly loss of self-determination and autonomy) and they questioned their relevance to age and health. These factors, along with a lack of support in helping to formulate an ACP, were identified as significant barriers to its implementation and uptake (McLennan et al., 2015).

The last finding was similar to that of Boddy et al. (2013), in which a clinician’s lack of knowledge and training about ADs appeared to be the most significant barrier that prevented staff and patients from discussing advance care planning. One participant, a physiotherapist, stated that ‘we know what they are but we really don’t know what they mean’ (p. 42). Another participant, a social worker, stated that ‘if the staff don’t understand, which they obviously don’t, they’re not going to start bringing it up with patients if they don’t know what they’re talking about’ (p. 42).

These statements support the hypothesis that knowledge and training about ADs is a critical factor in terms of their implementation and uptake.

4.4.3 System-reported barriers

System barriers have been defined as ‘institutional, professional, and societal factors perceived to limit communication regarding end-of-life [psychiatric] care’ (Anselm et al., 2005, p. 217).
Extant research has identified a number of system barriers that prevent the implementation of PADs, including non-clinical factors such as doctors’ subjective values and interpretations (e.g., religious or ethical objections), which could influence whether they respect a patient’s healthcare choices (Coleman, 2013; Exworthy, 2004; Thompson, Barbour, & Schwartz, 2003), health practitioners’ uncertainty about the application and legal status of PADs (Boddy et al., 2013; Carter et al., 2015; Henderson et al., 2010; Shields et al., 2014; Srebnik et al., 2005; Weller, 2010; Zelle et al., 2015), a lack of time, skills and coordination among health providers (Brodtkorb, Skisland, Slettebø & Skaar, 2016; Gravel et al., 2006; Jezewski et al., 2003; La Fond & Srebnik, 2002; Ramsaroop et al., 2007; Rhee et al., 2012; Scheyett et al., 2007; Seymour et al., 2010; Spoelhof & Elliott, 2012; Srebnik & Brodoff, 2003), staff requiring information and support to initiate PADs (Seymour et al., 2010; Srebnik et al., 2005; Swanson, Swartz, Ferron et al., 2006), professionals’ concern that overriding a PAD may result in being sued (Srebnik & Russo, 2008; Wilder et al., 2013) and no AD policy in the workplace to guide health professionals (Johnson et al., 2015).

Anselm et al. (2005) conducted a series of focus groups (N = 11) with residents (n = 24), clinicians (n = 10) and nurses (n = 33) to identify key barriers to end-of-life discussions. Collectively, 20 themes were stratified into three broad categories: patient, healthcare system and healthcare providers. The dominant themes regarding system barriers were communication (i.e., information sharing among workers), providers feeling unskilled (i.e., lack of specialised skills in conducting conversations about ADs), scheduling (i.e., busy work schedules preventing communication from occurring) and lack of external support (i.e., lack of effective policy to guide decision-making). These barriers were found to hinder communication between residents and nurses regarding end-of-life discussions.

Similarly, Jezewski et al. (2003) conducted a series of focus groups with oncology nurses (N = 677) across four US states to answer the question: “What do oncology nurses
need to increase their ability to assist patients with advance directives?’ Responses to the question generated four themes: time, education, support and clarity surrounding the nurse’s role in the context of treatment decision-making. In each of the four domains, communication was identified as the main barrier to completing ADs.

4.4.3.1 Lack of time

A common theme in the review of the literature is that health professionals lack the time required to help patients complete an AD. This was identified as a major barrier to the implementation and uptake of ADs.

Petro et al. (2004) reported that time was a significant barrier in helping people to complete a PAD. On a Likert scale ranging from 1 to 5, service providers were asked how useful it would be to have a service that would help consumers complete a PAD. Most participants believed that such a service would be ‘helpful’. However, three-quarters (79%) stated that it would take ‘considerable’ or ‘a great deal’ of time to complete a PAD (p. 417).

A study involving different types of professionals (N = 23) from different community settings reported that ‘a lack of time’ prevented them from discussing ADs with their patients (Rhee et al., 2012). Wilder et al. (2013) explored different views among five stakeholder groups regarding the implementation of PADs. More than two-thirds (71%) of administrators and slightly more than half (52%) of the clinicians reported that they did not have sufficient time to help patients understand and complete a PAD. Gergel and Owen (2015) found similar results involving patients with bipolar affective disorder with fluctuating competency. They discovered that the clinicians’ ‘lack of time and resources’ was a significant obstacle in helping patients with ADs.

The implications of these studies suggest that doctors and allied health professionals require additional support such as work reminders and opportunities (i.e., consultation times) to enable them to assist their patients to implement ADs.
There are mixed opinions on deciding the stage of a person’s health condition and the appropriate time at which PADs should be discussed and created (Gjerberg, Lillemoen, Førde, & Pedersen, 2015; Hemsley et al., 2019; Khazaal et al., 2014). Some believe that it should be conducted within the community before a patient becomes incompetent (Khazaal et al., 2014; Klaus, 1995; Miller et al., 2019). Hemsley et al. (2019) suggested that early discussions about ADs would enable a more ‘complete consideration of matters’ (p. 8). Of course, this is based on the assumption that the patient is competent and ready to engage in AD discussions.

Others have suggested that discussions should be conducted at the end of the hospital admission. This is because it is assumed that people’s psychiatric symptoms have subsided, and they are more cognitively engaged to make informed choices (Khazaal et al., 2014). However, a randomised trial with a one-year follow-up revealed that introducing ADs at the end of a patient’s expected hospital discharge did not reduce the number of compulsory readmissions. The authors concluded that ‘at follow up, several patients could not remember the directive, also suggesting a reduce ability to concentrate at recruitment’ (Papageorgiou et al., 2002, p. 516). This result suggests that the end of a person’s hospital admission is ‘not an appropriate time’ to discuss ADs because patients are not necessarily sufficiently recovered (impaired cognition) to complete a valid AD. Similarly, Gjerberg et al. (2015) concluded that a patient’s values or condition might change during the course of treatment, and therefore it is not appropriate to discuss ADs during or shortly after hospital admission. Few studies have addressed this topic, which presents a significant gap in the literature.

Overall, each of these studies has reported that doctors do not initiate discussions about PADs because they do not have time, may have limited or no knowledge of PADs, do not value PADs and do not believe it is their role to discuss PADs (Boddy et al., 2013; Cohen, McCue, Germain, & Woods, 1997; Eliasson et al., 1999; Kahana, Dan, Kahana, & Kercher,
The literature has indicated that having the support of a facilitator (i.e., independent advocate) to assist patients in notarising a PAD and to provide logistical support to clinicians could address most of these system-level barriers (Scheyett et al., 2008; Srebnik & Brodoff, 2003; Swanson, Swartz, Ferron et al., 2006; Swanson, Swartz, Elbogen et al., 2006; Swanson et al., 2008; Van Dorn, Swanson, Swartz, Elbogen, & Ferron, 2008). The next section will examine different strategies to overcome these intangible barriers.

4.5 Practical Strategies to Increase the Uptake of Psychiatric Advance Directives

To date, clinical and attitudinal survey research has focused almost entirely on barriers that prevent the uptake of PADs, with little attention paid to the development and evaluation of strategies to facilitate their implementation (Boddy et al., 2013; Lemon et al., 2019; Papageorgiou et al., 2002; Van Dorn et al., 2010). Although the data are limited, several studies have sought to address the issue by developing a number of strategies, including a registry database system, education training and knowledge, and discussions with patients.

4.5.1 Registry database system

A group of Australian researchers stated that the ‘greatest hope for embedding ACDs [advance care directives] across services and jurisdictions is the electronic medical record, which is an important facilitator of advance care planning’ (Johnston et al., 1995, p. 158).

Several studies have advocated for a national registry database system (e.g., AD-Maker) similar to that of the Living Wills Registry (Atkinson, 2007; Backlar et al., 2001; Boddy et al., 2013; Bogdanoski, 2009; Rhee et al., 2012; Shields et al., 2014; Spoelhof & Elliott, 2012; Srebnik & Brodoff, 2003; Swanson et al., 2000). There are several advantages to this approach. First, it can provide valuable information to healthcare workers about
whether a patient has a PAD, it can identify treatment preferences and it can show which treatments have worked (or not) in previous hospital admissions (Henderson et al., 2010; Swanson et al., 2000). Second, especially in times of critical care, it provides ready access to medical and psychiatric information about the patient, such as emergency contact details, medical conditions, medication side effects and illness history (Dexter, Wolinsky, Gramelspacher, Zhou et al., 1998; Elbogen, Swanson, Appelbaum et al., 2007; Elbogen, Swanson, Swartz et al., 2007; Henderson et al., 2008; Spoelhof & Elliott, 2012; Swanson et al., 2000; Wilder, Elbogen, Swartz, Swanson, & Van Dorn, 2007). Third, it may limit the need for surrogate decision-makers (Backlar et al., 2001; Rolnick et al., 2017), and it is always readily accessible (Bogdanoski, 2009).

Dexter et al.’s (1998) experiment with computer-generated reminders (i.e., pop-up messages to prompt health professionals to have conversations with their patients about ADs) yielded excellent completion rates (11% improvement rate) in ADs. However, as a standalone intervention, the computer reminder system did not facilitate the uptake of ADs; rather, a combination of interventions (e.g., proxies—healthcare representatives and instructive directives) optimised the completion rate for ADs.

These results are consistent with the findings of Heiman, Bates, Fairchild, Shaykevich and Lehmann (2004), who employed a cluster RCT that used a sample of elderly and chronically ill outpatients to determine whether physician reminders and mailing ADs to patients before a doctor’s appointment showed any significance in completion rates of ADs. This simple but cost-effective and time-saving strategy was found to be successful, and a 14% increase was reported.

Sherman (1998) tested a computer-assisted system to educate and assist patients with SMIs to complete an AD. Within a specified timeframe of 80 minutes, and with limited computer skills, most participants (n = 39, 65%) were successful in completing an AD.
Backlar, McFarland, Swanson and Mahler (2001, p. 430) also supported this type of registry by asking consumers, providers and surrogates whether they ‘would approve if the state placed data about each consumer’s PAD in a computerized database’, and most respondents (76%) supported the use of a state database. An earlier study by Jackson et al. (2009) demonstrated that only 40% of participants would use the internet to complete an AD.

In Victoria, Australia, a registry electronic health care database system exists to enable clinicians to view whether a patient has an AD. However, the system only applies to public hospitals in Victoria and is therefore not applicable to private health institutions or other states and territories. The Australian Government recently introduced a national storage system called ‘MyHealth’ to enable the public to upload medical documentation such as medical scans, blood tests and ADs (Hemsley et al., 2019). Although promising, this software is in its infancy and may not be accessible to those who are not computer literate or who are from a non-English-speaking background.

These studies demonstrate that computer devices can be a cost-effective tool in facilitating the uptake of PADs. However, studies have reported some difficulties regarding the application. An older study by Peto et al. (2004) expressed a concern that people with SMI and older people may not be computer savvy and may need assistance in navigating AD-Maker software. This observation was based on their study, which involved 103 participants who had experienced persistent mental health issues. The findings revealed that 55% of the participants required technical support in using AD-Maker compared with 44% who needed non-technical support.

Another group of researchers questioned whether the database system might breach a patient’s confidentiality because people who have no direct involvement with the patient can access the patient’s file without their knowledge or consent (Backlar & McFarland, 1998; Backlar et al., 2001). Swanson et al. (2003) expressed a concern that different clinicians on
any given day (i.e., as a result of frequent changes in staff) might recognise or dismiss a person’s AD. This concern could be mitigated by securing a longstanding relationship with the patient, which may in turn increase the likelihood of honouring the patient’s PAD (Winick, 1996).

Although this intervention has been identified as an effective communication tool for enhancing the uptake of ADs, further research is required to determine how to implement this computer software at both the macro level (e.g., different states and cities) and the micro level (e.g., different clinical and non-clinical settings), ensure it is user-friendly and cost-effective, and ensure it has in-built safeguards to protect patients’ privacy and confidentiality.

4.5.2 Educational training and knowledge

A literature review on the history of ADs stated that ‘the heart of any strategy designed to address patient choice in medical decision-making is education and effective communication’ (Brown, 2003, p. 10). However, a common theme that emerged in the literature review was that health professionals, patients and their families have little or no educational training about the availability and purpose of PADs (Backlar & McFarland, 1998; Brown, 2003; McLennan et al., 2015; O’Connell & Stein, 2005; Rein et al., 1996; Seymour et al., 2010; Shields et al., 2014).

Evidence shows that ADs are complex and confusing (i.e., language/terminology is often vague and not clear) (Boddy et al., 2013; Jezewski et al., 2003; McLennan et al., 2015; Peto et al., 2004; Rhee et al., 2012; Spoelhof & Elliott, 2012; Srebnik & Brodoff, 2003; Vogelstein, 2016; Zelle et al., 2015). Further, ADs vary in their structure and content (i.e., no continuity) (Hemsley et al., 2019; Srebnik et al., 2003) and patients do not know how to initiate or access an AD (i.e., procedure) (La Fond & Srebnik, 2002; McLennan et al., 2015; Rhee et al., 2012; Srebnik & Brodoff, 2003; Weller, 2010; Zelle et al., 2015), or even how to complete an AD in terms of what information is required (i.e., notarising) (Barker & Ritter,
In addition, it has been suggested that there are no AD templates for people from non-English-speaking backgrounds, which makes the process more difficult for people who are already marginalised (Detering et al., 2015; Hemsley et al., 2019). A more culturally responsive approach to ADs is needed to ensure that people have access to treatment services that are based on their treatment preferences and are in accordance with their AD. Detering et al. (as cited in Hemsley et al., 2019) found that the use of professional interpreters was effective in facilitating the uptake of ADs among people from non-English-speaking backgrounds.

A number of educational interventions have been proposed to counteract this problem, including video vignettes (Cohen et al., 1997; Douglas & Brown, 2002; Jezewski et al., 2003), pamphlets, do-it-yourself kits and laminated pocket guides (Brown & Jarrad, 2008; Gallagher, 1998; Jezewski et al., 2003; Sulmasy et al., 1996; Van Dorn et al., 2010), value worksheets, workbooks and flowcharts to inform practice regarding the implementation of ADs (Henderson et al., 2010; Rhee et al., 2012; Seymour et al., 2010), peer facilitators (Backlar et al., 2001; Elbogen, Swanson, Appelbaum et al., 2007; Jackson et al., 2009; Scheyett et al., 2007; Srebnik & Brodoff, 2003), group discussions (Ramsaroop et al., 2007; Spoelhof & Elliott, 2012), role playing (Elbogen, Swanson, Swartz et al., 2007) and educational policies (Backlar & McFarland, 1998). All of these interventions could assist with the promotion and execution of healthcare directives.

However, few empirical studies have determined the efficacy of these multicomponent interventions (Amering & Schaffer, 2007; Bravo, Dubois, & Wagneur, 2008; Ramsaroop et al., 2007). One systematic review investigated the effectiveness of these interventions and found that they had small to negligible effects on the uptake of ADs (Bravo et al., 2008).
might explain why there is a low prevalence rate in the uptake of ADs. An Australian survey found that less than 14% of the respondents (consumers) had prepared an AD (White et al., 2014).

Perkins (2000) and Backlar and McFarland (1998) recommended that new methods need to be developed to educate stakeholders about the availability and purpose of PADs. Unless this issue is addressed, the use of PADs will remain unchanged from the perspective of both patients and health providers.

4.5.3 Discussions with patients

The most effective and least expensive intervention is for health practitioners to have repeated interactive, open conversations about PADs with their patient (while competent) and the patient’s caregivers or next of kin (Bravo et al., 2008; Brock, 1993; Brodtkorb et al., 2016; Coulter et al., 2008; Ramsaroop et al., 2007; Spoelhof & Elliott, 2012; Tamayo-Velázquez et al., 2010; Teno et al., 1997). These conversations should consist of a person’s ‘circumstances, needs, wishes and concerns’ in relation to their medical condition and care (Johnston et al., 1995, p. 155).

Researchers have agreed that discussions about PADs should not be conducted in one sitting; rather, discussions should be held on a periodic basis for several reasons: the patient’s values and preferences might change over the trajectory of their illness, their circumstances or condition might change, it enables clinicians to obtain a complete picture of the patient’s values and wishes, and it gives the patient an opportunity to review and update their PAD (Backlar & McFarland, 1998; Brown, 2003; Hemsley et al., 2019; Hilden, Louhiala, & Palo, 2004; Johnston et al., 1995; Loewy, 2004; Rhee et al., 2012; Weissman et al., 1999). Henderson (2010) supported this idea and found that 80% of participants supported periodic reviews. However, the issue of whose role it is to initiate discussions about PADs remains unclear in the literature (Hemsley et al., 2019).
A study that explored people’s attitudes, knowledge and preferences regarding ADs found that 62% of patients believed that it was their responsibility to initiate the conversation about ADs, whereas 70% reported that they would feel more comfortable if their provider raised the issue (Jackson et al., 2009). Similarly, Johnston et al. (1995) found that most participants (n = 329 outpatients, n = 282 resident physicians and n = 272 practicing physicians) agreed that it was the physician’s responsibility to initiate the conversation about ADs. Overall, these studies confirm the general ‘expectation’ that it is the doctor’s responsibility to initiate conversations about ADs, and it reinforces the notion that doctors play an important role in influencing the uptake of ADs.

However, as previously mentioned, doctors lack time to adequately address this issue; therefore, others have suggested alternatives such as an ‘advocate or solicitor’ (Halpern & Szmukler, 1997, p. 326), a nurse (Brown, 2003; Jezewski et al., 2003; Uhlmann, Pearlman, & Cain, 1989), a mental health clinician (Swanson et al., 2000, p. 168), a caseworker (Srebnik et al., 2003), a physician (Eliasson et al., 1999, p. 2216) or even ‘a health educator or social worker’ (Henderson et al., 2008, p. 65). These authors have provided rational explanations for their recommendations but offer no specific details regarding when and where these discussions should occur, nor have they suggested an alternative. An independent person such as an ethicist (external from the hospital) might be a suitable alternative. This would limit the risk of potential conflicts of interest because they could exercise impartiality and objectivity in matters regarding PADs.

It is not clear who should be assigned the role of providing information and assisting with the implementation of PADs (Rein et al., 1996). Even the US Patient Self-Determination Act (1991) does not stipulate who should initiate discussions about ADs (e.g., patient, doctors or administrators) (Dexter et al., 1998). Srebnik and Brodoff (2003) stated that ‘it should ultimately be at the discretion of the consumer’ (p. 259).
A number of authors have stated that some patients may not want to be involved in the decision-making process and are content to allow their doctor to make decisions on their behalf (Kapp, 1989; Waterworth & Luker, 1990). This is predicated on the belief that their doctor will ‘do the right thing’ (Weinryb, 1995). It is common for people to have ‘implicit trust’ in the expertise of their doctor (or nurse), which might explain why there is a relatively low prevalence rate in the uptake of PADs (Gjerberg et al., 2015; Kapp, 1989). This idea arises from the assumption that doctors will act in the patient’s best interest, underpinned by the ethical principle of beneficence (Berglund, 2001; Gjerberg et al., 2015).

Based on this analysis, there is a strong need to educate health practitioners about the functions and purpose of PADs to ensure they engage in discussions with their patients. It is highly likely that patients will then be properly informed about PADs, thereby increasing their uptake rate (Srebnik et al., 2003; Swanson et al., 2000).

4.6 Conclusion

To effectively implement PADs and therefore increase their utilisation among patients with SE-AN, the barriers discussed in this chapter must be addressed collaboratively by all stakeholders, including policymakers, law institutes, patients, their families and carers, and mental health professionals. Particular attention should be paid to educating and training stakeholders regarding the functions and purpose of PADs, as well as developing support mechanisms to enable a patient with SE-AN to formulate and execute a PAD.
Chapter 5: Part Two: Ethical Considerations of Severe and Enduring Anorexia Nervosa

5.1 Introduction

The goal of this chapter is to expand on the ethical issues raised in Chapter 1. These include control, the therapeutic relationship, the least restrictive principle and competency. It is beyond the scope of this study to discuss the legal and medical aspects of the debate. Rather, this study provides an overview of the main ethical arguments relating to involuntary care of people with SE-AN.

5.1.1 Arguments in favour of forced treatment

Birley (1991) stated that ‘every citizen should have the right to be admitted against his or her will, to be treated without loss of dignity, in a first-class psychiatric service’ (p. 1). This provocative statement is strongly defended by those who support the ethical principles of beneficence and maleficence to preserve the sanctity of human life (Faith, 2002; Fost, 1984; Goldner et al., 1997; Holm et al., 2012; Levinsky, 1984; Lopez et al., 2010; Melamed et al., 2003; Tiller et al., 1993). One of the main justifications for imposing forced treatment on SE-AN patients (which violates their rights) is to prevent morbidity and mortality (Feiring & Ugstad, 2014; Tiller et al., 1993; Vandereycken & Beumont, 1998c; Werth Jr et al., 2003). In accordance with the ethical principles of beneficence (Beauchamp & Childress, 2001; Guarda et al., 2007), health professionals have a legal and moral obligation to act in the best interest of the patient; that is, they have a duty of care to preserve life when a patient refuses treatment and their health is at risk (Carney et al., 2007; Dresser & Boisaubin Jr, 1986; Goldner et al., 1997; Griffiths & Russell, 2000; Richmond, 2001; Schreyer et al., 2016).

Elzakkers et al. (2014) made an important distinction in the issue of involuntary treatment, stating that ‘it is not the use of detention per se, but rather how this is done that
matters to patients’ (p. 849). This implies that patients are amenable to acts of coercion if they are delivered in a non-punitive, negotiable, collaborative and respectful manner as opposed to being forceful and adversarial and thus traumatising the patient. Several studies have supported this hypothesis. For example, Tan et al. (2010) argued that the provision of ‘good and compassionate psychiatric care’ within a therapeutic context can mitigate the negative effects of compulsory treatment, even when it violates the person’s liberty. Similarly, Ayton et al. (2009) found no evidence that coercion negatively affects a patient’s autonomy in the long term. In fact, the study demonstrated that detained patients can engage in treatment therapeutically without perceiving it to be punitive. Verkerk (1999) and Gutheil and Appelbaum (1982) argued that coercion can be a means of helping a patient with a serious psychiatric illness to regain their autonomy (restore their capacity), particularly when the illness threatens their survival.

This is consistent with Stone’s (1975) theory that involuntary treatment can be effective (according to one’s interpretation of the word ‘effective’), and it has been argued that patients and their families are retrospectively grateful that treatment was imposed (Griffiths, Beumont, Russell, Touyz, & Moore, 1997; Guarda et al., 2007; Katsakou & Priebe, 2007; Manley et al., 2001; Tan, Hope, Stewart et al., 2003; Tan et al., 2006). In the context of anorexia, this means that once a person’s weight has been restored, and therefore medically stabilised (i.e., cognitive capacity has been restored), the patient retrospectively agrees that compulsory treatment was necessary to ensure their safety and wellbeing (Andersen, 2007; Beck & Golowka, 1988; Carney, Tait, Richardson, & Touyz, 2008; Guarda, 2008; Kullgren et al., 1996; Lepping, 2011; Tan et al., 2010). Melamed et al. (2003) labelled this approach as ‘tough love’, whereby patients eventually concede that forced treatment is the only way to keep them alive (p. 624). The phase ‘tough love’ is of course outdated and paternalistic and is not representative of the views of all health professionals.
Guarda et al. (2007) conducted an experiment to determine whether this prediction was accurate. Of the 139 inpatients surveyed, 46 did not endorse medical treatment at the time of admission; however, two weeks into their weight restoration, 20 of the 46 (mainly adults v. younger patients) felt that it was justified and necessary. These findings are consistent with previous studies and retrospectively support compulsory treatment (Newton et al., 1993; Tan, Hope, Stewart et al., 2003; Tan et al., 2010; Watson, Bowers, & Andersen, 2000).

Similarly, Varelius (2006) stated that while treatment may go against the patient’s decision to refuse medical help, it could be the only means of ‘truly respecting her autonomy’ (p. 118). He further explained that because treatment is enforced against her will, she can continue to live and have a future, which otherwise might not have happened. The justification for this approach is that once her weight has been stabilised, she can then engage in therapeutic treatment, commence recovery and attempt to lead a ‘normal’ life (Coggon, 2014; Davies et al., 2012; Lewis, 1999; Melamed et al., 2003).

However, a growing body of qualitative evidence suggests that involuntary treatment is not retrospectively ‘justified’ or ‘beneficial’ in the lives of those experiencing eating disorders (Katsakou & Priebe, 2006, 2007; Light et al., 2014). These studies provide anecdotal descriptions of involuntary treatments that have caused more harm than good, thereby contravening the ethical principle of non-maleficence.

Melamed et al. (2003) raised an interesting question regarding the treatment of AN patients: ‘Where is the boundary between the individual’s autonomy and the need for social intervention?’ (p. 63). According to Dresser (1984c), interfering with an individual’s autonomy can be justified when (a) ‘the anorexic patient’s life and health are seriously endangered; when the patient demonstrates incapacity to understand the important facts about the condition and its treatment’ (p. 44).
Although these arbitrary criteria may provide clinical guidance in determining the use of justified paternalism—particularly for patients with a shorter duration of the illness, or ‘mild cases’ (Errichiello et al., 2016; Russell et al., 1987; Warren & McGee, 2013)—others have argued that this information is not necessarily applicable to those who experience SE-AN (Andersen, 2007; Appelbaum & Rumpf, 1998; Scolan et al., 2013).

Draper (1998) and Campbell and Aulisio (2012) explained that due to the maturity of experience of the illness, people with SE-AN are in a better position to make judgments about proposed treatments and whether they have any therapeutic value in terms of improving their quality of life. That is, over the trajectory of the patient’s illness, they develop in-depth knowledge and gain personal insights into and experience about their illness in terms of what works and what does not work regarding their medical care and recovery (Bamford & Mountford, 2012; Exworthy, 2004; Geller et al., 2001; Kendall, 2014; Lloyd & King, 2003; Robinson et al., 2015; William, 1993).

Cassell (1977) supported this assertion by stating that ‘they have had plenty of time to learn about the disease, its treatment, and consequences. Such patients learn from books, from physicians and nurses, and perhaps most importantly, from other patients’ (p. 17). Carney (2008) and Campbell and Aulisio (2012) agreed that the clinician may neglect the patient’s ‘maturity of experience’, particularly when they conduct capacity assessments. The fact is that these patients have a long history of illness and generally know their own best interests (Dworkin, 1993). Further, they are familiar with the medical system and its treatment options (Bamford et al., 2016; Button & Warren, 2001). A qualitative study involving eight patients who had lived with SE-AN for 20–40 years supports this assertion. The authors claimed that these patients were ‘experts by experience’ and regarded their treatment as a form of ‘maintenance’ rather than a ‘cure’ (Robinson et al., 2015, p. 323).
Listening to and treating people with SE-AN as experts about their illness can give health professionals important ‘inside knowledge’, which may not be available otherwise, to better understand and support their patients (Conti et al., 2016). A study by Nevonen and Broberg (2000) supported this view and advised that clinicians should listen to their ‘patients’ own understanding’ about their eating disorder, and this in turn will lead to a better working relationship (p. 290). Coulter et al. (2008) cautioned that a ‘failure to recognise and support people’s self-care efforts encourages unnecessary dependency on professionals’ (p. 4).

This suggests that SE-AN patients have developed in-depth knowledge of and insights into their illness and are able to make informed treatment decisions about their general medical care (i.e., reject or accept treatment) based on their quality of life. The authors of a recent report on compulsory treatment in patients with SE-AN asked:

_How do we access the reasoning and motivations of patients who for years have experienced great psychological suffering, who can’t bear to see the torments to which family members are continuously subjected as a result of chronic, debilitating illness, and who see nothing but repeated frustration and futility in any of what’s being offered?_ (Yager et al., 2016, p. 7)

One way to access the reasoning and motivations of people with SE-AN is to explore the use of PADs. Conversations about treatment preferences could reduce ambiguities about the patient’s intention regarding seeking medical treatment, as well as clarify their treatment goals. In turn, this would guide the clinician in selecting appropriate treatments to meet their patient’s needs without resorting to coercive measures.

This analysis shows that involuntary hospitalisation can be argued to be a means of respecting a person’s autonomy by providing them with acute medical care through weight restoration, thereby averting or minimising the imminent risk of danger. Further, evidence has shown that some patients are retrospectively grateful that treatment was imposed. Compulsory treatment can be effective in restoring a person’s competency and social functioning and
providing short-term symptomology relief. In many instances, it gives people a ‘second chance’ to live, which might otherwise have been denied by the illness.

5.1.2 Arguments against forced treatment

Tan et al. (2003) stated that ‘It is a central tenet of the law and human rights that individuals should be able to make their own free choices, even if these choices are medical decisions that may be irrational, idiosyncratic, or unreasonable’ (p. 629). This supports the fundamental premise that paternalism has no role in the care of patients with anorexia, and it advocates that people have the right to refuse or accept treatment regardless of the outcome or their level of competency (Caplan, 2006; Draper, 2000; Gans & Gunn Jr, 2003; Giordano, 2010; Orbach, 1986; Rathner, 1998; Silber, 2011). A number of authors have contended that forced hospitalisation makes no difference in helping people to recover from anorexia (Russell, 2004; Tan et al., 2003a; Treasure, 2002; Vandereycken & Beumont, 1998c). Some have claimed that it would be ‘counterintuitive’ and ‘counterproductive’ because it would undermine the patient’s sense of autonomy and control in managing their medical affairs. In addition, forced treatment increases the likelihood of the individual becoming more resistant to treatment, thus limiting the possibility of recovering (Ayton et al., 2009; Beumont & Vandereycken, 1998; Giordano, 2005; Tan, Hope, Stewart et al., 2003; Watson, Bowers, & Andersen, 2000; Werth Jr et al., 2003).

Vandereycken and Vansteenkiste (2009) supported this by stating that coercive treatments have higher treatment dropout rates, less effective therapeutic outcomes and more hospital readmissions. O’Brien and Golding (2003) argued that coercion (in the form of forced treatment) reduces people’s self-esteem, limits their decision-making and leaves them feeling less than a full person. That is, it undermines their dignity and self-worth as a human being. Yager (1998) stated that forced treatment rarely works but that maintaining an ‘open-door’ policy for patients with chronic anorexia might be useful. Freckelton (2003) stated that
it would take longer for those who have been subjected to coercion to take responsibility for their recovery compared with patients who had decision-making control and power over their medical care.

Further, studies have reported that inpatient care offers little follow-up care post-hospital discharge (Escobar-Koch et al., 2010; Federici & Kaplan, 2008), is time-limited in dealing with the psychological effects of eating disorders (Cockell et al., 2004; Rance, Moller, & Clarke, 2017), violates the patient’s rights and autonomy by limiting their involvement in the decision-making process (Katsakou & Priebe, 2007; Wyder et al., 2013) and restricts their freedom of choice (Faith, 2002; Silber, 2011; Sjöstrand et al., 2015; Tan, Stewart, Fitzpatrick, & Hope, 2010). These iatrogenic factors stop people from recovering and limit their control over their illness. In some cases, they can worsen the illness and cause irrevocable harm to the person.

For example, involuntary treatment frequently damages the therapeutic relationship (loss of trust) and prevents patients’ from seeking therapy in the future (Dresser, 1984b; Lewis, 1999; Maher & Rosedale, 1993; Matusek & Wright, 2010; Richmond, 2001; Schreyer et al., 2016; Selvini-Palazzoli, 1978; Serfaty & McCluskey, 1998; Sjöstrand et al., 2015; Watson et al., 2000; Werth Jr et al., 2003). Although this might be true in some anecdotal cases, there is little evidence to support this assertion (Ayton et al., 2009; Carney et al., 2007; Elzakkers et al., 2014; Griffiths et al., 1997; Ramsay et al., 1999; Rathner, 1998; Russell, 2001; Tiller et al., 1993; Werth Jr et al., 2003).

Serfaty and McCluskey’s (1998) study of the effects of compulsory treatment on AN patients (N = 11 females, mean age = 33.1 years [SD = 13.5], mean duration of illness = 14.1 years [SD = 10.6]) found little evidence to suggest that treatment imposition causes damage to the therapeutic relationship. The findings revealed that after the active intervention was applied (compulsory treatment), only one patient (not on a compulsory order) refused further
treatment post-hospital discharge. However, the study had a relatively small sample size, thereby limiting the generalisability of the results.

Several authors have reported that forced treatment can worsen a person’s condition by making them more resistant to treatment, and in some cases, they retaliate by resuming their eating disorder behaviours (after inpatient discharge) and refusing all medical care (Dresser, 1984b; Goldner et al., 1997; Lemma-Wright, 1994; Russell et al., 2019; Westmoreland & Mehler, 2016). Not only does this lead to repeated hospital admissions, but patients are sometimes readmitted in a more serious state (Guarda et al., 2007; Melamed et al., 2003; Mitrany & Melamed, 2005; Ramsay et al., 1999; Swartz et al., 2003; Watson et al., 2000; Woodside et al., 2016). As a result, they often feel dejected and avoid psychological treatment because they mistrust the mental health system, and this jeopardises the prospect of achieving long-term recovery (Dresser, 1984c; Richmond, 2001; Tan, Hope, Stewart et al., 2003; Verkerk, 1999).

Dresser (1984b) stated that ‘involuntary treatment may actually engender chronicity’ (p. 318) in those with an eating disorder, but there is no credible evidence to support this claim (Goldner, 1989). However, there is anecdotal evidence to support the view that involuntary treatment can exacerbate and further traumatising a patient who previously experienced sexual abuse (Boyle, 2019), which may contribute to feelings of humiliation, shame and guilt, as well as a ‘feeling of powerlessness’ (Davies et al., 2012; Gans & Gunn Jr, 2003; Goldfarb, 1987; Skårderud, 2007). Unfortunately, there is not enough research in this area to support this conclusion, but it remains a legitimate concern for civil libertarians and is an area that requires further investigation (Goldfarb, 1987). To date, the DSM has remained silent on this topic.

Several authors have reported that the efficacy of treatment between voluntary and involuntary patients showed no difference in terms of weight gain, apart from the fact that
involuntary patients experienced longer periods of hospitalisation (Carney et al., 2008; Guarda et al., 2007; Holm et al., 2012; Russell, 2001; Thompson, 2004; Wyder et al., 2013). This was confirmed by Watson, Bowers and Andersen (2000) and Carney et al. (2006), who found few differences in terms of weight restoration between involuntary and voluntary patients.

In a controlled comparison study, Ramsay, Ward, Treasure and Russell (1999) compared 81 involuntary and 81 voluntary adult patients with anorexia. They concluded that involuntary patients gained similar weight as voluntary patients but took a longer time to achieve the weight gain (OR = mean 113 days v. 88 days).

Recent outcome studies have shown that duration of the illness (>10 years), serious comorbid mental health conditions (e.g., obsessive-compulsive personality features), chronicity of the illness (i.e., lower BMI rates at admission), more hospital admissions and social adjustment problems are strong prognostic factors of poor treatment outcomes (Douzenis & Michopoulos, 2015; Errichiello et al., 2016; Fichter, Quadflieg, Crosby, & Koch, 2017; Holland, Hall, Yeates, & Goldacre, 2016; Holm et al., 2012; Lo Sauro, Castellini, Lelli, Faravelli, & Ricca, 2013; Russell, 2001; Surgenor, Maguire, & Beumont, 2004; Zipfel et al., 2000). The studies concluded that involuntary treatment has no significant effect on a person’s weight restoration when compared with voluntary patients. The data revealed that compulsory treatment offers some short-term relief by reducing the starvation effects associated with the illness, but it does not reduce long-term effects or address the underlying causes of the illness (Colton & Pistrang, 2004; Dresser, 1984b; Goldner et al., 1997; Ward et al., 2015; Williams et al., 2010; Zipfel et al., 2000). In addition, eating and body concerns remain major psychopathological features post-hospital admission, particularly for older patients with a longstanding illness (Watson et al., 2000).
An issue that is often overlooked by clinicians and researchers and that is ‘not spoken about’ is that some patients die while in involuntary care (Carney et al., 2019; Robinson, 2012; Robinson & Jones, 2018). Researchers are unsure whether this is due to complications related to the illness or to the care that is being given (Robinson, 2012). Thus, clinicians are unwilling to discuss or even admit that involuntary care does not always save lives because they ‘fear criticism, lawsuits or disciplinary action’ (Robinson, 2012, p. 112).

This is an area that has been neglected in the AN literature and requires further research (Robinson, 2012). These findings might change the views of health professionals, families and medical ethicists regarding the ethics and effectiveness of involuntary treatment of eating disorders.

Although there is an abundance of data to support the use of compulsory treatment, there are surprisingly few studies (mainly anecdotal evidence) that support the view that compulsory treatment is effective in saving lives. Further, there is little understanding of the long-term outcomes (Douzenis & Michopoulos, 2015; Fairburn, Shafran et al., 1999; Gowers et al., 2000; Kallert, Glöckner, & Schützwohl, 2008; Kallert et al., 2011; Lemma-Wright, 1994; Priebe et al., 2010; Roth, Appelbaum, Sallee, Reynolds, & Huber, 1982; Tiller et al., 1993; Ward et al., 2015; Watson et al., 2000; Werth Jr et al., 2003). Jacobsen (2012), Schreyer et al. (2016) and Campbell (1997) noted that these paternalistic measures have been used in psychiatric wards for many years, but there is no empirical evidence to support their use.

Clausen and Jones (2014) conducted a systematic review into involuntary treatment for people with AN and found that there is a paucity of follow-up studies about the long-term effects of involuntary versus voluntary hospital care. In addition, there is little comparative data (nationally or internationally) regarding the frequency of involuntary admissions and its use in eating disorders (Rathner, 1998). Clausen and Jones’s (2014) analysis of involuntary
treatment reported a rate of 13–44%, but these figures could be skewed (i.e., underestimate the true value of reports) given that voluntary admission often becomes involuntary admission—a common but unreported occurrence (Clausen & Jones, 2014; Kjellin & Wallsten, 2010; Olofsson & Jacobsson, 2001). This latter point was illustrated in a study in which 16% of the patients with anorexia were initially admitted as voluntary patients but were later sanctioned as involuntary patients (Ramsay et al., 1999).

This figure is liable to change further as a result of other variables, such as hospital characteristics (e.g., policies/procedures and unit practices), staff attitudes, statutory legal requirements and differences between institutions, states and countries regarding the frequency and type of coercive measures used in psychiatric settings, such as the use of the Mental Health Act (Carney et al., 2006; Clausen & Jones, 2014; Goldberg et al., 1980; Kjellin & Wallsten, 2010; Krieger, Moritz, Weil, & Nagel, 2018; Sjöstrand et al., 2015; Tan et al., 2003; Tort-Herrando, Van Lier, Olive-Albitzur, Huulsbos, & Muro-Alvarez, 2016; Völlm & Nedopil, 2016; Yager et al., 2016).

It is difficult to obtain ethics approval to conduct clinical trials to determine the efficacy of compulsory treatment (compared with no treatment) involving patients with severe and persistent psychiatric problems (Ayton et al., 2009; Mitchell & Eckert, 1987; Tan et al., 2003a). There are a number of ethical concerns: patients may not be able to provide informed consent, they are more likely to drop out of long-term randomised trials due to their unpredictable and resistant behaviours, they lack motivation and they are ambivalent towards treatment (Agras et al., 2004; Darcy et al., 2010; Guarda & Heinberg, 2004; Halmi et al., 2005; Mitchell & Eckert, 1987; Stiles-Shields et al., 2013; Surgenor et al., 2004; Westwood & Kendal, 2012).

Indeed, it would be an untenable position that contradicts Kantian ethics ‘respect for the dignity of the subject’ (Pedroni & Pimple, 2001, p. 3) to create a research design whereby
a person’s life could be compromised (i.e., withholding treatment) (Douzenis & Michopoulos, 2015; Gowers et al., 2000; Guarda, 2008; Jacobsen, 2012; Priebe et al., 2010; Tan et al., 2008; Tan et al., 2006; Theander, 1985; Vandereycken, 1998; Watson et al., 2000).

5.1.3 Anorexia and control—the ‘Holy Grail’

In Charles Dickens’s *Nicholas Nickleby*, Mr Squeers says ‘Subdue your appetites, my dears, and you’ve conquered human nature’ (Dickens & Browne, 2004, p. 86). This implies that control over one’s body and appetite is perceived as the ‘ultimate validation of womanhood’, particularly in Western cultures, where ‘thinness’ is highly prized and offers divine happiness and, ultimately, control (Chase, 2001; Dresser, 1984b; Garner, 1997; Keel & Forney, 2013; Levine & Harrison, 2004; Ramsay & Treasure, 1996; Walsh, 2013). Nowhere is this clearer than in the case of people experiencing AN (Bruch, 1979; Fairburn, Shafran et al., 1999; Garner & Garfinkel, 1997; Hepworth, 1999; Orbach, 1986).

Individuals with AN go to great lengths to lose weight. They regurgitate (vomit) food, exercise excessively, avoid high-caloric foods such as carbohydrates, and in some cases they use laxatives and diuretics to further increase their weight loss (Dresser, 1984b; Goldner et al., 1997). Several authors have reported that these dieting behaviours help the individual to cope with the negative effects of the illness by being in control (Halmi et al., 2005; Kaplan & Garfinkel, 1999; Sallas, 1985; Schmidt & Treasure, 2006; Skårderud, 2007; Tan, Hope, & Stewart, 2003a; Walsh, 2013).

The concept of control is a multidimensional phenomenon and is defined as a psychological phenomenon that causes significant cognitive and behavioural disturbances (Bruch, 1979; Crisp, 1995; Fairburn, Shafran et al., 1999; Hepworth, 1999; Nordbø et al., 2006; Skårderud, 2007; Surgenor, Horn, Plumridge, & Hudson, 2002). It is an important factor in the aetiology and maintenance of AN, whereby people have an extreme need to be in control to sustain their anorexic behaviours (Dresser, 1984b; Fairburn, Shafran et al., 1999;
Essentially, it is a means of having power over something or someone (Lawrence, 1979; Westwood & Kendal, 2012) or maintaining a sense of autonomy (Crisp, 1995; Giordano, 2005; Halmi, 2013; Hepworth, 1999; Lemma-Wright, 1994). In the case of AN, it usually involves controlling the body by self-regulating weight, shape, food and exercise (intra-active control) (Brewerton & Dennis, 2016; Orbach, 1986; Ramjan, 2004; Tan, Hope, Stewart et al., 2003; Vandereycken & Beumont, 1998a; Yager, 1998), controlling people such as parents and therapists (interactive control) (Crisp, 1995; Surgenor, 2003; Vandereycken & Beumont, 1998b) and controlling their environment (APA, 2013; Crisp, 1995), and it is a major contributing factor in treatment refusal (Fassino & Abbate-Daga, 2013; Goldner, 1989; Radu et al., 2016; Surgenor, 2003).

Further, people's perception of control varies accordingly. An early study stated that people who resist treatment are attempting to maintain control, whereas relinquishing control would be perceived as an act of being ‘out of control’, resulting in a sense of failure (Sallas, 1985). Another study reported that patients perceived weight loss as a means of being in control, whereas gaining weight was seen as a failure of self-control (APA, 2013).

It can be concluded that the pursuit of thinness is not driven just by an obsession with weight, but by an undeniable desire to be in ‘control’ of one’s body and life (Garner & Bemis, 1982; Goldner, 1989; Loewy, 2004; Mitrany & Melamed, 2005; Nordbø, Espeset, Gulliksen, Skårderud, & Holte, 2006; Selvini-Palazzoli, 1978). It has been proposed that unravelling the complexities of control could lead to a better understanding of the disorder and possibly lead to the development of better treatments (Fairburn, Shafran et al., 1999; Jarman et al., 1997; Strober, 1982).
Sallas (1985) and Surgenor (2003) suggested that developing a collaborative, non-authoritarian and respectful therapeutic relationship with the patient could be a means of reducing the struggle for power and control and thus aid a person’s recovery. This leads to the next topic: the therapeutic relationship.

5.1.4 Therapeutic relationship—‘an important prerequisite’

Lemma-Wright (1994) wrote that a working alliance is an important prerequisite to help the patient change their behaviour. Others have stated that a collaborative relationship depends on developing a strong therapeutic alliance (APA, 2006; Ciao et al., 2016; Guarda, 2008; Herpertz et al., 2011; Maine, 1985; Pike et al., 2004). Marzola et al.’s (2019) study of inpatients with SE-AN reported that motivation to change is strongly correlated with a strong therapeutic alliance.

Indeed, one of the major therapeutic goals in mental health is to develop a collaborative alliance with patients and their families/caregivers to ensure that patients’ medical needs are met and that they are properly informed about their treatment choices (Bergum & Dossetor, 2005; Huycke, 2000; Nordbø et al., 2006; Rathner, 1998). This is in line with Victoria’s Mental Health Act 2014, which states:

*The Mental Health Act encourages psychiatrists and other mental health practitioners to develop strong relationships with people using mental health services, and to provide them with information and support to make informed choices about their care. (Victorian Government Mental Health Act 2014)*

From an ethical point of view, adopting a collaborative approach could be considered an act of respecting the patient’s autonomy and dignity so they will feel more empowered and have a greater tendency to take responsibility for their illness and recovery (Ciao et al., 2016; Coulter et al., 2008; Golan, 2013; Offord, Turner, & Cooper, 2006; Ramjan & Fogarty, 2019; Sallas, 1985; Van Ommen, Meerwijk, Kars, Van Elburg, & Van Meijel, 2009). Researchers who support this view have argued that ‘the quality of the therapeutic relationship will play a significant role in the success of the intervention’ (Manley et al., 2001, p. 150).
Many studies support this conclusion. For example, Natt (2018) highlighted the importance of ‘being understood’, which helps patients to forge closer trusting relationships with their healthcare providers. This in turn facilitates their engagement in treatment services and helps them to maintain a sense of optimism for a better life. Rance et al. (2017) explored the views of 12 women with and without a formal diagnosis of AN and demonstrated that the therapeutic alliance between patients and clinicians is an important factor in treatment success and recovery. The participants emphasised the importance of ‘trust’, ‘self-disclosure’ and wanting a ‘real’ relationship with their clinician, and these were considered important attributes in the development of a therapeutic alliance.

Similarly, in Fox and Diab’s (2015) study, participants described having a good rapport with the nursing staff. They felt confident talking about their day-to-day emotions and felt that they were listened to about their needs. In fact, this was reported as being the ‘largest theme’, which supports the assertion that the therapeutic relationship is fundamental in helping people to recover from SE-AN. A thematic study conducted by Tierney (2008) examined adolescent patients with AN who had experienced both inpatient and outpatient care. A major finding of the study was that patients preferred professionals to demonstrate sensitivity (e.g., refraining from making negative remarks about their weight) towards their plight of living with AN. It can be assumed from this statement that practitioners who do not demonstrate sensitivity towards their patients are less likely to form closer relationships and might inadvertently obstruct their patients’ recovery and treatment progress.

Hannon et al. (2017) found that an empathetic and compassionate approach enables clinicians to forge close alliances with patients with SE-AN. Two participants in the study highlighted the importance of developing trust with staff in relation to their recovery: Eilidh did not feel ‘judged’ and Yvonne stated that it was ‘helping me carry on’ (p. 287).
In contrast, a number of studies indicate that establishing a therapeutic relationship with patients with SE-AN can be challenging for clinicians because of the nature of the symptoms, such as comorbidities, denial of the illness, lack of motivation to change and uncooperative nature (Agras et al., 2004; Bamford et al., 2016; Beumont & Vandereycken, 1998; Geller et al., 2001; Stockford et al., 2018; Wonderlich et al., 2012). This can lead to frustration and conflict (possibly a form of countertransference), which can, in turn, perpetuate negative and stigmatising attitudes (pessimism) towards people with AN, undermining the moral value of fidelity (Crisp, 2005; Feiring & Ugstad, 2014; Geller et al., 2001; Giordano, 2005; Maier et al., 2014; Ramjan, 2004; Russell, 2004; Yager, 1998; Zugai, Stein-Parbury, & Roche, 2018).

In an Australian study, Fleming and Szmukler (1992) explored the attitudes of health professionals (doctors, nurses, psychiatric trainees and medical students) towards patients with different mental health issues in a general public hospital. The data revealed that a high proportion of respondents held negative attitudes towards eating disorder patients when compared with people who experienced schizophrenia or who had overdosed on drugs.

Button and Warren (2001) interviewed 36 AN patients with a mean duration of illness of 7.5 years who were treated in a specialised eating disorders clinic. One of the most striking findings of the study was that half of the respondents did not consider inpatient care helpful. This was partly because of the negative attitudes of the nursing staff, as well as too much emphasis placed on weight restoration. Interestingly, half of the respondents reported that psychotherapy/counselling was the most helpful aspect of inpatient care.

This result accords with Fox and Diab’s (2015) study, which investigated the experiences of people with SE-AN regarding their experiences with hospital care. Under the theme of ‘staff pessimism’, participants described their experiences in a general medical ward similar to those described in this study. Issues such as professional abandonment, a lack of
understanding of their illness and nurses’ negativity affected their recovery and engendered a sense of ‘hopelessness’ in relation to effectively managing their illness. Colton and Pistrang (2004) questioned female adolescent patients about their experiences regarding hospital treatment. The adolescents reported that they ‘felt neglected and not cared for’ by nursing staff, which affected their recovery time in the hospital ward. In turn, this elicited feelings of ambivalence towards seeking treatment, thus reinforcing the patients’ negative perceptions of healthcare professionals.

This pessimism also extends to the flawed idea that SE-AN is perceived as a condition that is untreatable and self-imposed (Andersen, 2007; Crisp, 2005; Dresser, 1984b; Giordano, 2005; Ramjan, 2004; Tiller et al., 1993). Ramjan (2004) reported that nurses perceived patients as being responsible for causing their illness, stating that patients ‘caused their own harm’ and they ‘should fix it themselves’ (p. 498). This lack of empathy suggests that anorexia is not considered a legitimate psychiatric condition that deserves medical attention when compared with ‘really unwell kids’ (p. 498).

Similarly, Tierney (2008) interviewed adolescent patients with anorexia regarding their treatment experiences. Participants reported seeing their GP for an initial consultation but were later referred to a general medical ward. Five participants reported that their needs were ‘overlooked by staff’, and they felt that their illness was perceived by nursing staff as a ‘self-infliction’, which made them feel as though they were ‘wasting valuable healthcare resources’.

Ramjan (2004) stated that ‘blaming the victim, labelling and stigmatising adolescents as “anorexic”, and appearing to have favourites among patients, all made the establishment of therapeutic relationships arduous’ (p. 500).

To reduce the negative effects of ‘therapeutic pessimism’ and prevent the therapeutic relationship from deteriorating, a number of skills and attributes have been cited in the AN
literature to help clinicians maintain a therapeutic relationship (Beumont & Vandereycken, 1998; Fox & Diab, 2015). The therapeutic ‘armamentarium’ includes adopting a non-judgmental attitude, demonstrating acceptance of the illness, good communication and transparency, building rapport, developing trust and honesty, showing empathy and warmth, working at a slow pace, and demonstrating respect and integrity for the patient (Bamford et al., 2016; Bamford & Mountford, 2012; Bruch, 1979; Carney, Tait et al., 2006; Duker & Slade, 1988; Finelli, 2001; Geller et al., 2001; Guarda, 2008; Manley & Leichner, 2003; Murray et al., 2011; Pike et al., 2004; Ramjan & Fogarty, 2019; Rathner, 1998; Robinson et al., 2015; Warren & McGee, 2013; Yager, 1998). As with any relationship, decision-making plays a vital role in determining the quality of the relationship.

5.1.5 Therapeutic alliance and decision-making

Several studies have reported that people with SE-AN felt excluded from the decision-making process regarding their care, and they believed their autonomy was violated, which impeded the development of the therapeutic relationship with their healthcare professional (Darcy et al., 2010; Escobar-Koch et al., 2010; Katsakou & Priebe, 2007; Noble & Douglas, 2004; Ramjan & Fogarty, 2019). A number of authors have argued that involving clients in the decision-making process would increase their engagement and participation in treatment services and promote an ethos of self-determination and empowerment (Bordin, 1979; Escobar-Koch et al., 2010; Golan, 2013; Gowers et al., 2000; Kirsh & Tate, 2006; Manley & Leichner, 2003; Vandereycken & Vansteenkiste, 2009). Silber (2011) made a pertinent point, stating that ‘it is not whether the patient lacks the capacity to consent or refuse treatment, but rather it is the context and relationships involved in the quality of care’ (p. 268). This implies that the act of establishing a strong therapeutic alliance by allowing patients to make decisions regarding their medical needs would be more beneficial for the patient in terms of long-term treatment and recovery.
This seems to be consistent with the view of Winick (1999), who stated that patients who ‘feel less coerced into accepting treatment, and who believe that entering treatment reflects their own choice, are more invested in treatment and benefit more from it than patients who feel coerced and disrespected by the treatment process’ (p. 48). Thus, ignoring or not respecting a patient’s treatment preferences might increase their sense of being coerced (La Fond & Srebnik, 2002). Goldner et al. (1997) stated that developing a genuine alliance with the patient could prevent treatment refusal and reduce the need for involuntary treatment. Therefore, respecting a patient’s autonomy involves allowing them to have a voice in the decision-making process regarding their care, even when their decisions might seem risky or have a deleterious effect (Dworkin, 1993; Rathner, 1998; Tan et al., 2008; Wyder et al., 2013).

A number of studies have supported this argument. Katsakou and Priebe (2007) reviewed qualitative papers (n = 5) on people’s experiences with involuntary treatment. Most participants described having a closer therapeutic alliance with their doctor when they were informed about their rights and treatment. As a result, participants felt less coerced and more valued and respected, and they felt a greater sense of control over their care. Conversely, some participants expressed negative views about their health providers when they were not involved in the decision-making process. These participants experienced a high degree of coercion and felt that their liberty, rights and autonomy were violated.

These results correspond with those of another study, which examined participants’ views regarding treatment of and recovery from AN (Darcy et al., 2010). Most participants reported that they had no involvement in the decision-making process because the treatment was against their will and their doctor was the main decision-maker. A key finding of the report was a significant difference in patients’ motivation to recover. The results indicated that increased involvement in decision-making enhanced the patients’ motivation to recover.
and normalised their eating behaviour. In contrast, patients who were not involved in the decision-making process exacerbated their eating disorder symptoms and felt that their autonomy was violated. A study conducted by Tan et al. (2003) found that some patients felt a greater sense of choice and control in the decision-making process, which resulted in greater acceptance of hospital treatment. In turn, this led to a reduction in treatment resistance and improved the therapeutic alliance between health professionals and patients and their families.

A large-scale qualitative research study by Escobar-Koch et al. (2010) circulated a questionnaire among users of 144 US and 150 UK eating disorders services. The data were thematically analysed using content analysis. The aim of the study was to elicit the views of service users about the provision and delivery of eating disorders services. One significant finding was that service users (11% in both samples) wanted to be actively involved in the decision-making process and to negotiate treatment plans. However, it was found that 10.2% of US users and 9.2% of UK users were not able to voice their opinions or make decisions about their care, and thus were excluded from the decision-making process. The main reasons were that the health professionals did not provide a client-centred standard of care and were not flexible with healthcare plans that would meet the needs of individual patients. The authors concluded that there is a need to engage patients in the decision-making process, which would result in an increase in ‘user satisfaction’ and achieve ‘therapeutic success’ (p. 558).

The extant research shows that respecting a patient’s decisions regarding their medical care can increase their sense of wellbeing and self-esteem (Murray et al., 2011; O’Brien & Golding, 2003), help them make greater therapeutic progress, help them remain in treatment for longer periods (Holm et al., 2012; Vandereycken & Vansteenkiste, 2009) and help them develop their decision-making abilities and feel more in control (O’Brien & Golding, 2003; Ramjan & Fogarty, 2019). This in turn strengthens the therapeutic relationship (Button &
Warren, 2001; Draper, 2003; O’Brien & Golding, 2003), reduces the incidence of hospital readmissions (Madder, 1997; Matusek & Wright, 2010; Tan, Hope, Stewart et al., 2003), lessens the chronicity of the illness (Madder, 1997; Tan, Hope, Stewart et al., 2003), reduces mortality (Draper, 2000; Gilbert, 2005; Manley et al., 2001; Sjöstrand & Helgesson, 2008; Stice, 2001; Vandereycken & Beumont, 1998c), increases treatment adherence (Escobar-Koch et al., 2010; Koruth, 2008) and prevents repeated suicidal behaviour (Berg, Rørtveit, & Aase, 2017; Manley & Leichner, 2003).

Gull’s (1874) edict not to give up on patients with anorexia is an important lesson for therapists when establishing a therapeutic relationship with people with SE-AN. A similar sentiment was expressed by Ramjan and Fogarty (2019, p. 40), who encouraged therapists to persevere with building strong therapeutic relationships with their patients, and others have advocated for ‘forbearance and self-compassion’ (Russell et al., 2019, p. 3). This can help to facilitate effective treatment for people with AN and, in some cases, it can be instrumental in their recovery (Bruch, 1979; Finelli, 2001; Manley & Leichner, 2003; Marzola et al., 2019; Matusek & Wright, 2010; Murray et al., 2011; Ramjan & Fogarty, 2019).

5.1.6 Least restrictive alternative principle

The iatrogenic effects of psychiatric care can be reduced by using the ‘least restrictive principle’ (Feiring & Ugstad, 2014; Melamed et al., 2003; Woodside, 2002). By definition, the principle ‘requires avoidance of those [intrusive means] which are unnecessary or whose cost-benefit ratios, weighed from the patient’s standpoint, are unacceptable’ (Gallagher, 1998, p. 759).

A number of writers have advocated that the principle of least restrictive care should be applied in circumstances in which patients are competent to make decisions and, in some cases, when they are not competent (Appelbaum & Rumpf, 1998; Dresser, 1984c; Melamed et al., 2003; O’Brien & Golding, 2003; Russell, 2001). The aim of this approach is to reduce the
need to use coercion by encouraging patients to engage with treatment services on a voluntary basis (Kjellin & Nilstun, 1993; Werth Jr et al., 2003).

For example, the use of coercive measures such as civil commitment should only be used as a last resort to reduce harm or avert imminent danger to a person’s life (Atkinson, 2007; Bonnie, 2012; Dresser & Boisaubin Jr, 1986; Feiring & Ugstad, 2014; Kendall, 2014; Pozón, 2015). Voluntary hospital admission that includes the patient’s consent is a preferable course of action (Crisp, 1995; Holm et al., 2012). This would uphold the ethical principle of respect for autonomy while maintaining a duty of care (Knapp & Vandecreek, 2007; Norvoll et al., 2017). In addition, it would increase the likelihood of treatment success (Dresser & Boisaubin Jr, 1986).

Vandereycken and Beumont (1998c) argued ‘that to speak of enforced treatment of anorexia nervosa is misleading. True therapy necessarily involves the patient’s co-operation’ (p. 10). Working from this maxim, a therapeutic goal could then be to minimise the need for compulsory treatment, for the shortest possible time, without affecting the patient’s autonomy (MacDonald, 2002; Yager et al., 2016). This suggests that the goals of treatment should be congruent with the views of the patient to maximise therapeutic outcomes, but not to the detriment of their health (Dresser & Boisaubin Jr, 1986; Nordbø et al., 2006). That is, involuntary treatment should be considered an absolute last resort when all other therapeutic interventions, such as outpatient care, have been exhausted (Appelbaum & Rumpf 1998; Campbell, 1997; Dresser, 1984c; Goldner, 1989; Kendall & Hugman, 2014; MacDonald, 2002; Maher & Rosedale, 1993; Russell, 2001; Touyz & Carney, 2010).

The WHO determined that people with mental health issues (including those with eating disorders) should be treated using the least restrictive principle:

*Care and treatment provided in the least restrictive environment. In order to uphold this principle, legislation should be framed so that involuntary (formal) hospital admission is the last resort. This can be achieved through: clearly defined grounds for detention; procedural safeguards when the power to detain is*
used; an obligation to discharge when grounds for detention are no longer met; an independent review of the decision to detain. (WHO, 2001)

Another way this can be achieved is by implementing PADs as part of the patient’s treatment plan. Studies have generally supported the use of PADs to minimise the iatrogenic effects of coercion—particularly for people with SMI and those who have been hospitalised (Shields et al., 2014; Swanson et al., 2003; Swanson et al., 2000; Van Dorn et al., 2010). The utility of PADs is consistent with the principle of least restrictive alternative care because it enables the patient and healthcare provider to discuss treatment preferences (Atkinson, 2010; Atkinson, 2007; Freestone et al., 2015; Halpern & Szmukler, 1997; Kring & Davison, 2007).

For example, allowing the patient to have a say in the refeeding program, such as the use of a gastric peg (a less confronting option than consuming a normal diet), can be an effective therapeutic intervention in the care of people with SE-AN because it enables them to regulate their own weight gain without compromising their health, and it is considered the least restrictive measure (Serfaty & McCluskey, 1998).

Ethically, this approach can be viewed as supporting an individual’s right to self-determination by offering treatments that will enable the patient to ‘initiate, sustain and regulate their own weight gain’ (Duker & Slade, 1988, p. 88) with minimal interference, thereby empowering the patient to take responsibility for their eating disorder (Wills & Olivier, 1998). Further, it is a means of achieving a balance between the ethical principles of autonomy and beneficence (Beauchamp & Childress, 2001; Giordano, 2012; Maher & Rosedale, 1993; Russell, 2001; Werth Jr et al., 2003).

Of course, when a patient requires medical rescue but refuses treatment, the least restrictive principle can still be applied. As shown in Table 5.1, Goldner (1989) devised a number of strategies that can help health professionals to overcome treatment refusal while maintaining a therapeutic relationship that promotes adherence to treatment in patients with SE-AN (Elbaky et al., 2014).
Table 5.1

_Treatment Principles for Managing Treatment Refusal_

1. Seek to engage in a sincere and voluntary alliance
2. Identify reasons for treatment refusal
3. Provide careful explanations for treatment recommendations
4. Be prepared to negotiate
5. Weigh the risks versus benefits of treatment impositions
6. Allow the patient to retain autonomy
7. Avoid battle scare tactics
8. Convey balance of control versus non-control
9. Ensure methods of treatment are not inherently punitive
10. Involve the family
11. Obtain legal clarification and support
12. Consider legal means of treatment imposition only when refusal is judged to constitute a serious risk
13. Consider differential treatment in chronic AN
14. Conceptualise refusal/resistance as an evolutionary process

*Note. Adapted from Goldner (1989, pp. 303–305)*

This position would promote a collaborative alliance and provide an opportunity for both parties to engage in a process of mutual cooperation (Widdershoven & Berghmans, 2001). This would usually result in building rapport and trust between the patient and the doctor while adhering to the ethical principle of duty of care (Werth Jr et al., 2003).

Inevitably, there will be cases in which no amount of negotiation or collaboration will change the mind of a refractory patient; in such circumstances, force-feeding may be the only option to avoid death (Dresser, 1984c; Fost, 1984; Goldner, 1989; Mitrany & Melamed, 2005; Thiels, 2008; Yager et al., 2016). It is in these scenarios that a patient’s competency becomes questionable (Dresser & Boisauvin Jr, 1986; Westmoreland & Mehler, 2016).

5.1.7 Competency—‘an ethical quandary’

Arguably, the most contentious issue in this ethical debate is how to determine a patient’s competency to either refuse or accept treatment (Beauchamp & Childress, 2001;
Beumont & Vandereycken, 1998; Brock, 1993; Dworkin, 1993; Goldner et al., 1997; Johnstone, 2009; Kitchener, 1984; Tan et al., 2008; Vandereycken, 1998; Widdershoven & Berghmans, 2001). Indeed, what constitutes competency has been subject to much debate in the legal and medical literature (Beauchamp & Childress, 2001; Beumont & Carney, 2003; Elbogen, Swanson, Appelbaum et al., 2007; Hotopf, 2006; Johnstone, 2009; Kitchener, 1984; Roth et al., 1982). To date, few empirical studies have investigated the issues of competency and decision-making among people with AN (Tan, Hope et al., 2003a; Tan et al., 2006; Turrell et al., 2011). This could be related to the ethical constraints of accessing patients with AN. The terms ‘capacity’ and ‘consent’ are associated with the concept of competency and are used frequently and interchangeably, but they have ambiguous meanings and are open to misinterpretation (Appelbaum, 2007; Atkinson, 2007; Beumont & Carney, 2003; Boyle, 2019; Dresser, 1984a; Tan, Hope et al., 2003a).

To clarify, ‘competency’ is a legal term that describes a patient who has ‘the ability to understand treatment information, process the information to arrive at a choice, and the ability to communicate that choice’ (Stewart & Tan, 2007 p. 345), whereas the term ‘consent’ refers to ‘acquiescence to treatment, based in showing capacity, voluntariness, adequate information’ (Beumont & Carney, 2003, p. 590) and the term ‘capacity’ can be defined as ‘the ability to perform a task’ (Beauchamp & Childress, 2001, p. 112). For example, when patients are able to conceptualise that they need to maintain an optimum weight, it could be argued that they have gained ‘sufficient insight’ to be able to refuse or consent to treatment (Carney, Tait et al., 2006). However, for patients who deny that they are underweight, it could be said that the illness has impaired their judgment, and therefore they are not able to arrive at the same conclusion (Melamed et al., 2003; Roth et al., 1982; Werth Jr et al., 2003).

Some experts have considered this an oversimplification of an otherwise complex problem (Backlar, 2004; Halpern & Szmukler, 1997). They claim that a person’s capacity
should not depend on the diagnosis alone but should be based on a case-by-case scenario, taking into account the patient’s ‘specific’ and ‘global’ competency (Brock, 1993; Draper, 2000; Gans & Gunn Jr, 2003; Giordano, 2005; Manley et al., 2001; Matusek & Wright, 2010; Melamed et al., 2003; Tan, Hope et al., 2003a).

Matusek and Wright (2010) defined global competency as having the capacity to make rational decisions or ‘value judgments’ in other domains of a person’s life, such as work and school. In contrast, ‘specific competency’ pertains to a particular domain, usually in the context of a person’s mental illness, such as an eating disorder (Draper, 1998; Matusek & Wright, 2010; Melamed et al., 2003). It is in this domain that much of the controversy exists, based on the assumption that a low BMI coupled with egosyntonic symptoms can affect a person’s ability to make judgments (Adair et al., 2007; Buchanan & Brock, 1989; Matusek & Wright, 2010; Russell, 2001; Turrell et al., 2011).

The term ‘egosyntonic’ refers to people’s belief that their behaviours ‘fit’ with their sense of who they are; that is, they value their symptoms and do not want the illness to leave (Beat Eating Disorders, 2017; Crisp, 1997; Douzenis & Michopoulos, 2015; Fedyszyn & Sullivan, 2007; Geller et al., 2012; NICE, 2017; Schmidt & Treasure, 2006; Tan et al., 2010; Treasure, 2002; Winkler et al., 2017). This prevents the individual from understanding the full extent of their illness and its consequences (APA, 2000; Holm et al., 2012; Marzola & Abbate-Daga, 2019; Winkler et al., 2017). It prevents them from seeking professional support, affects their ability to engage in therapy and reduces their treatment compliance (or they refuse treatment altogether) (Bamford & Mountford, 2012; Elbaky et al., 2014; Fairburn, Shafran et al., 1999; Franko & Keel, 2006; Garner & Garfinkel, 1997; Guarda, 2008; Holm et al., 2012; Tan et al., 2003a; Werth Jr et al., 2003). In these circumstances, a patient’s refusal of treatment would be denied based on their incompetency.
However, civil libertarians have argued that a mental illness does not necessarily prevent a person from being competent (Giordano, 2005; Mill et al., 1962; Winick, 1996).

There are mixed data regarding the issue of competency among those with AN. Tan et al. (2006) conducted a qualitative study to determine whether patients with AN who had low BMI could demonstrate decisional capacity. The salient finding of the study was that ‘some patients gave accounts of the preservation of clear thinking and a good capacity to reason and be involved in treatment decisions, even when patients were at a very low weight and very unwell’ (p. 271).

In contrast, Turrell et al. (2011) found that adolescents with AN lacked the ability to engage in reasoning in all domains, including comparative, logical, generative consequences and consequential reasoning. Statistically, significant differences were observed in both the community (control group) and the AN participants, showing that the community participants outperformed people with AN in their reasoning abilities. This suggests that there are other factors (e.g., egosyntonic and depression) on top of their diagnosis that can contribute to the patient’s lack of capacity.

Two models are commonly used to determine a person’s competency: the MacArthur Competence Assessment Tool-Treatment and the Mini-Mental State Examination (Appelbaum, 2007; Atkinson, 2007; Tan et al., 2006). However, there are doubts about their effectiveness and reliability, as well as concerns regarding when and on whom these tests should be conducted, and at which point in the trajectory of the illness could the patient’s competency be measured and defined (Backlar & McFarland, 1998; Beauchamp & Childress, 2001; Boddy et al., 2013; Brown, 2003; Buchanan & Brock, 1989; Halpern & Szumukler, 1997; Johnstone, 2009; Manley et al., 2001; Srebnik & Brodoff, 2003; Tan et al., 2006).

Further, different models of competency assessment are designed for different patient groups,
and this raises the question of which model would be best suited to provide a valid clinical assessment in patients with AN (Appelbaum, 2007).

The circumstances, clinical situations and timeframes vary so much among the people being tested that situational competency is difficult to assess (Appelbaum, 2007; Banner & Szmukler, 2013; Beauchamp & Childress, 2001; Bergum & Dossetor, 2005; Breeze, 1998; Buchanan & Brock, 1989, 2007; Dresser, 1984b; Gallagher, 1998; Manley et al., 2001; Rathner, 1998; Roberts & Dyer, 2007). For example, Backlar (1995) stated that ‘what we wish for when we are in one state may no longer be what we want or require when we are in an altered state’ (p. 106). She further stated that a patient’s values and interests may change over time—particularly when their capacity has been restored—even on a temporary basis. That is, their competency can ‘fluctuate’ and, accordingly, their values change over the course of their illness (Bogdanoski, 2009; Foti et al., 2005; Gergel & Owen, 2015; Tan et al., 2006).

This problem is further compounded by a difference of opinion among various clinicians. Some have argued that a patient’s decision to refuse or accept treatment is caused by the illness. However, others insist that it is a legitimate ‘free will’ decision and is not ‘contaminated’ by the illness (Bogdanoski, 2009). This problem can be overcome by seeking assistance from a legal counsel or an independent ethicist (McSherry, 1997).

There is also an issue of severe malnutrition and its effects on a person’s competency (Geller et al., 2012). This, too, can easily be resolved. As an adjunct to the competency assessment, a full physical examination should be undertaken to determine whether there are any abnormalities (e.g., electrolyte imbalances) that could affect the patient’s competency (Dresser & Boisaubin Jr, 1986). Geppert (2015) claimed that the neuropsychiatric symptoms of long-term starvation (e.g., cognitive impairment) can be improved by nutritional repletion and weight gain, thus restoring and normalising competency in people with severe AN.
In the bioethics literature, ‘competency/capacity’ appears to be contentious and is an ‘elusive’ and ‘nebulous’ concept with no clear arbitrary line of demarcation (Barker & Ritter, 1998; Beauchamp & Childress, 2001; Elbogen, Swanson, Appelbaum et al., 2007; Maher & Rosedale, 1993; Tan et al., 2006). By its very nature, ‘decisional incapacity is not an “all or nothing” phenomenon, but rather a fluctuating occurrence throughout the course of mental illness’ (Shields et al., 2014, p. 762). Concomitant factors such as a person’s global competency, BMI, egosyntonic features and comorbidities such as depression and anxiety can significantly affect a person’s competency (Buchanan & Brock, 1989; Draper, 2000; Maher & Rosedale, 1993; Manley et al., 2001; Touyz & Carney, 2010). For this reason, it has been argued that these factors must be taken into account when conducting capacity assessments (not based solely on diagnosis), and these assessments should be carried out on a periodic basis to accurately measure the patient’s competency (Appelbaum, 2007; Haughey & Watson, 2015; Roth et al., 1982).

One possible way to circumvent this problem is through the use of PADs (Backlar & McFarland, 1998; Bogdanoski, 2009; Elbogen, Swanson, Appelbaum et al., 2007; Srebnik & Brodoff, 2003). Clinicians are encouraged to work collaboratively with patients by discussing their treatment options in the event that they lose capacity (Halpern & Szmukler, 1997). This process would eliminate any doubts or concerns about a person’s capacity, competence or consent while maintaining respect for their autonomy.

5.2 Conclusion

This review of the AN literature found that ethical principles of beneficence and autonomy are not mutually exclusive; rather, they can be integrated into clinical decision-making when caring for people with SE-AN. A recurring theme that was reflected in the current discussion—and that is arguably the most contentious issue—is deciding on the best course of action (treatment) to protect a patient’s best interests.
Those who support the principle of autonomy have argued that involuntary treatment is not effective on a long-term basis for people with SE-AN; reportedly, it can alienate and cause long-term irreparable damage to the therapeutic alliance. Evidence has also shown that involuntary treatment is not successful in reducing the incidence of relapses and is not effective in helping people to recover. Further, this imposition infringes on the patient’s right to self-determination and autonomy and is therefore a violation of human rights.

Libertarians have supported the premise that the most effective therapy for patients with SE-AN is to develop a fiduciary relationship based on humanistic qualities. In turn, this will help to achieve better and more sustainable clinical outcomes, prevent treatment refusal, reduce dropout rates and increase treatment adherence rates. Most importantly, it will encourage patients to take greater responsibility for their illness so they can live in a world that is not dominated by SE-AN.

Proponents who support the position of beneficence have argued that allowing the patient to have a ‘choice’ and ‘freedom’ to refuse treatment may exacerbate the severity of the disorder, possibly even causing death. Empirical and theoretical studies have shown that weight restoration in conjunction with pharmacotherapy and psychotherapeutic treatment is an effective intervention (albeit on a short-term basis) in saving lives. Further, studies have suggested that people with SE-AN are grateful and retrospectively thank those who enforce treatment. It has been proposed that involuntary treatment can be successfully implemented by applying the least restrictive principle without impinging on the patient’s autonomy and while still upholding the duty of care.

The central issue of the debate is how to determine whether a patient has the capacity to consent to or refuse treatment. This analysis has demonstrated that adopting a collaborative approach that involves all key stakeholders through the use of PADs is an effective way to ensure the safety and best interests of patients.
The aim of this literature review was to demonstrate the need to develop an ethical model (see Section 1.8) that incorporates the use of PADs as a method of counterbalancing the ethical principles of beneficence and respect for autonomy. The ultimate goal is to reduce the iatrogenic effects of psychiatric care for adult females with SE-AN. The next chapter aims to provide a methodological framework to develop an ethical decision-making model.
Chapter 6: Research Methodology

6.1 Introduction

This chapter provides an overview of the philosophical underpinnings of the research. The aim of this chapter is to explain the relationship between the theories of constructivism—interpretivism (ontology), symbolic interactionism (epistemology) and phenomenology when exploring the ‘conditions’ and ‘processes’ underlying the ‘lived experience’ of SE-AN. These social models of theories will form the analytic framework of the study. The GT method was used to analyse the data, while reflexivity maintained the credibility and trustworthiness of the research process.

6.2 Philosophical Underpinnings

6.2.1 Introduction

In social science, it is important for researchers to position their philosophical and methodological framework to achieve consistency and rigor in the research process and to answer the research question (Carpenter & Suto, 2008; Holloway, 2005b; Taylor, 2005). A number of philosophical approaches and methods were used in this study to investigate the phenomenon of SE-AN. As shown in Figure 6.1, these philosophical approaches are interrelated and are characterised by four key paradigms—epistemology, ontology, axiology and methodology—which relate to people’s everyday existence, interaction, meaning, experience and language (Bloomberg & Volpe, 2015; Crotty, 1998; Holloway, 1997; Silverman, 2005). Some writers have replaced these terms with ‘worldview’, which is a more inclusive term that describes people’s ‘realities’, ‘assumptions’, ‘beliefs’ and ‘attitudes’ about their living worlds; however, they share the same meaning (Avis, 2005; Corbin & Strauss, 2014; Creswell, 2013; Slevitch, 2011).

These concepts have been contextualised into four basic questions (Annells, 1996, p. 383): What is the form and nature of reality? What can be known about reality (ontology)?
What is the nature of the relationship between the knower (the inquirer) and the would-be knower, and what can be known (epistemology)? Should the inquirer go about finding whatever he or she believes can be known (methodology)? Denzin and Lincoln (2017, p. 97) conceptualised axiology as: How will I be as a moral person in the world? These questions will be answered during the analysis.

Figure 6.1. Underlying philosophical assumptions.

6.2.2 Theoretical sensitivity versus objectivity—a paradigmatic debate

In the area of ontology, there is a debate about the nature of reality and how it exists in both quantitative and qualitative research (Avis, 2005; Bryman, 2012; Clark, 1998; Denzin & Lincoln, 2017; Gasson, 2004; Holloway, 1997; Lincoln & Guba, 1985; Maguire, 1987; Patton, 2015c; Ratner, 2002; Slevitch, 2011). There are two different interpretations (Ratner, 2002). In traditional scientific research, reality has been articulated as ‘subjectivity versus objectivity’ (Crotty, 1998, p. 14), whereas in qualitative research, ‘sensitivity stands in contrast to objectivity’ (Corbin & Strauss, 2014, p. 78). Although the term ‘sensitivity’ is the preferred choice—specifically in relation to GT—subjectivity is often used when describing
people’s realities. However, the terms can be used interchangeably because of their shared meaning (Holloway, 1997). For the sake of this discussion, the term ‘sensitivity’ will be used here. To better understand the debate, it is important to provide an overview of what constitutes reality from both the positivist and interpretivist perspectives, and to compare their differences (Barker & Pistrang, 2015; Denzin & Lincoln, 2012; Holloway, 2008; Sarantakos, 2005).

A research paradigm that adopts a positivist approach defines reality as a single external reality that can be empirically validated and universally applied using the classical hypothetical–deductive method (Bloomberg & Volpe, 2008; Bryman, 2012; Kvale, 1996; Marks & Yardley, 2004; Patton, 2015c; Ponterotto, 2005; Ratner, 2002; Schwandt, 2014). This nomothetic approach requires the researcher to be objective to avoid contaminating the data (Barker & Pistrang, 2015; Bryman, 2012; Holloway, 1997, 2008; Sekaran & Bougie, 2016). In this sense, objectivity is a *sine qua non* in the data analysis (using statistical models) because it ensures the accurate testing of hypotheses. Therefore, it negates sensitivity (subjectivity) in its measurements, thereby increasing its validity to obtain objective knowledge—a position known as naïve realism (Annells, 1996; Bryman, 2012; Crotty, 1998; Hennink et al., 2010; Holloway, 1997; Kvale, 1996; Lincoln & Guba, 1985; Ponterotto, 2005; Sekaran & Bougie, 2016). Put differently, ‘if I can see it, measure it, record it, it’s true’ (Maguire, 1987, p. 2). At its core, this paradigm is defined as being fixed and independent of the mind. It is a reductionist scientific method used to determine the validity of a theory. An understanding of these scientific laws can help in establishing ‘absolute’ truth (Charmaz, 2008; Sarantakos, 2005d).

In contrast, Berger and Luckmann’s (1967) social theory of social constructivism argues that reality is a constantly shifting emergent paradigm that is individually experienced and socially constructed (interpretivist), and it believes there are multiple truths—not one
single objective reality—that can be scientifically valid and culturally derived (Bloomberg & Volpe, 2008, 2015; Bryman, 2012; Charmaz, 2006, 2008a; Charmaz et al., 2017; Creswell, 2013; Crotty, 1998; Denzin & Lincoln, 2008; Hennink et al., 2010; Kvale, 1996; Nkansah & Chimbwanda, 2016; O’Donoghue, 2006; Patton, 2015c; Ponterotto, 2005; Saldaña, 2015; Sarantakos, 2005d; Sengstock, 2008; Shearson, 2014; Slevitch, 2011).

According to Crotty (1998), this theory has two different interpretations of the epistemological status of constructing knowledge: constructionism and constructivism. Constructivism can be defined as ‘the meaning-making activity of the individual mind’, whereas constructionism is the ‘collective generation [and transmission] of meaning’ (p. 58). That is, people can construct knowledge based either on their individual experiences of objective reality or through a cultural lens whereby a person’s social norms and values have shaped their perceived sense of reality (Crotty, 1998). Although there are differences between the two concepts, both are concerned with ‘the construction of knowledge and the construction of social reality’ (Adler, 2013, p. 113).

This theoretical perspective asks the question: What is the nature of the relationship between the knower (the inquirer) and the would-be knower, and what can be known (Annells, 1996, p. 383)? Thus, it aims to generate in-depth knowledge of the phenomenon—a position known as epistemology. Therefore, this theory strongly rejects the idea that reality is a physical entity—that is, a world that can be quantified and measured, and thus independent of the human mind and experience (Avis, 2005; Crotty, 1998; Holloway, 1997; Sarantakos, 2005). Rather, it is a social construct wherein knowledge is co-created by examining multiple perspectives (e.g., patients and health professionals), including the researcher’s own subjective views, emotions and professional background—a position known as relativism (Annells, 1996; Avis, 2005; Charmaz et al., 2017; Creswell, 2013; Denzin & Lincoln, 2008; Hennink et al., 2010; Holloway, 1997, 2008; Riley, 1996).
Therefore, social constructivism aims to understand the lived experiences of individuals from their perspective, and how they make sense of their worlds (Bloomberg & Volpe, 2008; Creswell, 1998, 2013; Holloway; 2005). However, the question has been raised whether having insight knowledge (i.e., preconceived notions) about the phenomenon might potentially contaminate the data, that is, researchers might impose their personal biases or a priori assumptions, and thereby compromise the validity of the data (Flick, 2014; Kushner & Morrow, 2003; McCosker, Barnard, & Gerber, 2001).

This issue has been a central concern for those supporting a positivist stance, particularly with regard to external and internal validity (Lincoln, Lynham, & Guba, 2011). Researchers such as Barney Glaser, a constructionist, have advocated a tabula rasa position (i.e., avoiding writing a literature review before data analysis) in order to eliminate potential bias (Charmaz, 2008b; Creswell, 1998; Cutcliffe, 2000; Dick, 2005; Flick, 2014; Kushner & Morrow, 2003).

However, social constructivists have argued that some knowledge obtained through personal or professional experience about the study topic is necessary to conceptualise the data (e.g., identify similar or different incidents) at a more intimate level (Charmaz, 2008a; Corbin & Strauss, 2014; Dey, 1993; Holloway, 2005; Kushner & Morrow, 2003). Corbin and Strauss (2014) reiterated this position by stating that ‘professional knowledge and experience can enhance sensitivity. Though experience can blind researchers’ perception, it can also enable researchers to understand the significance of some things more quickly’ (p. 78). This idiographic approach allows the researcher to get closer to the data by using their sensitivity, which enables them to make interpretations about the data (Barker & Pistrang, 2015; Charmaz, 1995; Holloway, 2008; Oliver, 2012; Plummer & Young, 2010; Sandelowski, 2010; Slevitch, 2011; Strauss & Corbin, 1990, 1998).
A number of authors have argued that qualitative researchers need to demonstrate a degree of ‘sensitivity’ to extrapolate hidden meanings and nuances grounded in the data, but this is not achievable using conventional quantitative methods during the analytical process (Charmaz, 1995; Charmaz et al., 2017; Corbin & Strauss, 2014; Patton, 2002; Plummer & Young, 2010). This seems to be consistent with a hermeneutical approach, specifically Heideggerian phenomenology, which encourages the researcher to draw upon their ‘tacit knowledge’ and use ‘deep reflective’ skills to unearth hidden meanings embedded in the data (Denzin & Lincoln, 2017; Ponterotto, 2005, p. 129).

Several authors have shared this view by stating that researchers who adopt a phenomenological approach are not outsiders when conducting research (i.e., detached from the experience); rather, they are considered insiders because of their shared experiences (Bergum & Dossetor, 2005; Charmaz et al., 2017; Hertz, 1997; Holloway, 2008; Riley, 1996). Researchers often have a personal connection with the research topic and therefore bring their own insights, histories and personal experiences from ‘being in the world’ (Heidegger, 1962) into the study. This provides an interpretive lens about the social phenomenon (Bloomberg & Volpe, 2008; Charmaz et al., 2017; Clark, 1998; Corbin & Strauss, 2014; Creswell, 1998, 2013; Holloway, 2005b; Oliver, 2012; Patton, 2015c).

Charmaz (2006) added that ‘theory depends on the researcher; it does not and cannot stand outside of it’ (p. 130). Therefore, to gain an insider’s perspective of the social phenomenon, the researcher plays an active role in the research process in terms of data gathering and analysis (Avis, 2005; Bloomberg & Volpe, 2015; Charmaz, 2000; Creswell, 2013; Hennink et al., 2010; Merriam, 1988; Nkansah & Chimbwanda, 2016). Chenitz and Swanson (1986a) supported this position and stated that the researcher must ‘take the role of the other’ (author’s interpretation—learning from each other—intersubjectively) to understand a person’s perspective (realities) about their social worlds (p. 46). Avis (2005)
stated that ‘the researcher cannot detach themselves from the evidence they are generating’, and if they do so, this might lead them down a pathway of ‘mindless empiricism’ (pp. 6–7).

While the sensitivity (subjectivity) of the researcher is acknowledged in qualitative studies—particularly with a social constructivist approach, the researcher has an obligation to maintain a degree of neutrality to circumvent any potential biases and values that may be imposed on the data to ensure the trustworthiness of the findings (Bryman, 2012; Marshall & Rossman, 2010; Sarantakos, 2005a). Lincoln and Guba (1985) recommended that the ‘biases, motivations, interests or perspectives of the inquirer’ should be identified and made explicit (see Declaration for details) before the study (p. 290). In social research, this is generally achieved through the use of reflexivity (Creswell, 2013).

6.2.3 Reflexivity

By definition, reflexivity is ‘an awareness of the influence the researcher has on what is being studied and, simultaneously, of how the research process affects the researcher’ (Probst & Berenson, 2013, p. 814). Reflexivity provides the researcher with an opportunity to be transparent and accountable for the creditability of the research findings (Berger, 2015; Berglund, 2001; Hammersley & Atkinson, 2007; Plummer & Young, 2010). In doing so, they will answer the ethical/axiological question: How will I be as a moral person in the world [of research] (Denzin & Lincoln, 2017, p. 97)? This question implies that the researcher has a responsibility to ensure that their interpretations of the data are not tainted by their personal biases, values and assumptions, but rather provide ‘authentic accounts’ of the participants’ stories (Bryman, 2012; Corbin & Strauss, 2014; Hennink et al., 2010; Maxwell, 2012; Probst & Berenson, 2013). Indeed, this question is consistent with the ethical principles of veracity (truth-telling), fidelity (honesty) and showing respect for the participants’ views and opinions (Beauchamp & Childress, 2001; Johnstone, 2009). However, these principles could be compromised, particularly during data analysis, when the researcher engages in a process of
introspection and critical reflection of the interpretation of the data (Hennink et al. 2010).

Corbin and Strauss (2014) explained that:

\[ \text{It is when it comes to analysis that perspectives, biases, and assumptions can have their greatest impact. The impact comes in the meaning given to data, the concepts used to stand for that meaning, the questions that are asked, and comparisons that are made. (p.46)} \]

As mentioned earlier, my lived experience of SE-AN, being a male and being well acquainted with the ED literature could threaten the trustworthiness of the findings. That is, I could impose my androcentric values and biases about the phenomenology of the lived experience of SE-AN and make erroneous assumptions about the true ‘meaning’ of the data.

Carpenter and Suto (2008) claimed that it is important to understand the researcher’s location within the research to enhance the trustworthiness of the research findings. They argued that researchers are the main research instrument and therefore have the responsibility to monitor their involvement in the research process to defend their ‘epistemological claims’.

A number of ‘checks and balances’ have been described—peer checking, journal writing, debriefing with supervisors—which enabled the researcher to detect potential biases (or subjectivity) that might compromise the integrity of the research, thus negating these assumptions (Corbin and Strauss, 2014). These are discussed further in Section 7.7.

However, it should be noted that research biases can occur even among the most conscientious of researchers, despite their attempts to adhere to the strictest research protocols and procedures (Janesick, 2003; Marshall & Rossman, 2010; Maxwell, 2012; Morrow, 2005; Thorne, 2008). No research is ‘value free’. Subjectivity challenges the notion of objectivity (or in this case, reflexivity challenges internal validity), and this is a fundamental difference between the paradigms (Berger, 2015; Denzin & Lincoln, 2008; Hammersley & Atkinson, 2007; Probst & Berenson, 2013; Slevitch, 2011). Nowhere is this more evident than in understanding the phenomenology of the ‘lived experience’ of SE-AN, whereby subjectivity
can illuminate the contextual factors—structural and psychological—of the social phenomenon.

### 6.2.4 Phenomenology

Given that this is an explorative study that focuses on understanding how people interpret, experience and understand their living world, a phenomenological approach has been used to describe the essence of the ‘lived experience’ (*Verstehen*) of females with SE-AN (Bryman, 2012; Creswell, 1998; Crotty, 1998; Denzin & Lincoln, 2008; Hennink et al., 2010; Holloway, 2008; Patton, 2015c; Thorne, 2008; Todres, 2005).

In the 1970s, phenomenology was first formalised by Edmund Husserl (Gubrium & Holstein, 2003). Similar to social constructionism, phenomenology is concerned about understanding peoples’ lived experiences and the meanings that they assign to these experiences (Patton, 2015; Schwandt, 2014; Sarantakos, 2005). The difference is that there is no objective or subjective reality that shapes peoples’ worldviews. Rather, interaction with others can create a conscious awareness of social reality (Patton, 2015; Sarantakos, 2005). Therefore, the process of meaning-making is based on the meanings that people attribute to the actions of others, and about one’s self (Bryman, 2012). This process is not too dissimilar to symbolic interactionism, whereby people create meaning through social interactions (Charon, 2009). In phenomenology, it is incumbent on the researcher to make interpretations of these meanings and then extrapolate the findings to the phenomenon (Bryman, 2012; Patton, 2015).

Historically, social scientists have used a phenomenological approach to discover how ‘individuals define, interpret and experience their environments’ (Saunders, 1997, p. 9). Specifically, in the fields of psychology and psychotherapy, phenomenology has been used to improve our understanding of mental health illness by exploring the lived experiences of people with mental health problems and their immediate environments (Holloway, 1997,
2008; Smythe, Ironside, Sims, Swenson, & Spence, 2008). That is, ‘phenomenology is about exploring and developing insights into the world as it is experienced’ (Paton, Martin, & Weir, 2004, p. 178). Indeed, the main premise of phenomenology is to seek the truth by exploring the subjective experience of others. This approach is antithesis to the positivist position (Bryman, 2012; Patton, 2002; Smythe et al., 2008; Thorne, 2008).

According to Patton (2015c), this can be achieved by conducting in-depth interviews with people who have direct experience with the phenomenon of interest—in this case, people with SE-AN. This firsthand knowledge provides personal insights into the phenomenon—that is, ‘how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others’ (p. 115). In this study, this knowledge helped to verify and develop a model to guide decision-making regarding the care of people with SE-AN.

To allow participants to tell their stories, a central principle of phenomenology is that researchers bracket—a mathematical term (Holloway, 1997, p. 117)—their personal beliefs and experiences, avoid making judgments and engage with people’s everyday existence—a concept known as *epoche* (Bloomberg & Volpe, 2008; Creswell, 1998; Holloway, 1997; Patton, 2015c). However, a number of authors have argued that it is difficult, if not impossible, to bracket one’s personal judgments given the explorative and interpretative nature of qualitative research (Bloomberg & Volpe, 2008; Creswell, 1998; Morrow, 2005; Padgett, 2008; Ritchie, Lewis, Nicholls, & Ormston, 2013). For example, it would go against the fundamental principle of symbolic interactionalism, whereby the researcher and participants are co-researchers and thus engage in a process of sharing experiences about, and interpretations of, the phenomenon (Denzin & Lincoln, 2008; Hennink et al., 2010; Keddy, Sims, & Stern, 1996; Wimpenny & Gass, 2000).
6.2.5 Symbolic interactionism

George Herbert Mead (1934) and Herbert Blumer (1969) are the founders of symbolic interactionalism (SI), which is a theory that has been universally applied to social research to understand the meaning and interpretation of human behaviour (Charmaz, 2014; Chenitz & Swanson, 1986a; Crotty, 1998; Holloway, 2008; Patton, 2015c; Sarantakos, 2005). The underlying principle of SI is to identify how meaning is created through the process of social interaction in people’s everyday natural settings (Chenitz & Swanson, 1986a; Patton, 2015c; Plummer & Young, 2010; Sarantakos, 2005).

This principle is analogous to that of social constructivism, whereby knowledge and meaning-making is constructed through interactions with others (Patton, 2015). Both perspectives—SI and social constructivism—work from the assumption that people ‘create meaning as opposed to acquiring it’ (Ertmer & Newby, 1993, p. 55). Thus, meaning-making is not inherited—that is, people are not born with innate meaning; rather, they cultivate or construct meaning (Bittner, 1983; Charmaz, 2014; Denzin, 2001; Handberg et al., 2014; Plummer & Young, 2010; Saunders, 1997). Therefore, these theories assume that ‘reality’ is independent of our minds (Charon, 2009).

It is also assumed that these socially constructed meanings can then be modified through an interpretive process—the self, the world and social action—thereby influencing people’s actions and interactions with others (Charon, 2009; Chenitz & Swanson, 1986; Denzin, 2001; Handberg, Thorne, Midtgaard, Nielsen, & Lomborg, 2014; Morgan & Smircich, 1980). This idea was developed by Blumer (1969), who formulated a model of understanding based on three basic principles:

*Human beings act towards things on the basis of the meanings that things have for them.*

*The meaning of such things is derived from, or arises out of the social interaction that one has with one's fellows.*
These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters. (Blumer, 1969, p. 2)

These different interpretations determine how people perceive, experience and understand their living world (Crooks, 2001; Denzin, 2001; Kvale, 1996; LaRossa & Reitzes, 2009; Oliver, 2012; Patton, 2015c; Plummer & Young, 2010). This point was reiterated by Patton (2015c), who stated that ‘people create shared meanings through their interactions, and those meanings become their realities’ (p. 133).

The theory of SI also suggests that people can construct meaning through objects or symbols (as language) within their environment (Bluff, 2005; Charon, 2009; Handberg et al., 2014; Holloway, 1997; Milliken & Schreiber, 2012; Morgan & Smircich, 1980; Patton, 2015c). For example, patients with SE-AN are exposed to and interact with social objects (e.g., nurses, other patients and institutional practices) and physical symbols (e.g., hospital beds, food, drips and hospital garments), all of which add meaning and context to their perceived reality (Annells, 1996; Blumer, 1969; Denzin & Lincoln, 1998b; Handberg et al., 2014; Mead, 1934/1964). Of course, not all symbols are known as symbols, rather, they became symbols when people have attached meaning to them (Klunklin & Greenwood, 2006).

Therefore, it is postulated that meaning-making is not fixed or immutable, but is fluid and flux, as well as modifiable through social interactions with others and within a variety of environments (Chamberlain-Salaun, Mills, & Usher, 2013; Charon, 2009; Dey, 1993; Flick, 2006; Holloway, 2005a; Liamputtong, 2013a; Milliken & Schreiber, 2012; Oliver, 2012).

Methodologically, focus groups and semi-structured interviews that involved non-directive and open-ended questions, along with prolonged engagement techniques, were used to capture and make participants’ worldviews explicit, to understand the meanings they attached to their lived experiences (verstehen) and to generate knowledge about the phenomenon (Chenitz & Swanson, 1986a; Patton, 2015; Smith, Harré, & Van Langenhove,
ETHICAL CONSIDERATIONS IN COLLABORATIVE CARE IN SE-AN

1995). These methods enabled the researcher to answer the question: How should the inquirer go about finding whatever they believe can be known (Avis, 2005; Bittner, 1983; Creswell, 1998; Crotty, 1998; Flick, 2014; O’Donoghue, 2006; Ponterotto, 2005; Ritchie et al., 2013; Sarantakos, 2005d; Taylor, 2005)?

According to Taylor (2005), these techniques are well suited to qualitative research and are tied in with the philosophical underpinnings of epistemology, ontology and axiology. They provide an opportunity for participants to talk about their beliefs (ontology) and values (axiology), and to provide true descriptions (epistemology) of their lived experiences. Creswell (2013) believed that open-ended questions play a vital role in encouraging dialogue and thus obtaining meaningful responses about a person’s social reality. Taylor (2005) and Sharkey and Larsen (2005) added that building rapport and developing mutual trust through prolonged engagement are essential components in obtaining rich data from participants. In addition, to better understand the sociocultural factors that affect the study participants, researchers are encouraged to routinely visit the living environments of participants—in this case, the hospital—to capture their worldviews and understand the conditions that give rise to the phenomenon (Creswell, 2013; Milliken & Schreiber, 2012).

These techniques were employed in this study to understand and explore the relationship between patients and healthcare professionals and to determine whether these interactions perpetuate coercion. For example, coercion could be perpetuated through the use of practices such as civil commitment, forced medication and social pressure, and through the use of everyday language and their attached meanings (e.g., rights, competence and incompetence, danger, respect, control and duty of care) (Holloway, 2005a; Sarantakos, 2005).

Therefore, a key question is: How do women construct knowledge about living with SE-AN through interactions with healthcare professionals? An understanding of this
interrelationship might shed light on how to mitigate the iatrogenic effects (coercion) of psychiatric care and thereby resolve the ethical conflicts of forced treatment. These constructed shared meanings can then be used to build a decision-making model.

To facilitate this process, GT methodology was used to explicate the social and structural conditions that influence these interactions to generate a model based on the participants’ subjective meanings grounded in the data (Bluff, 2005; Crotty, 1998; Wuest, 2011).

6.3 Why Use Grounded Theory—A Justification

An emerging group of qualitative researchers have advocated support for further social inquiry into the research on AN (Bakker et al., 2011; Bell, 2003; Carney, Tait et al., 2006; Jarman et al., 1997; Russell, 2004; Tan et al., 2006; Tierney, 2008). Indeed, it has been proposed that ‘the absence of qualitative, phenomenological research in eating disorders is a weakness in developing theory and practice’ (Hepworth, 1994, p. 179).

Given that there is a need for qualitative research to investigate eating disorders, the researcher chose to use the GT approach for several reasons. First, it can fill the gap in the literature in terms of understanding the SE-AN phenomenon, its relationship with PADs and the iatrogenic effects (coercion) of psychiatric care. Second, GT is compatible with the aims of the study, particularly in relation to developing an ethical decision-making model. In fact, one of the tenets of GT is to develop practical knowledge (Corbin & Strauss, 2014). Third, it enables the researcher to use their personal experience (i.e., living with anorexia) to enhance theoretical sensitivity towards participants’ stories and the data they provide (Annells, 1996; Corbin & Strauss, 2014; Oliver, 2012).

Therefore, the GT methodological approach was chosen because it was decided by the research question (Barker & Pistrang, 2015; Charmaz, 2000, 2014; Griffin, 2004; Jeon, 2004; Kvale, 1996; Maxwell, 2012; Silverman, 2004), it can be used as a heuristic device (Corbin &
Strauss, 2014; Janesick, 2003; Maxwell, 2012; Patton, 2015c; Saldaña, 2015), it can help generate data from multiple perspectives (Bakker et al., 2011; Chamberlain-Salaun et al., 2013; Charmaz, 2012; Corbin & Strauss, 2014), it can promote social change (Charmaz, 2012; Denzin & Lincoln, 2012; Wuest, 2011), it has the capacity to develop a theoretical framework (model) (Corbin & Strauss, 2014; Flick, 2014; Henwood & Pidgeon, 1995; Higginbottom & Lauridsen, 2014; Janesick, 2003; Wuest, 2011), it is used as a method when existing theory (beneficence v. autonomy) offers no solutions (Holloway, 2005a) and it provides a means to allow females to express their voice (Crooks, 2001).

In short, qualitative researchers put ‘meaning’ (words) into numerical numbers (Dey, 1993; Few, Stephens, & Rouse-Arnett, 2003; Maxwell, 2012; Merriam, 1988; Patton, 2015c; Punch, 2013; Rolfe, 2006). Holloway’s (2008) description of social researchers epitomises qualitative health research. He averred that social researchers ‘humanise medicine and healthcare by an emphasis on the personal experience of persons “living through” events and taking account of their feelings and thoughts’ (p. 9). Thus, the above considerations justify the use of the chosen methodology.

6.4 Grounded Theory Methodology

In their seminal book titled *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Glaser and Strauss (1967) developed GT as a method based on inductive reasoning rather than using quantitative verification procedures such as logico-deductive theory (Annells, 1996; Barker & Pistrang, 2015; Charmaz, 2000; Goulding, 1998; Jeon, 2004; Marks & Yardley, 2004; Sarantakos, 2005b; Smith et al., 1995; Strauss & Corbin, 1990, 1998). This is a fundamental difference between two research approaches (Charmaz, 1995).

Glaser and Strauss (1967) argued that data analysis needs to go beyond its descriptive parameters and move towards a theory-based investigation: ‘Our basic position is that
generating grounded theory is a way of arriving at a theory suited to its supposed uses … [rather than] generated by logical deduction from prior assumptions’ (p. 3).

This thinking was influenced by Glaser and Strauss’s (1967) professional training in sociology, although with different epistemological frameworks. Glaser was trained at the University of Columbia using a positivist approach, whereas Strauss was taught interpretivism at the University of Chicago under the supervision of Herbert Blumer and Robert Park (Charmaz, 2008; Hennink et al., 2010).

This integrated ‘knowledge’ formed the basis of GT, which was adapted to enable researchers to inductively build a theory based on the principles of symbolic interactionism (Chazman, 2008; Corbin & Strauss, 2014; Hennink et al., 2010; Milliken & Schreiber, 2012). In its application, GT was first used successfully to understand the meanings that people attach to the experience of dying in hospital care (Glaser & Strauss, 1965, 1967).

Thus, GT is an emergent method based on the inductive principle, which enables researchers to investigate a social phenomenon to explicate its meaning and significance related to a problem of concern (Charmaz, 2008). Through data analysis, the method elicits ‘thick descriptions’ (Geertz, 1973) from participants regarding their social worlds, and these descriptions form the building blocks to generate a theory (Charmaz, 2000; Glaser, 2010; Patton, 2005).

A major strength of the GT method is its flexibility in data analysis as opposed to formulaic procedures. Further, researchers can collect large amounts of rich and meaningful data, it is a method that can be used in conjunction with symbolic interactionism, different disciplinary approaches (quantitative or qualitative) and paradigms (objectivist and constructivist) can be applied, and it is less expensive than quantitative methods (Charmaz, 2008b; Glaser, 2000; Punch, 2013).
A further strength is that it provides a set of procedures (step by step approach) to assist in the interpretation and analysis of the data to ensure the rigour of the qualitative study (Charmaz, 1995, 2000; Dey, 1993; Holloway, 2005). These include the constant comparative method (Corbin & Strauss, 2014; Lincoln & Guba, 1985), theoretical sampling (Bryman, 2012; Fassinger, 2005; Whitman & Wosczynski, 2004) and theoretical saturation (Corbin & Strauss, 2014). Each method is outlined below.

6.4.1 Constant comparative method

The constant comparative method is an iterative and cyclical process that allows the researcher to explore differences and similarities in the data to generate propositions and inductively build concepts (Barker & Pistrang, 2015; Bluff, 2005; Chamberlain-Salaun et al., 2013; Charmaz, 2008a; Curry, Nemhbad, & Bradley, 2009; Edwards & Jones, 2009; Flick, 2014; Gasson, 2004; Holloway, 1997; Kushner & Morrow, 2003).

It is a data reduction method in which large amounts of data are synthesised into specific units of meaning—codes, concepts and categories. This process is simultaneously carried out during data collection and analysis, from the time of conception to the end of the research, to generate a theory (Barker & Pistrang, 2015; Bloomberg & Volpe, 2015; Charmaz, 2000; Charmaz et al., 2017; Denzin & Lincoln, 2012; Gasson, 2004; Kushner & Morrow, 2003; Lincoln & Guba, 1985; Strauss & Corbin, 1990, 1998). This was reiterated by Mullen (1994), who stated that:

*Grounded theory uses comparison as an analytical tool to generate concepts and hypothesis and to interrelate them through core variables which are both parsimonious and broad in scope. The final goal is middle-range theory in a specific content area ... or formal theory that is the theory generalised over a number of specific areas. (pp. 127–145)*

Qualitative researchers generally use the comparative method to identify and group similar incidents together to formulate a unit of meaning (a code) that is labelled (with a word or phrase) from the participants’ descriptions (Barker & Pistrang, 2015; Fassinger, 2005;
Holloway, 2005a; Spiggle, 1994; Strauss & Corbin, 1990, 1998). In turn, these groupings (combined data) facilitate the development of concepts, which are arranged in a hierarchical order from a lower to a higher level (Barker & Pistrang, 2015; Corbin & Strauss, 2014). The lower-level concepts form the foundation of the theory and represent details and variations of the theory, whereas higher-level concepts are more abstract in nature and provide more explanatory information about the theory, thus forming the structure of the model (Corbin & Strauss, 2014; Goulding, 1998; Patton, 2015a). Data analysis coding was initially more descriptive but later became more analytical and theoretical in order to tell the participants’ stories (Charmaz, 2006; Edwards & Jones, 2009).

Through the process of concept abstraction, concept mapping (i.e., presenting findings in a diagrammatic or pictorial form) was used to generate a hierarchical coding system to clarify the author’s thinking, visualise the data and map relationships between concepts (Artinian, 1986; Corbin & Strauss, 2014; Creswell, 2013; Dey, 1993; Holloway, 1997, 2008; O’Leary, 2014; Padgett, 2008). Subsequent data analysis was performed using theoretical sampling and was supported by the constant comparative method to refine and identify new concepts and themes (Charmaz, 1983, 2000; Holloway, 1997; Patton, 2015c).

6.4.2 Theoretical sampling

According to Corbin and Strauss (2008), theoretical sampling ‘collect[s] data from places, people, and events that will maximise opportunities to develop concepts in terms of their properties and dimensions, uncover variations, and identify relationships between concepts’ (p. 143).

The notion of theoretical sampling explores several questions: who, what, where, how and when (Corbin & Strauss, 2014; Holloway, 2005a; Jeon, 2004; Liamputtong, 2013a). These questions dictate where (i.e., setting) and with whom (i.e., cases) data should be collected, as well as what should be examined (i.e., information) and when and how it will be
further explored, to increase knowledge of the phenomenon being studied (Charmaz, 2006; Corbin & Strauss, 2014; Gillespie, Chaboyer, St John, Morley, & Nieuwenhoven, 2015; Padgett, 2008; Strauss & Corbin, 1990, 1998).

This interplay is driven by the researcher’s theoretical ideas about the evolving model (Berglund, 2001; Charmaz, 2000; Corbin & Strauss, 2014; Goulding, 1998; Patton, 2015c). For example, as interviews progressively become more structured—that is, as they hone in on specific issues of the study (informed by previous interviews)—new information emerges (e.g., a variable or factors from certain participants) to refine ideas or develop a more in-depth explanation about the emerging concepts (Charmaz, 2000; Charmaz, 2008a; Faifua, 2014; Holloway, 2005a, 2008; Holloway & Todres, 2005; O’Donoghue, 2006; Patton, 2015c). To add more clarity to the coding data and perhaps find new explanations about the phenomenon, the researcher may be required to interview new participants (Gasson, 2004), re-examine transcripts of interviews with previous participants (Charmaz, 2008b; Corbin & Strauss, 2014; Fassinger, 2005), revisit a previous setting (Charmaz, 2008b) or reinterview the same participants but with different research questions (Berger, 2015; Morse, 1990; Padgett, 2008). Therefore, theoretical sampling is not static and is not undertaken in a rigid manner; rather, it is an iterative process that is conducted concurrently with the data analysis (Barker & Pistrang, 2015; Bryman, 2012; Charmaz, 2000; Corbin & Strauss, 2014; Gasson, 2004; Patton, 2015c).

Theoretical sampling enables the researcher to explore uncharted places (e.g., hospitals) with different participants and to identify unique events and happenings that can assist in the development of new information that is relevant to the construction of the model (Bryman, 2012; Charmaz, 1983; Corbin & Strauss, 2014; Gasson, 2004; Sarantakos, 2005c; Strauss & Corbin, 1990, 1998). This analytical process is repeated until theoretical saturation
is reached (Bryman, 2012; Charmaz, 2008a; Corbin & Strauss, 2014; Holloway, 1997; Kleist & Gompertz, 1997; O’Donoghue, 2006; Patton, 2015c; Whitman & Wosczynski, 2004).

6.4.3 Theoretical saturation

Theoretical saturation is a concept that is synonymous with GT (Charmaz, 2008a; Corbin & Strauss, 2014) and goes hand-in-hand with theoretical sampling (Charmaz, 2008b; Gasson, 2004; Holloway, 1997). Generally, qualitative researchers collect large amounts of raw data, but they are often unsure of exactly when to stop the data gathering and analysis. To assist with this process, theoretical saturation has been developed to help researchers make judgments about data saturation (Goulding, 1998; Patton, 2015b).

Saturation occurs ‘when no new categories or relevant themes are emerging’ from the data (Corbin & Strauss, 2014, p. 139)—that is, when the researcher has exhausted all possibilities of discovering new meanings or explanations to fill the categories by comparing different settings with different people under different conditions (Charmaz, 1983; Charmaz, 2008b; Corbin & Strauss, 2014; Dey, 1993; Holloway, 1997; Nakkeeran & Zodpey, 2012; O’Donoghue, 2006; Riley, 1996).

6.5 Conclusion

The philosophical theories of SI and constructivism are inextricably underpinned by a phenomenological approach. These theories are concerned with how people create meaning through their interactions and how they interpret their world. They are applied to develop knowledge about women’s lived experience of SE-AN, and therefore considered a legitimate source of knowledge. To preserve this knowledge, this study uses reflexivity to reduce the researcher’s biases in the interpretations of the data and to ensure the trustworthiness of the research.

To elucidate the interplay between this meaning and knowledge, GT method was used along with the techniques of the constant comparative method, theoretical sampling and
theoretical saturation. These techniques offer flexibility to assist the researcher with the analysis and interpretation of data and to help build a provisional theory that best captures the main issue relating to the phenomenon. The next section describes the sampling and recruitment procedures, data collection techniques and ethical considerations of the research.
Chapter 7: Method

7.1 Introduction

This chapter will focus on the methods used to obtain data while addressing the design aspects of the project, including ethical considerations, recruitment of participants and sampling approaches, demographic information for participants, data collection and analysis methods, and evaluation criteria. It is important to note that the following procedures apply to both individual and focus group participants, but with some variation.

7.2 Ethical Considerations

All research is governed by the ethical principles as outlined in the National Statement on Ethical Conduct in Human Research (NHMRC, 2007). It is the responsibility of ethical review committees to ensure that these ethical principles—in particular, beneficence (and nonmaleficence)—are adhered to when weighing up the risks and benefits of research proposals (NHMRC, 2007; Roberts & Dyer, 2007).

This study was approved by two institutional review boards: the Human Research Ethics Committee (Approval No. HREC/16/Austin/9) of the Austin Hospital and the Human Research Ethics Committee at the Royal Melbourne Institute of Technology (RMIT). Approval was granted to conduct qualitative research involving adult females with SE-AN. Three major ethical considerations were discussed in each application: informed consent, confidentiality/privacy, and potential risks and benefits (Kvale, 1996; NHMRC, 2007). These ethical considerations are outlined below.

7.2.1 Informed consent

Informed consent is grounded in the ethical principle of respect for autonomy, whereby a person has the freedom to autonomously decide (with no direct or indirect interference) whether to participate in the research (Beauchamp & Childress, 2001; Bryman,

Section 9.10 of the *Charter of Human Rights and Responsibilities Act 2006* reiterates this point, stating that no person should be ‘subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent’.

Fry and Johnstone (2008) argued that informed consent is a mechanism to protect patients’ rights, prevent unnecessary harm and help the researcher to avoid fraud and duress when conducting research. Therefore, it is a prerequisite of social science research to ensure that all participants are properly informed and comprehend the nature of the research project, including their role within it, before they provide consent (Coons & Watson, 2013; Munhall, 1988; NHMRC, 2007; Oliver, 2010, 2013).

A signed participant information and consent form (see Appendix F) and a plain language statement (see Appendix D) were obtained from each participant. They contained the following information:

- a statement about the voluntary nature of the research
- a complete description of the study procedures
- an explanation of the risks and benefits of the research
- an explicit statement that each participant could withdraw their consent at any time without prejudice
- contact details of the research team if the participants had any questions about the research (Berglund, 2001; Munhall, 1988; Seidman, 2013).

A signed copy was given to each participant so they had a written reminder of the agreement (Arksey & Knight, 1999; Corbin & Strauss, 2014). No monetary provisions or ‘substantial or irresistible tokens of appreciation’ (Gabard & Martin, 2011, p. 227) were offered to the participants. This would have been a form of coercion and a breach of the
principle of respect for autonomy (Carpenter & Suto, 2008). Indeed, the NHMRC (2007) stated that ‘the consent of a person to participant in research must not be subject to any coercion or to any inducement or influence which could impair its voluntary character’ (p. 12).

A recent Australian study that involved 84 research organisations (e.g., universities, hospitals, pharmaceutical companies and market research organisations) supported this view (Fry et al., 2005). The results indicated that it was standard practice for about one-third of respondents (34%) to provide some form of reimbursement. However, more than half of the respondents (54%) indicated that they would not provide financial incentives because it was considered unnecessary (46%) or an inducement (33%) that would compromise the voluntary nature of participation (22%). Further, it was viewed as unfairly targeting vulnerable people from low socioeconomic backgrounds by influencing their choice to participate (16%). Of the respondents who reported offering financial incentives, 72% stated that there were no written guidelines, policies or procedures to assist them in deciding whether it was appropriate to offer incentives. These figures suggest that offering monetary incentives could undermine the doctrine of informed consent, the ethical principle of respect for persons and the integrity of conducting scientific human research. The data also highlight the gap between ‘ethics committees, research institutions, and researchers’ (Meerpohl et al., 2015, p. 7) regarding policies and procedures concerning the use of ‘inducements and incentives’, as well as implications for the recruitment of participants.

7.2.2 Confidentiality and privacy

A basic tenet of human research, and indeed a moral imperative, is to uphold the rights of all research participants by protecting their confidentiality and privacy (see Section 3.5.3) (Carpenter & Suto, 2008; Kvale, 1996; NHMRC, 2007; Nkansah & Chimbwanda, 2016). This
was achieved by upholding the moral principle of fidelity (see Section 3.5.2) and following the research protocols (Fry & Johnstone, 2008; NHMRC, 2007), which are outlined below.

Confidentiality

- All interviews were conducted by the researcher at the Austin Hospital at a mutually agreed time.
- Electronic data were stored on the principal supervisor’s and the researcher’s computer with separate and secure passwords.
- The data were locked up at the Department of Psychology, RMIT University, Bundoora Campus, and will be destroyed after five years.
- The study results were reported as aggregate data rather than specific identifiable case studies.

Privacy

- The name of the research participants or any references regarding their identification (e.g., address and occupation) were protected using pseudonyms (Kvale, 1996).
- The researcher obtained ethical clearance and consent from participants to transcribe audio recordings (verbatim) using a professional transcriber.
- Access to the data was restricted to the investigators (Berglund, 2001; Carpenter & Suto, 2008).

7.2.3 Potential risks and benefits

In all research projects, the ethical principle of nonmaleficence is critically important in determining potential risks and benefits to the research participants and protecting the interests of the scientific community and its stakeholders (Backlar, 1999; Berglund, 2001; Roberts & Dyer, 2007).
The Institutional Review Boards of Austin Hospital and RMIT University categorised this study as ‘more than low risk’ because the research participants were receiving medical care and were therefore vulnerable and may have been at risk of further harm or discomfort. It is a research imperative to advance research knowledge without compromising the health and wellbeing of participants. This is a utilitarian approach in which people are not used as a means to an end—that is, to serve their self-interests; rather, this approach aims to provide tangible benefits to research participants (Berglund, 2001; Carpenter & Suto, 2008; Munhall, 1988). In this study, this was achieved by implementing a research protocol—namely, a number of supportive strategies—to minimise the risk of emotional and psychological harm.

All interviews were conducted in the ward at the Austin Hospital. For safety reasons, the allocated interview room was situated next to the nurse’s station to enable staff to quickly intervene if necessary. At the start of the interview, the participants were provided with an overview of the research and were asked to review and sign a consent form. They were informed of their right to withdraw from the interview at any time without providing a reason, and that they did not have to discuss any issue if they felt uncomfortable. Participants were given the option to have a break to prevent interview fatigue. They were also reminded that names and personal details would be deleted from the audio recordings. Finally, the researcher debriefed the participants to gauge their level of distress and to seek feedback (verbal) regarding their experience of being interviewed. To the researcher’s knowledge, no participant experienced distress; in fact, the feedback indicated that they were grateful for the opportunity to make a contribution to the research.

Hutchinson, Wilson and Wilson (1994) identified a number of benefits of qualitative interviews for participants, including ‘catharsis, self-acknowledgment, sense of purpose, self-awareness, empowerment, healing and providing a voice for the disenfranchised’ (p. 94). The following vignette encapsulates this point:
That was actually—it was good, because, um, I didn’t realise—I think—I’ve probably come a lot further than I realised and a lot of the things that we—that I spoke about with you, even a year ago would have reduced me to tears. But it didn’t. I could actually verbalise them. (Participant: Sue)

Overall, this project is likely to positively affect the studied population because the ethical decision-making model will be used as a therapeutic tool to enable mental health treating teams to support patients’ preferred treatment choices and facilitate collaborative care, especially during periods of decision-making incapacity (Swanson et al., 2007).

7.3 Sampling

7.3.1 Recruitment process

A purposive (non-random) sample approach was used to collect the data (Bloomberg & Volpe, 2008; Morrow, 2005; O’Donoghue, 2006; Weiss, 1994). Mays and Pope (1995) defined purposive sampling in the context of ‘people who either possess characteristics or live in circumstances relevant to the social phenomenon being studied’ (p. 110). Thus, adult females with SE-AN were selected because of their lived experience of an eating disorder, and clinicians were chosen because of their professional expertise in eating disorders (Barker & Pistrang, 2015; Creswell, 2013; Denzin & Lincoln, 2008; Polkinghorne, 2005).

All participants, including the focus group participants, were recruited from an acute and general psychiatric ward in a large metropolitan public hospital in Melbourne, Australia. The inpatient treatment program primarily focuses on medical stabilisation, nutritional rehabilitation and weight restoration (Bakker et al., 2011; Boughtwood & Halse, 2010; Dresser, 1984b; Hay et al., 2019). The multidisciplinary treating team used a CBT approach to address patients’ body weight, shape and eating distortions.

7.3.1.1 Individual participants

Each participant was approached by the unit manager (registered psychiatric nurse), whose role was to briefly explain the research project. A recruitment letter (see Appendix E)
and a plain language statement (see Appendix D) were distributed to invite the person to contact the research team if they were interested in participating.

For those who expressed an interest in participating in the research, a telephone conversation was held between the researcher and the individual to further explain the details of the research and to establish a mutually agreed time to meet. This also provided an opportunity for the participant to ask any questions or clarify any matters regarding the research—for example, regarding the principal interviewer conducting the interview, how long the interview would take and who would have access to the data. Equally, it was an opportunity for the researcher to clarify their role in the research—namely, the interviewer was not part of the hospital clinical team but was from the university, and the interview details would not be discussed with the clinical team or any other person at the hospital. The researcher did not want the participants to think he was colluding (suspicious of any new person) with the treating team, but wanted to be seen as an independent researcher seeking to explore and understand the relevant conditions of SE-AN.

The recruitment process lasted approximately six months and involved attending fortnightly clinical meetings with the multidisciplinary team. These meetings enabled the clinical team to raise any concerns and provide feedback relating to the operational aspects of the research, such as reviewing and selecting potential participants for the project.

7.3.1.2 Focus groups

A convenience sample was used to recruit focus groups members. According to Bryman (2012), a convenience sample is defined as ‘a sample that is selected because of its availability to the researcher’ (p. 710).

All selected participants were part of the multidisciplinary team at the Austin Hospital and had direct contact with individual participants (consumers). An information pack containing a plain language statement (see Appendix D), a consent form (see Appendix F)
and an interview guide (see Appendix G) were circulated among prospective staff members. This was to ensure that the staff members were properly informed about the study and that they understood their involvement—particularly their rights and responsibilities (Seidman, 2013). All recruited members were invited to participate on a voluntary basis, with the option of withdrawing at any time (O’Leary, 2014; Seidman, 2013). Those who chose to participate signed a consent form and agreed to be interviewed.

7.3.2 Inclusion and exclusion criteria

According to the NHMRC (2007), the decision to include or exclude potential participants for research should consider the ethical principle of justice. This means that the selection criteria should not be prejudicial or discriminatory towards participants, but rather ‘justifiable’ (Carpenter & Suto, 2008; NHMRC, 2007).

7.3.2.1 Individual participants

To participate in this study, participants had to meet the following inclusion criteria: female, formally diagnosed as having or having had SE-AN, a minimum duration of illness of six years, aged between 18 and 65 years, able to give informed consent, currently receiving or had experienced hospital care, and medically stable. These characteristics were important to enable the researcher to develop in-depth knowledge about the phenomenon of SE-AN and to help answer the research question.

The exclusion criteria were males, people who disclosed suicidal thoughts, those who were admitted as index admissions, those with severe comorbidities such as major depression, and those under the age of 18 years. There is evidence to suggest that minors are not able to provide informed consent due to their cognitive and emotional development (Bell, 2010; Matusek & Wright, 2010; Tan et al., 2006, 2010). The justification for excluding these participants is to avoid and minimise further risk of ‘harm, discomfort or inconvenience’ (NHMRC, 2007, p. 12).
7.3.2.2 Focus groups

The selection criteria for the focus groups participants were: allied health practitioner, doctor or nurse with clinical experience working with SE-AN patients, currently working in the acute psychiatric ward at the Austin Hospital and able to provide informed consent. There were no exclusion criteria.

7.3.3 Sample profile—individual participants

Table 7.1 presents the demographic data of individual interviewees and the principal characteristics of the sample group (N = 5). All participants had been formally diagnosed with SE-AN in accordance with their psychiatrist’s assessment. Participants were recruited from the same acute adult general psychiatric unit in Melbourne, Australia. Of the five participants, one was on involuntary admission status. The mean duration of illness for this patient group was (mode = 10, range 6, −22) 11.4 years (SD 6.1).

7.3.4 Sampling profile—focus groups

Tables 7.2 and 7.3 present the demographic data of the focus groups and the principal characteristics of the sample group (N = 8). All participants were representative of the multidisciplinary team, were from different professional backgrounds and had worked directly in acute hospital settings (albeit in different capacities), treating people with a range of eating disorders.
Table 7.1

*Demographics of the Individual Interview Participants*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Jo</th>
<th>Mary</th>
<th>Sue</th>
<th>Jade</th>
<th>Amy</th>
</tr>
</thead>
<tbody>
<tr>
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<td>37</td>
</tr>
<tr>
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<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
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<td>10</td>
<td>6</td>
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<td>6</td>
<td>10</td>
</tr>
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<td>Voluntary</td>
<td>Voluntary</td>
<td>Voluntary</td>
</tr>
<tr>
<td>Level of education</td>
<td>Bachelor degree</td>
<td>Year 12</td>
<td>Cadetship</td>
<td>Bachelor degree</td>
<td>Diploma</td>
</tr>
<tr>
<td>Type of income</td>
<td>Sickness benefits</td>
<td>Sickness benefits</td>
<td>Sickness benefits</td>
<td>Sickness benefits</td>
<td>Sickness benefits</td>
</tr>
<tr>
<td>Relationship status</td>
<td>Single</td>
<td>Single</td>
<td>Single</td>
<td>Single</td>
<td>Single</td>
</tr>
</tbody>
</table>

Table 7.2

*Demographics of Focus Group 1 Participants*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Cathy</th>
<th>Jane</th>
<th>Emma</th>
<th>Peta</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Age</td>
<td>29</td>
<td>45</td>
<td>29</td>
<td>36</td>
</tr>
<tr>
<td>Years of clinical experience</td>
<td>5</td>
<td>3</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Asian</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Clinical role</td>
<td>Occupational therapist</td>
<td>Clinical psychologist</td>
<td>Psychiatrist registrar</td>
<td>Social worker</td>
</tr>
<tr>
<td>Level of education</td>
<td>Bachelor degree</td>
<td>Masters</td>
<td>Masters</td>
<td>Bachelor degree</td>
</tr>
</tbody>
</table>
Table 7.3

Demographics of Focus Group 2 Participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Mandy</th>
<th>Cindy</th>
<th>Tracy</th>
<th>Dianna</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>F</td>
<td>F</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>Age</td>
<td>27</td>
<td>29</td>
<td>23</td>
<td>25</td>
</tr>
<tr>
<td>Years of clinical experience</td>
<td>1</td>
<td>8</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Clinical role</td>
<td>Intern doctor</td>
<td>General nurse</td>
<td>Registered psychiatric nurse</td>
<td>Registered psychiatric nurse</td>
</tr>
<tr>
<td>Level of education</td>
<td>Bachelor degree</td>
<td>Post-graduate diploma</td>
<td>Bachelor degree</td>
<td>Post-graduate diploma</td>
</tr>
</tbody>
</table>

7.3.5 Sample size—a justification

In this study, the sample size was determined by saturation (Corbin & Strauss, 2014). The sample size reached saturation at five participants with SE-AN and two focus groups, each containing four clinicians. To justify the sample size, Onwuegbuzie and Leech (2007) suggested the following:

*Identify a corpus of interpretative studies that used that same design as in a proposed study (e.g., grounded theory, ethnography) and wherein data saturation was researched. The researcher then could examine the sample sizes used in these studies with a view of selecting a sample size that is within the range used in these investigations. (p. 118)*

Following this guidance, six articles have been published (Hannon et al., 2017; Light et al., 2014; Offord et al., 2006; Robinson et al., 2015; Stockford et al., 2018; Tierney, 2008) that were comparable to this study. All six studies reached saturation with similar numbers: five consumers, five consumers and five carers, seven consumers, eight consumers, six consumers and 10 consumers, respectively. The studies also used a thematic approach to data analysis to understand patients’ subjective experiences of living with AN, but in different settings and with different age groups. This small number was sufficient to explore a range of topics and therefore gain access to knowledge about the SE-AN phenomenon. This is because
the participants were able to express themselves clearly and reflect on their experiences throughout the interviews.

7.4 Data Collection

Data were collected through semi-structured face-to-face interviews and focus groups. They were audio-recorded, professionally transcribed verbatim and anonymised within two weeks of the interviews being conducted to ensure strong authenticity (Kvale, 1996; Lincoln & Guba, 1985; Polgar & Thomas, 2008; Stewart & Shamdasani, 2014). Each participant was asked to nominate their own pseudonym so they could feel part of the research process, and to protect their anonymity (O’Leary, 2014). The average length of the individual interviews was around 60 minutes to prevent participant fatigue and ensure adequate coverage of the topics (Winters & Carvalho, 2014). Focus group participants received an equal amount of time.

At the end of the interviews, the participants were asked to answer a number of questions to provide demographic data (see Tables 7.1–7.3). Individual participants were asked to provide a brief summary of their psychiatric history, and focus group participants were asked to provide information about their clinical experience with eating disorder patients. In both instances, this information enabled the researcher to identify similarities and differences with other sample groups found in the literature (Berglund, 2001). All interviews were scheduled at a mutually agreed time and conducted in the Austin Hospital’s adult acute psychiatric ward.

7.4.1 Interview guide and process

Patton stated that the overarching purpose of interviewing is ‘not to put things in someone else’s mind but rather to access the perspective of the person being interviewed’ (Patton, 1980, p. 196). To facilitate this, an interview guide ‘aides memoire’ was used, which consisted of a number of broad, open-ended questions and prompts (see Appendix G and Appendix H) (Arksey & Knight, 1999; Creswell, 1998; O’Donoghue, 2006; Taylor, 2005).
The purpose of these guides was to elicit ‘thick’ descriptions from respondents, guide and direct the interview conversation, and gather information (i.e., contextualised experiences of the participants) to achieve the research objectives (Arksey & Knight, 1999; Faifua, 2014; Merriam, 1988; O’Donoghue, 2006; Patton, 2015c). However, it should be noted that this guide was used as an adjunct. The interviews were primarily conducted using a ‘professional conversational’ approach as recommended by Kvale (1996, p. 5). This approach involved a number of steps and was guided by the participants’ responses (Strauss, Rhodes, & George, 2015).

Initially, the researcher introduced a research topic, followed by an open-ended question (Stewart & Shamdasani, 2014). The researcher was then able to ask a series of follow-up questions based on the responses received (Creswell, 1998; Kvale, 1996). During the interviews, field notes and participant observations were recorded to enhance the depth and richness of the data (Hennink et al., 2010).

### 7.4.2 Field notes and participant observations

Participant observations are a hallmark of all qualitative research (Wolcott, 2009). While there have been some new (e.g., participatory rural appraisal) and revised (e.g., GT—a shift from positivist to postpositivist) qualitative research methods, participant observation remains the method *par excellence* (Chenitz & Swanson, 1986b; Plummer & Young, 2010; Taylor, 2005). It is widely used as an adjunct method (or as a single method, i.e., ethnography) to investigate a phenomenon of interest to generate ‘naturally occurring data’ (Taylor, 2005, p. 38). Traditionally, participant observations are carried out through prolonged engagement with participants in their natural setting (a single setting) in an unstructured and unobtrusive manner (Barker & Pistrang, 2015; Chenitz & Swanson, 1986b; Hennink et al., 2010; Holloway, 1997; Sarantakos, 2005c; Schwandt, 2014; Thomas, 2010; Wolcott, 2009). However, the technique has since been modified. Today, many researchers
use the technique over shorter periods, during direct contact with research participants and in multiple settings (Berglund, 2001). This approach was employed in this study.

Field notes were written after the interviews to allow the researcher to reflect on the material and record any significant observations that had occurred (Maxwell, 2012; Padgett, 2008; Schwandt, 2014). Padgett (2008), Chenitz and Swanson (1986b) and Holloway (1997) stated that field notes should aim to answer the why, what, where, when and how questions to draw together meanings and perspectives from qualitative interviews—that is, what is observed (and heard), and how and why such interactions occur (Charmaz, 2006; Silverman, 2005).

The recordings reflected the participants’ physical appearance, behaviour (e.g., sitting position, positive or negative emotional reactions to questions), impressions, tone of voice and any incidental information that appeared to be pertinent to the investigation (Barker & Pistrang, 2015; Creswell, 1998; Maxwell, 2012). In addition, I recorded my assumptions and biases about the interviews in an effort to maintain a level of self-awareness (Corbin & Strauss, 2014; Creswell, 1998). This was important for two reasons. First, it helped to identify any potential biases or assumptions that could arise from my personal experience of living with SE-AN. Second, it was helpful to check in with my own emotional state. Both of these factors could possibly interfere with the data collection and analysis (Chenitz & Swanson, 1986b; Padgett, 2008).

In accordance with GT principles, the field notes and observations were used to assist with the data analysis, especially in relation to understanding the social processes underlying the phenomenon (Silverman, 2005). The field notes were dated and transferred into Nvivo software (for more details on Nvivo, see Section 7.6) to ensure dependability and credibility of the data (Bloomberg & Volpe, 2008; Bryman, 2012; Holloway, 2008).
7.5 Grounded Theory—Data Analysis

The following statement exemplifies the essence of qualitative data analysis: ‘A researcher can think of analysis as “mining” the data, digging beneath the surface to discover the hidden treasures contained within’ (Corbin & Strauss, 2014, p. 88).

7.5.1 Introduction

This section provides a detailed exposition on the analytical steps involved in GT, which uses a three-step coding process—opening coding, axial coding and selective coding—to develop a theory-based model. This analytic process was applied to transcripts, and thematic codes, concepts and themes emerged from the data. Figure 7.1 illustrates the analytical steps involved in constructing the model. The analysis used computer-assisted qualitative data analysis software (CQDAS) in conjunction with three techniques—memo-writing, diagramming and coding—which are outlined below.

![Grounded Theory—Data Analysis Diagram](image)

*Figure 7.1. Grounded theory—data analysis.*

7.5.2 Qualitative data analysis software

CQDAS is becoming an increasingly popular data management tool in assisting qualitative researchers to engage in collaborative and independent research (Flick, 2013; Patton, 2015a; Saldaña, 2015; Silverman, 2005). Qualitative data analysis software (QSR International Pty Ltd. Version 11, 2012) was chosen to code and analyse the transcripts for several reasons: it helped to manage, sort and group large amounts of textual data (Berglund,
2001; Liamputtong, 2013b; Patton, 2015c); it helped to facilitate the process of comparing, categorising and linking codes (Charmaz, 2000; Dey, 1993; Flick, 2014; Holloway, 2005a); it helped to generate diagrams (i.e., mind mapping) to graphically visualise the data (Charmaz, 2014; Saldaña, 2015); and it assisted in developing the theory (Carpenter & Suto, 2008). Finally, it enabled the maintenance of an audit trail by documenting memos, writing field notes and constructing a hierarchical code framework—all of which enhanced the dependability of the findings (Dey, 1993; Faifua, 2014; Flower, Bishop, & Lewith, 2014; Liamputtong, 2013b; Lincoln & Guba, 1985; Saldaña, 2015).

### 7.5.3 Memoing and Diagramming

Thorne (2008) suggested that the data obtained may not always be relevant to the emergent codes, categories and themes, and should not be applied to the analysis. Therefore, the researcher’s job is to carefully filter out information that is not relevant to the conditions of the phenomenon, and to identify what is significant—that is, ‘something important, meaningful, or potentially useful’ in the research investigation (Bloomberg & Volpe, 2008, p. 175). This can be facilitated through the use of memo-writing, which is a technique that involves writing down inductive or deductive field notes or ideas (e.g., abstract ideas and hypotheses) about the data (Charmaz, 2008a; Fassinger, 2005; Gasson, 2004; Lincoln & Guba, 1985; O’Donoghue, 2006).

According to Corbin and Strauss (2014), the task of writing memos involves ‘examining it [data], making comparisons, asking questions, coming up with concepts to stand for meaning, and suggesting possible relationships between concepts’ (p. 107). Thus, memos are a form of brainstorming that enables the researcher to jot down ideas, hunches and interpretations to figure out what is happening within the data (Charmaz, 2006; Corbin & Strauss, 2014; Maxwell, 2012; Morrow, 2005). It may be the case that certain recurring words
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or sentences capture nuances of meaning, which can later be linked when building the theory or model.

Holloway (2008), Corbin and Strauss (2014) and Creswell (1998) emphasised the importance of sketching out ideas (memos) onto paper and then transforming them into diagrams. This can be especially helpful in breaking down condensed raw data into simple ideas, as well as identifying patterns of data—that is, ‘see where the story of the data is going’ (Saldaña, 2015, p. 248). Memos and diagrams can help to flesh out ideas and themes (meanings) about the emerging theory (Denzin & Lincoln, 2008; Fassinger, 2005; Lincoln & Guba, 1985).

Memos also provide an opportunity to keep track of the analysis (memos are dated with details) by systematically documenting observations, insights, procedural/analytical questions and decisions so they can be reviewed periodically throughout the analytical stages (Corbin & Strauss, 2014; Faifua, 2014; Fassinger, 2005; Holloway, 2005a, 2008; Maxwell, 2012; Pandit, 1996). Hence, memos add to the dependability of the research findings (Smebye & Kirkevold, 2013).

In summary, memo-writing and diagramming play an integral role in GT, particularly in the development and formulation of a substantive theory or model (Chenitz & Swanson, 1986a; Corbin & Strauss, 2014; Holloway, 2008; Jeon, 2004; Saldaña, 2015).

7.5.4 Coding

Coding is an inductive process that requires the researcher to identify and label patterns of data (ideas) that may be relevant to the emerging theory (Bryman, 2012; Charmaz et al., 2017; Corbin & Strauss, 2014; Holloway, 1997; Joffe & Yardley, 2004; Saldaña, 2015). Theoretically, a code can be defined as a unit of meaning (e.g., keywords, phrases, names, discrete events and statements) that has theoretical significance to the phenomenon being studied (Charmaz, 1983; Charmaz, 2008a; Punch, 2013). A unit of meaning (code) can vary
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from one word or sentence to a full paragraph (Creswell, 2013; Gasson, 2004; Merriam, 1988; Ratner, 2002; Saldaña, 2015). For example, one sentence may consist of a number of codes, thereby forming a potential concept/category (Holloway, 1997; Koruth, 2008; Liamputtong, 2013b; Saldaña, 2015; Spiggle, 1994). Hence, a group of related codes is referred to as a category (Charmaz, 1983; Holloway, 2005a, 2008). At a more general level, codes explain what people are doing (i.e., behaviours) and what is happening in their specific setting (i.e., actions) (Charmaz, 2000; Corbin & Strauss, 2014; Creswell, 2013; Sarantakos, 2005c). According to Charmaz (1983), ‘codes … serve as a shorthand device to label, separate, compile, and organise data’ (p. 111). Further, Charmaz (2014) used the image of a skeleton to illustrate the importance of the coding process, stating that coding ‘generates the bones of your analysis … Integration will assemble those bones into a working skeleton’ (p. 113). Thus, codes form the analytic framework of the analysis, and they emerge from the data to form the building blocks of a theory or model (Corbin & Strauss, 2014).

7.6 Overview of Data Analysis

The data analysis consisted of three separate steps: identifying meaning, categorising and integrating (Barker & Pistrang, 2015), and were carried out in accordance with GT theory principles (Corbin & Strauss, 2014). The first step in the analysis was to have the audio transcripts professionally transcribed. I then carefully listened and immersed myself in the data to look for possible discrepancies (mistakes from the transcriber) between the audiotapes and the transcripts (Arksey & Knight, 1999). To ensure the accuracy of the data, I repeatedly reviewed the transcripts. During this process, I became more familiar with the data and gained a good sense of the participants’ stories. Corbin and Strauss (2014) supported this line of inquiry and stated that ‘the idea behind this first reading is to enter vicariously into the life of participants, feel what they are experiencing, and listen to what they are saying through their words or actions’ (p. 86).
The next stage was to sort and organise the data into a hierarchical coding system to formulate codes, concepts and themes. This was achieved using the principles of open coding, axial coding and selective coding (Corbin & Strauss, 2014; Skårderud, 2007). The analytical process is divided into three stages, but they are not necessarily mutually exclusive (Charmaz, 1983; Charmaz, 2008a).

7.6.1 Open coding

Corbin and Strauss (2008) defined open coding as ‘breaking the data apart and delineating concepts to stand for blocks of raw data’ (p. 195). Its primary purpose is to separate, sort and synthesise the data according to their meaning (Charmaz, 2006; Charmaz et al., 2017). This requires the researcher to break down the data from the interview transcripts and field notes line-by-line and/or word-by-word into smaller bits of data to identify potential codes (ideas about the data)—a process known as micro-analysis (Bryman, 2012; Charmaz, 2000; Charmaz, 2008a; Corbin & Strauss, 2014; Dey, 1993; Schwandt, 2014; Strauss & Corbin, 1990, 1998).

Although micro-analysis occurs in the open coding stage, it can be applied at any stage of the analysis process; therefore, it is an ongoing and non-linear process (Charmaz, 2000; Charmaz, 2006; Corbin & Strauss, 2014; Hennink et al., 2010; Holloway, 2005a; Maxwell, 2012; Saldaña, 2015). Micro-analysis requires the researcher to be completely neutral and open-minded about the data—that is, open to ideas from which to draw out concepts and uncover their individual properties (attributes or characteristics of the concept) and dimensions (variations within properties) (Charmaz, 2008a; Corbin & Strauss, 2014; Crooks, 2001; Holloway & Todres, 2005; Kushner & Morrow, 2003; Silverman, 2004).

7.6.2 Axial coding

Corbin and Strauss (2008) identified axial coding as the second stage of the coding process, and it involves ‘crosscutting or relating concepts to each other’ (p. 195). There are
two stages in the analysis. The first stage involves exploring the relationships between the codes based on their similarities and differences, and then grouping these codes into clusters (Charmaz, 1983; Chenitz & Swanson, 1986c; Gasson, 2004; Saldaña, 2015). The second stage focuses on linking the subcategories and consolidating them into thematic categories (Charmaz, 2008a; Corbin & Strauss, 2014; Denzin & Lincoln, 2008; Dey, 1993; Pandit, 1996; Shattell et al., 2006); that is, it is about putting the data back together to make sense of the storyline (Bryman, 2012; Charmaz, 2008a, 2014; Holloway, 2005a; Punch, 2013). These units of meaning are more abstract and have more explanatory power in the hierarchical coding structure (Corbin & Strauss, 2014).

Charmaz (2014) believed that axial coding develops into a scaffolding framework to enable the researcher to apply the analysis. To assist with the process of analysis, a number of authors advocate that the researcher must be inquisitive, creative, flexible and open about the data (Bloomberg & Volpe, 2008; Charmaz, 2008a; Corbin & Strauss, 2014; Holloway, 2005a). They note that the data have little meaning during the initial stages of the analysis but become more relevant when these qualities have been demonstrated. Thus, it will help the researcher to formulate extrinsic meanings about the data to develop a core category. In addition, the researcher is encouraged to be self-reflective—that is, stand back to mull over and evaluate the data. At this point, the researcher could ask: What are the data telling us (Corbin & Strauss, 2014, p. 72)? This technique is useful in contextualising the text and clarifying the author’s thinking in terms of theory development (Charmaz, 2008a; Corbin & Strauss, 2014).

In the early stages of data analysis, questioning the data is a pivotal part of the analytic proceedings of GT (Charmaz, 1983; Charmaz, 2006; Corbin & Strauss, 2014; Saldaña, 2015; Strauss & Corbin, 1990, 1998). Axial coding gives the researcher an opportunity to interpret the data by asking questions such as ‘who, when, where, why, how, and with what
consequences’ (Gasson, 2004, p. 83). These questions can help generate a set of propositions and hypotheses about the phenomenon and thereby identify a provisional core category about it (Charmaz, 2000; Charmaz et al., 2017; Gasson, 2004; Oliver, 2013; Patton, 2015c). A key aspect of axial coding is the progression towards saturation (Corbin & Strauss, 2014; Saldaña, 2015) (see Section 6.5.5 for an explanation of this concept).

### 7.6.3 Selective coding

Selective coding, or theoretical coding, is the final stage of coding, and it involves systematically generating a conceptual model (Bryman, 2012; Corbin & Strauss, 2014; Fassinger, 2005; Pandit, 1996). According to Strauss and Corbin (1998), selective coding ‘is a process of integrating and refining the theory, it is the process where all categories are unified around the core category’ (p. 143). That is, it is viewing how these categories fit together (or interrelate with one another) to formulate core categories (Chenitz & Swanson, 1986c; Corbin & Strauss, 2014; Marks & Yardley, 2004). It involves a higher level of abstraction because it identifies the core category, or central theme, that explains the social processes regarding the phenomenon—that is, the experience (storyline) of living with SE-AN and the role of PADs (Bryman, 2012; Corbin & Strauss, 2014; Holloway, 2005a; Saldaña, 2015; Sarantakos, 2005a).

Corbin and Strauss (2014) explained that the core category should be broad enough to capture the experiences of all research participants, and have the greatest explanatory power—that is, capturing the essence of the phenomenon. Corbin and Strauss (2014) established the following criteria to help researchers identify a core category:

1. It must be sufficiently abstract so that it can be used as an overarching explanatory concept tying all other categories together;

2. It must appear frequently in the data. This means that within all, almost all, cases there are indicators that point to that concept;
3. It must be logical and consistent with the data. There should be no forcing.

4. It should be sufficiently abstract so that it can be used to do further research leading to the development of general theory;

5. It should grow in depth and explanatory power as each of the other categories is related to it through statement relationships. (p. 189)

These criteria will be further explained and applied in Chapter 8 of the ‘findings’.

Further, the core category (or categories) will represent the building blocks of the model that is ‘grounded’ in the data to explain the conditions and processes that underpin the phenomenon of SE-AN (Ely, 1997; Glaser, 1978; Hennink et al., 2010; Holloway, 2008; Jeon, 2004; Maxwell, 2012; Patton, 2015c; Sarantakos, 2005a).

7.7 Rigor/Trustworthiness

A trustworthy study is one that is carried out fairly and ethically and whose findings represent as closely as possible the experiences of the respondents ... Trustworthiness is not a matter of blind faith, it must be demonstrated. (Padgett, 2008, p. 184)

Qualitative fieldwork requires the researcher to capture common and divergent worldviews of its research participants to provide a ‘truthful’ and accurate account of their individual experiences (Anzul, Ely, Freidman, Garner, & McCormack-Steinmetz, 2003; Arksey & Knight, 1999). These worldviews are reflected in the research findings and presented as quotations (Berglund, 2001; Crooks, 2001; Faifu, 2014; Goulding, 1998; Griffin, 2004; Holloway, 2005b; Munhall, 1988; O’Leary, 2014).

Lincoln and Guba (1985) developed criteria to judge the quality of the findings and therefore evaluate their trustworthiness. The model in this study consists of four criteria—credibility/authenticity, confirmability, dependability and transferability—that are designed to improve the overall validity and rigor of the research (Carpenter & Suto, 2008; Faifu, 2014; Gasson, 2004; Holloway, 2008; Lincoln & Guba, 1985).
7.7.1 Credibility/authenticity (truth value)

Credibility can be established by making ‘truth claims’ about participants’ subjective experiences (Denzin & Lincoln, 2012; O’Donoghue, 2006; O’Leary, 2014; Patton, 2015c). In doing so, it requires the researcher to demonstrate authenticity, which is defined as reporting each participant’s experience in such a way that it maintains an honest and ‘accurate description’ without imposing any biased interpretations from the researcher (Bryman, 2012; Holloway, 2008; Krefting, 1991; McLeod, 2003; Morrow, 2005; O’Leary, 2014).

This was achieved by using direct quotations (or anecdotes) from the participants (Holloway, 2005a). To ensure the authenticity of the quotations, each participant (including the focus groups) would normally be required to review (e.g., make alterations, additions or deletions) and verify the findings—a process known as ‘respondent validation’ or ‘member checking’ (Bryman, 2012; Maxwell, 2012; Mays & Pope, 2000; Porter, 2007; Ritchie et al., 2013). However, this was not possible within the scope of this study (see Section 10.7). Thus, techniques such as ‘prolong engagement, persistent observation, and triangulation’ were used to ensure the credibility of the findings (Lincoln & Guba, 1985, p. 301).

7.7.2 Confirmability (neutrality)

Confirmability means that the ‘findings of an inquiry are determined by the subjects (respondents) and conditions of the inquiry and not by the biases, motivations, interests, or perspectives of the inquirer’ (Lincoln & Guba, 1985, p. 290). That is, confirmability involves linking the data to their sources (Holloway, 2008; Morrow, 2005; Patton, 2015c). This can be achieved by using the strategies (i.e., auditing) outlined in dependability to ensure that reported categories, emerging themes, interpretations and conclusions reflect the person’s lived experience (Dey, 1993; Krefting, 1991; Patton, 2015c; Sandelowski, 1993; Shenton, 2004; Thomas & Magilvy, 2011).
Corbin and Strauss (2014) recommended writing reflective field notes after interviews to minimise interference with the truth (emergent data) and to self-monitor one’s personal feelings, biases and insights. They stated that ‘a research journal is a good place to keep a record of reactions during data collection and analysis upon which a researcher can do a type of self-analysis’ (pp. 54–55).

To identify and make explicit my values and biases, I engaged in a process of self-analysis otherwise known as reflexivity. I wrote self-reflective memos, debriefed with my supervisors and used peer-checking (i.e., sharing self-observations) to help balance my biases and identify any potential blind spots that could have interfered with the research (Corbin & Strauss, 2014; Morrow, 2005; Probst & Berenson, 2013; Riley, 1996). In addition, my ‘theoretical sensitivity’ was enhanced when I engaged with the raw material (Chamberlain-Salaun et al., 2013; Corbin & Strauss, 2014; Creswell, 1998, 2013; Ponterotto, 2005). Maintaining a self-reflective journal of experiences, reactions, emotions, assumptions and biases helped to reduce the risk of contaminating the data (Denzin & Lincoln, 2008; Henwood & Pidgeon, 1995; Morrow, 2005; Taylor, 2005). Conversely, by adopting a ‘checks and balances’ approach, this information was a source of data analysis—particularly in relation to challenging the researcher’s interpretation of the data (Chamberlain-Salaun et al., 2013, p. 542).

A personal reflective statement (see Declaration for details) was written at the outset of the research to disclose any personal biases or assumptions relating to the subject matter (Holloway, 2008; Mays & Pope, 2000). The process enhanced the dependability of the research because I was able to construct an audit trail of what I brought to the study (Charmaz, 2008a; Holloway, 2008; Oliver, 2012; Sharkey & Larsen, 2005; Taylor, 2005).
7.7.3 Dependability (consistency)

In relation to dependability, ‘the way in which a study is conducted should be consistent across time, researchers, and analysis techniques’ (Gasson, 2004, p. 94). In this study, dependability was established through an audit trail by preserving transcripts, field notes, theoretical memos and audiotape recordings, as well as maintaining chronological records of codes (e.g., a code cookbook through Nvivo) (Bloomberg & Volpe, 2015; Bryman, 2012; Holloway, 2005a; Lincoln & Guba, 1985). In theory, this helped the researcher to monitor the analysis process and thereby establish the rigor of the work (Berger, 2015; Holloway, 2005b).

7.7.4 Transferability (applicability)

Denzin and Lincoln (2008) described social scientists as ‘bricoleur’ researchers who use pragmatic approaches to produce theoretical findings (e.g., policies, programs and models) that are aimed at addressing the social problem about the phenomenon of interest. Similarly, Liamputtong (2013b) stated that qualitative researchers must be accountable for moving research findings into practice. Annells (1996) argued along similar lines, stating that ‘postmodern researchers are not concerned about the “truth” of the research product but rather the pragmatic applicability of the results’ (p. 391).

In qualitative research, this is commonly known as the ‘transferability’ of the study (Flick, 2014; Holloway, 2008; Krefting, 1991; Ritchie et al., 2013; Rosaline, 2000; Slevitch, 2011; Thomas & Magilvy, 2011). Carpenter and Suto (2008) succinctly defined it by asking the question: To what degree can the study be generalised or applied to other individuals or groups, contexts or settings (as cited in Liamputtong, 2013a, p. 26)?

The theoretical and analytical data generated from this research (i.e., the ethical decision-making model) can be applied to a wide range of clinical contexts and populations. Thus, the applicability of the model is not limited to SE-AN patients but could be applied to
other people with mental health problems in a variety of settings (e.g., palliative care, residential aged care facilities, respite care facilities, and outpatient and inpatient care facilities) and by a variety of professionals. For example, the model could be applied to patients experiencing schizophrenia, those with bipolar affective disorder and those with an intractable and irreversible illness such as advanced dementia, Parkinson’s disease or an acquired immunodeficiency disorder (Appelbaum, 2007; Carter et al., 2015; Hope, 1996; Touyz & Carney, 2010).

The contextual similarities are that these groups of people have experienced hospital care without their full consent in one form or another, experienced some degree of fluctuating decisional capacity, demonstrated fluctuating attitudes in accepting treatment, been diagnosed with severe and enduring mental or chronic health problems, and experienced some form of coercion (Appelbaum, 2007; Atkinson, 2007; Elbogen, Swanson, Appelbaum et al., 2007). In addition, an important finding in the literature review was that these groups expressed an interest in formulating an AD. These contextual factors ‘fit’ and reflect the social realities of those who are experiencing SE-AN (Charmaz, 2008a; Gasson, 2004; Holloway, 2005b, 2008; Lincoln & Guba, 1985). These observations suggest that the model is not fixed but fluid (Ritchie et al., 2013).

7.7.5 Triangulation

By definition, triangulation is a technique that involves at least two perspectives relating to an issue (or phenomenon) under investigation (Flick, 2018). Morrow (2005) stated that ‘the more variety in the data sources one is able to obtain, the greater will be the richness, breadth, and depth of the data gathered’ (p. 256). The present study employed two types of triangulation—methodological (participant observation, semi-structured interviews and focus groups) and data triangulation (multiple quotations from participants, clinicians and people with SE-AN)—to enhance the validity and generalisability of the study (Arksey & Knight,
Triangulation enabled the researcher to analyse the research question from multiple perspectives to determine whether the data (e.g., observable relationships within interview data) converged or showed distinct differences (Bloomberg & Volpe, 2008; Creswell, 1998; Flick, 2018; Mays & Pope, 2000; Nakkeeran & Zodpey, 2012; Patton, 2002). Different data sources (and different perspectives) may yield different results (e.g., themes), but the data may also corroborate findings, showing no differences, and therefore build a coherent justification of the themes (Berglund, 2001; Creswell, 2013; Flick, 2018; Patton, 2015c; Schwandt, 2014; Stake, 2012). Thus, for example, the theme of ‘autonomy’ might have different meanings for different participants, but they may all share the view that a person’s autonomy should be respected.

7.8 Conclusion

In summary, an essential component of conducting qualitative research is the generation of qualitative data that are representative of the views and experiences of the research participants. This was achieved through data collection, sampling, recruitment procedures and establishing ethical protocols.

GT provides the analytical tools required to develop a theory that is grounded in the data. The use of open, axial and selective coding, along with memoing, questioning, diagramming and the constant comparative method, helped the researcher to analyse the data to excavate meanings, make interpretations and identify relationships between codes, concepts and categories regarding the emergent theory. The qualities of being flexible, open-minded and dynamic about the data also played an important role. The absence of these qualities could impede the discovery of the theory.
To verify the credibility of the findings and minimise the researcher’s bias, the strategies of credibility, confirmability, dependability, transferability and triangulation were applied in all phases of the research process—namely data collection, data analysis and interpretation. Section 10.3 will reflect on the importance of these strategies, particularly in synthesising the results of the analysis and integrating them into the development of an ethical decision-making model.

The next chapter will present a number of key findings that represent the participants’ views and are evaluated in accordance with Lincoln and Guba’s criteria.
Chapter 8: Results

8.1 Introduction

This chapter will discuss and present the main findings of this thesis. The findings are based on the views, attitudes and beliefs of females living with SE-AN and the clinicians who participated in the focus groups. Interview responses were based on three broad topics: participants’ experiences of living with SE-AN, participants’ experiences of hospitalisation and PADs. Focus group participants explored two key topics: involuntary treatment and PADs. The purpose of this chapter is to hear the ‘voices’ of the participants regarding these topics. A brief summary of the study parameters is provided so readers can conceptualise the ‘fieldwork’ and thereby understand how the findings support the emerging model.

8.2 Brief Overview of the Construction of the Ethical Decision-Making Model

This study was based on qualitative data analysis of adult females living with SE-AN and focus groups involving clinicians from a diverse range of professional backgrounds. All participants contributed new knowledge about the phenomenon of SE-AN—specifically, the relationship between PADs and the iatrogenic effects (coercion) of psychiatric care. The process of generating data was in accordance with GT principles (Corbin & Strauss, 2008, 2014; Ritchie et al., 2013).

The main theme of ‘lack of control’ emerged in the analysis to best explain the participants’ main ‘conflict, obstacle, problem, issue, or concern’ (Stern & Porr as cited in Saldaña, 2015, p. 250) in relation to living with SE-AN. The core theme was interlinked with four subordinate themes: ‘managing my illness’, ‘debilitating illness’, ‘collaborative care’ and ‘health care services’, all of which provide an explanation to the lived experience of SE-AN.
To illustrate these findings, I have used quotations from the participants to ensure that their ‘voices’ are heard and to verify the validity of the research findings (Hennink et al., 2010; Holloway, 2005a). I chose to use specific quotes that were exemplary and explicit in conveying their intended meaning (Hennink et al., 2010; Holloway, 2008; Kvale, 1996; Skårderud, 2007). Thus, verbatim quotes vary in size depending on their contextual meaning and relevance to the text (Holloway, 2008). Generally, quotations were kept short (no more than half a page) to maintain the interest of the reader (Hennink et al., 2010; Kvale, 1996).

Some quotations use an ellipsis (…) to indicate that some of the text has been left out to condense the text and improve readability, but without changing the meaning (Hennink et al., 2010; Holloway, 1997). Square brackets […] have been used to add words to clarify the participants’ thinking or to emphasise their non-verbal behaviour (e.g., pause, laughter or crying) (Hennink et al., 2010; Holloway, 2008).

Overall, quotations have been used to illustrate the ‘social world’ of each participant, support and confirm the findings, provide context, and add human interest (Corbin & Strauss, 2014; Hennink et al., 2010; Holloway, 1997; Oliver, 2013).

The coding and interpretation of the data were facilitated by mind-mapping and Nvivo qualitative software to graphically visualise, and to explicate (i.e., identify connections and interrelationships) the data (Charmaz, 2014). Table 8.1 shows the main superordinate and subordinate themes that emerged from the data.
Table 8.1

**Conceptual Themes**

<table>
<thead>
<tr>
<th>Superordinate themes</th>
<th>Subordinate themes</th>
<th>Themes</th>
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<tbody>
<tr>
<td>Reclaiming the ‘self’</td>
<td>Managing my illness:</td>
<td>Recovery</td>
</tr>
<tr>
<td></td>
<td>‘A different frame of mind’</td>
<td>Voluntary hospitalisation</td>
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<td></td>
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<td>Periods of remission</td>
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<td>Maturity of illness</td>
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<td>Future after anorexia</td>
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<tr>
<td>Autonomy and choice</td>
<td>Collaborative care:</td>
<td>Decision-making</td>
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<tr>
<td></td>
<td>‘everything’s 50–50’</td>
<td>Family support</td>
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<td></td>
<td></td>
<td>PADs</td>
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<tr>
<td>Quality of life</td>
<td>Debilitating illness:</td>
<td>Identity</td>
</tr>
<tr>
<td></td>
<td>‘I was too weak and too sick. So I</td>
<td>Stigmatised with a mental illness</td>
</tr>
<tr>
<td></td>
<td>stopped working’</td>
<td>Bereavement/suicide</td>
</tr>
<tr>
<td>Flexibility of healthcare services</td>
<td>Healthcare services:</td>
<td>Patient-centred</td>
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<tr>
<td></td>
<td>‘Patient-centred approach’</td>
<td>Multi-disciplinary team</td>
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<td></td>
<td></td>
<td>Specialised eating disorder clinics</td>
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<tr>
<td>Accessing services</td>
<td>Healthcare services:</td>
<td>Limited of specific services</td>
</tr>
<tr>
<td></td>
<td>‘The underpinning attitude is that</td>
<td>Lack of specialised staff</td>
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<tr>
<td></td>
<td>we are a waste of a good hospital bed’</td>
<td>General medical ward</td>
</tr>
</tbody>
</table>

8.3 Core Category: Lack of Control

The core category of ‘lack of control’ was the key issue in the analysis and was developed from in vivo codes (Corbin & Strauss, 2014; Creswell, 1998). It was the central concern of all participants, including those from focus group 2, and it was related to all of the subthemes and had the greatest explanatory power (Corbin & Strauss, 2014).

Although the phrase ‘lack of control’ was not explicitly detailed in the transcripts, its meaning and significance were present throughout the data and often substituted with terms such as ‘consumed’ and ‘choice’. Nordbø et al. (2006) reported a similar situation whereby informants used the term ‘control’, but its ‘meaning’ was used in different contexts.
Throughout the following discussion, examples will be provided (highlighted using a different colour in the text) to enable the reader to comprehend and contextualise its meaning. This core category was linked to the broader subordinate themes—‘managing my illness’, ‘debilitating illness’, ‘collaborative care’ and ‘healthcare services’—and was frequently observed within the interview transcripts. Figure 8.1 illustrates the interrelationship between the themes and subthemes that reflected the participants’ experiences of living with SE-AN.

According to the literature review, control is a central feature of living with SE-AN, and some would argue that it is the main perpetuating factor sustaining the illness (Bell, 2003; Bruch, 1979; Colton & Pistrang, 2004; Dawson et al., 2014; Murray et al., 2017; Nordbø et al., 2006; Strober, 1982; Tan, Hope, Stewart et al., 2003; Vandereycken & Beumont, 1998c). Control can be defined as ‘when patients perceive they have the power and capacity to influence their life or their illness’ (Jeon, Kraus, Jowsey, & Glasgow, 2010, p. 5). Previous studies have identified that control can be a coping mechanism that enables patients to manage their psychiatric symptoms (Fox, Larkin, & Leung, 2010; Lawrence, 1979; Reid, Burr, Williams, & Hammersley, 2008; Tan, Hope, Stewart et al., 2003).
Figure 8.1. Core theme: lack of control.
To date, most studies have focused on the concept of control (or a subtheme related to control) and its relationship between patients’ perceptions of their illness and hospital treatments (Colton & Pistrang, 2004; Fox et al., 2010; Jarman et al., 1997; Offord et al., 2006; Reid et al., 2008; Serpell, Treasure, Teasdale, & Sullivan, 1999). These studies were designed to broaden our understanding of the health needs of people with anorexia, and to understand the meaning behind the paradoxical concept of control. Therefore, this study aims to contribute towards furthering this knowledge. The main finding of this study supports this hypothesis and collaborates the findings of previous studies (Button & Warren, 2001; Jarman et al., 1997; Lawrence, 1979; Rance, Clarke et al., 2017; Skårderud, 2007; Tan, Hope, Stewart et al., 2003; Whitney et al., 2005). However, it must be emphasised that the following reported findings were non-specific—that is, they occurred in both eating disorder clinics and general hospital wards.

It was evident that a lack of control affected many aspects of the patients’ lives. The women described experiences where they lacked control not only in their medical care but also struggled to maintain control over their personal life and their illness. These experiences included receiving limited opportunities to participate in the decision-making process, feeling disempowered and controlled by others and experiencing difficulty in accessing specialised care services (frequently referred to as inappropriate services such as a general medical ward). In addition, many had experienced acts of coercion in current or past hospital admissions.

Over the trajectory of their illness, the women had difficulty in managing their illness and succumbed to the debilitating effects of living SE-AN. In most cases, they lost friends, partners, education and employment, and even the will to live. It appears that the effects of bereavement had a profound effect on their ability to maintain some sense of order (control) and normalcy in their life.
Even being diagnosed with a mental illness such as SE-AN resulted in social stigma and caused shame and embarrassment. In some cases, it led to ongoing depression and anxiety problems. Participants in focus groups spoke about a lack of control in two domains. First, they felt a lack of control over their patients when they behaved in a recalcitrant manner (e.g., not complying with meal plans) and when refusing treatment, and they felt the need to contain patients by enforcing treatment through measures such as involuntary treatment. Rarely, this meant revoking their voluntary status and detaining them under the *Mental Health Act*. Second, others reported that they felt a lack of control in the context of having limited training in eating disorders, and they were not sure how to effectively engage with their patients. In these instances, the senior staff were relied upon to provide guidance and support to recently appointed staff members.

Overall, the core category was logical and consistent in explaining that the women felt a lack of control in regard to the decision-making process, accessing treatment resources, accessing information and resources to enable a person to initiate and complete a PAD, and managing the negative effects of social stigma. This category has been interpreted in previous studies (Fox et al., 2010; Lawrence, 1979; Reid et al., 2008; Tan, Hope, Stewart et al., 2003), and it provides scope for further research. This thesis will build on or extend the ideas of the previous findings to elucidate the complexities and processes underlying the concept of control in the context of SE-AN.

It is important to note that all participants elected to offer past and present experiences regarding living with SE-AN. While some researchers may dismiss the past experiences as not relevant, it is the author’s intention to integrate the past experiences with current experiences to better understand the phenomenon. Indeed, it is a mark of respect to listen to the participant’s whole story rather than fragments. Given that the author has adopted a constructivist–interpretivist approach to understanding people’s ‘mean-making’ in relation to
living with AN, it seems justified, and indeed appropriate, to explore these reflections to add a greater depth of knowledge of SE-AN. Thus, I will incorporate these reflections and make inferences and interpretations based on the ‘totality’ of these experiences. The superordinate core theme of ‘lack of control’ will now be further examined in regard to its relationship to the subordinate themes.

8.4 Finding 1: Reclaiming the Self

The superordinate theme of reclaiming the self was conceptualised through participants’ descriptions about their coping strategies in managing their illness. Figure 8.2 illustrates the first subordinate theme, ‘managing their illness’, which emerged from the participants’ discussions about their experiences of living with SE-AN. This theme is interlinked with five subthemes and reflects the underlying ethical principles of autonomy and self-determination in which people with SE-AN are attempting to exercise control to manage their chronic illness.

**Figure 8.2. Subtheme 1: ‘managing my illness’**.

This theme emphasises the patient’s role in taking responsibility and ownership for managing their illness. Hence, after a protracted period of living with AN and experiencing multiple hospital admissions, four participants described their experiences (actions) of
wanting to recover. This was mainly in the context of treatment engagement and voluntary hospitalisation. Amy (aged 37, with a 10-year duration of illness) stated that:

*I wanted to live, I wanted to live life. Hence why I asked for this admission now cause [because] I just want to be completely free of my eating disorder ... eating disorder free, binge free, purging free. Just pure freedom. (Participant: Amy)*

*It’s always been voluntary, um, but it’s because I’ve got to a point where I don’t really have any other option, and it’s for my own health and safety. (Participant: Jade)*

Jade (aged 24, the youngest age of the cohort, and with an illness duration of six years) described hospitalisation as a ‘rescue point’ and stated: ‘Probably would have kept deteriorating … I needed some sort of help’. Sue (aged 57, with a 10-year duration of illness) reported that:

*I think that something like anorexia and an eating disorder is not just a physical thing. And it’s not even just a mental thing. It takes your entire life from you. It takes your family from you ... it isolates you to the point where you would prefer death ... [she later states] ... I put myself in the program ... I was eager to participate. (Participant: Sue)*

Recognition of the need for medical treatment was motivated by the fear of death. Most patients reported a low BMI and were in an acute stage of their illness with cachexia. As a result of the illness, many patients had experienced severe medical complications throughout their life. In some cases, this resulted in multiple visits to an intensive care unit (ICU). All participants described instances in which they had come close to dying, stating that they would have died if they had not sought medical treatment. The following statements reflect this concern:

*I have no energy and collapsed and went into a coma ... I was attached to a machine in intensive care for two months basically keeping me alive. (Participant: Sue)*

*Population of patients is generally, yes, very, very, very unwell um and they’ve got to a point where um they often require immediate um or very prompt hospitalisation. (Participant: Cindy, general nurse, focus group 2)*

*So what the abuse that we put our bodies through by having an eating disorder is reaching extreme points. (Participant: Sue)*
I’m at risk of sudden death because um potassium and electrolytes [deficient]. (Participant: Mary)

However, most participants expressed a strong desire to have a better quality of life that was not dominated by AN. Statements such as ‘Because I can be quite strong’ (Participant: Sue) and ‘it’s a daily battle trying to stay here and, you know, to try and get better versus just going home and letting myself die’ (Participant: Mary) are reflective of the patients’ self-determination to recover from this insidious illness.

Managing their illness was interlinked with the subtheme of maturity of illness. This theme suggests that over the trajectory of a patient’s illness, they develop in-depth knowledge and gain personal insights into managing their illness in terms of what works and what does not work regarding their medical care. As illustrated by one participant:

over the course of the six years, I’ve become more aware of the thought patterns and behaviour patterns that are associated with your particular diagnosis ... I guess becoming more wise, becoming a lot more intuitive—watching out for certain signs and everything like that that you associate with it, and coming up with different coping mechanisms. (Participant: Jade)

Another participant stated that ‘I’ve got a great dietician in Wangaratta, and like all the years [over the years], I know how to re-feed myself anyway out of all the treatment you’ve had—I’ve had’ (Participant: Amy).

Most participants spoke about their illness within the context of spatial and temporal time. Thus, two subthemes emerged from the data: ‘future after anorexia’ and ‘periods of remission’. There were mixed views regarding what constituted a future. According to Amy, her future involves completing her TAFE course and being present for her children when they grow up. The following statements illustrate this theme:

I’m going to be recovered and have another healthy baby. My kids are going to grow up. My daughter is going to have the happiest life. I just wanted my kids to be happy, and then one day I woke up and I thought well hey, I can be happy too, I’m alive. I can still do this ... I’m in my second year of nursing. (Participant: Amy)
Throughout the duration of the illness, there are different stages of where you’re at—it’s not really a linear approach—and it can kind of very much go up and down, along the way, at various degrees of that. (Participant: Jade)

From a clinician’s perspective, the concept of recovery was acknowledged as having different meanings for different individuals:

Recovery I think is different is like different for every patient and each patient has their own perspective of what recovery is to them. One of our patients right now, her recovery goals are just that she would like to be out playing with her younger nieces and nephews. (Participant: Dianna, psychiatric nurse, focus group 2)

Unfortunately, two participants had difficulty imagining a future without their eating disorder:

At the moment I’m kind of at the point where I’ve—I’ve given up. I don’t think that things will ever get better, I feel like this is how I’m going to be forever. (Participant: Mary)

I haven’t had the ability to see a future. All I could see was an eating disorder—when I say eating disorder, the anorexia. So future health, no, because I honestly didn’t believe I had a future. (Participant: Sue)

Of course, this does not necessarily mean that these women will not recover or have a future. It could simply mean that they are in different spatial and temporal times with their recovery. From the researcher’s observation, the fact that they are currently receiving treatment suggests an attempt at recovery. These excerpts highlight that the definition of recovery is an ambiguous and elusive concept that has different meanings for different people with SE-AN, and for families and clinicians.

Further data analysis revealed a relationship between recovery and ‘periods of remission’, which was a consistent subtheme across the data. All participants described having periods of relapses and remission but admitted that, overall, they were not completely symptom-free; that is, ‘it’s always there’ (from the author’s experience of living with SE-AN). Jade used the evocative term ‘undercurrent’ to describe this phenomenon:

I guess a lot of people have kind of said that you know, look, full recovery from anorexia is possible. That you can, you know, you can be completely free of it, and everything. I must say, I’m a bit of a sceptic when it comes to that, because um, I’ve also heard of a lot of other people that have kind of said, well, you get to a
point where it doesn’t affect your life anymore, but you’ve still got [referring to symptoms], like, an undercurrent, I guess. (Participant: Jade)

Although this subtheme has a theoretical meaning in the concept of recovery, there are no consistent patterns of data (or identified variables) to explain this homogeneous finding. Nevertheless, anecdotal accounts suggest that women with SE-AN have periods of remission that can continue for many years, sometimes lasting up to 13 years. All participants, with the exception of Jade, highlighted the significance of this finding:

*I’ve maintained my weight at a hospital free weight for the last 13 years. (Participant: Amy)*

*I haven’t binged for about four years now ... my last admission here was 2015 ... And I haven’t been to a clinic or anything since then. (Participant: Jo)*

*I haven’t had any involuntary admissions for probably two or three years until the beginning of this year. (Participant: Mary)*

*I was fine more or less for about, say, three and a half to four years. (Participant: Sue)*

Jade did not have any significant periods of remission, although she described periods (albeit short) where the AN was not so pronounced. She stated:

*Throughout those six years I’ve been sort of in and out of treatment and everything like that, in multiple different settings and stuff, and at different stages, you find different peaks and troughs of motivation. (Participant: Jade)*

The word ‘hope’ was not explicitly mentioned by participants, but it was mentioned by a focus group member who stated that people with SE-AN have periods of remission and relapses. The fact that they return to hospital for treatment (a short voluntary hospital admission) is a testament that they have maintained a sense of hope and that recovery is possible:

*We do have recovered people come back and talk to us as well, which instil a lot of hope ... you know which is incredibly rewarding and it just reminds us that it’s definitely possible. Therefore we can promote that hope to the clients as well. I think it’s very rewarding ... you know so-sort of seeing someone’s journey from start to finish on the inpatient ward. (Participant: Jane, clinical psychologist, focus group 1)*
8.5 Finding 2: Autonomy and Choice

There was a general consensus among all participants that a person’s autonomy should be respected to increase their control over their medical care and to enhance collaboration between patients and healthcare professionals.

8.5.1 Superordinate theme: autonomy and choice

The second theme, ‘collaborative care’, was interlinked with four subthemes that were all related to the superordinate theme of autonomy and choice. Several findings emerged from the data.

![Diagram](image)

*Figure 8.3. Subtheme 2: ‘collaborative care’.*

Decision-making emerged as a theme when participants discussed their experiences of hospitalised treatment. It also became relevant when the topic of PADs was raised. Decision-making was considered a significant issue for all individual participants and focus groups, and it was related to matters regarding hospital treatment and the illness.

The general consensus was that participants believed that ‘decision-making was taken somehow out of your hands’, and they felt a lack of control regarding medical care in terms of making choices about, and taking control of, their health and wellbeing. Most participants reported feeling disempowered and excluded by not being involved in the decision-making
process, and they were resigned to the fact that the doctor ‘knows best’. As a result, they did not feel confident (insufficient autonomy) to make independent decisions; rather, they acquiesced to the doctor’s authority for decision-making:

*You feel as if it’s, it’s all being—decisions are being made on your behalf and [from] my perspective is a sense that you are not participating in your recovery; that it’s all being taken somehow out of your hands. (Participant: Sue)*

*I’ve always been driven by, like, what the professionals think is best. (Participant: Jade)*

*I’m always getting told, you know, they’re medically trained and I’m not, and I try and advocate for myself and make a decision about my health. So I can see that there’d be a disagreement. (Participant: Mary)*

*They [doctors] already predetermined what they’re going to give you … there’s no negotiating … there’s no point even arguing with them … people don’t like control being taken off them. (Participant: Amy)*

The last statement highlights the patient’s feeling of disempowerment. Mary wanted to advocate for herself but felt that it was not possible in case it led to a difference in opinions. That is, she felt that her opinions did not matter because she was not medically trained.

Further, an issue of power differentials is apparent. Mary’s statement conveys her belief that the doctors know best because they are medically trained; therefore, this precludes Mary from having a voice in the decision-making process. Jade reiterated her belief that the doctor knows best, stating that ‘they [doctors] know what is best because they’ve had the experience with treating people before, so they kind of know what works well for people’ (Participant: Jade).

The emerging theme of competency frequently shaped the views of the focus groups and patients regarding a person’s capacity to make decisions and their right to formulate a PAD or to refuse treatment. Participants had mixed views regarding what constitutes a loss of competency, but they agreed that a low BMI, evidence of irrational thought (as opposed to an absence of psychotic symptoms) and its gradual occurrence (as opposed to a sudden loss) are contributing factors:

*How do you determine competency if someone’s got a BMI of 14 or 16 or 13? (Cindy: general nurse, focus group 2)*
I think the thing to say about PADs and anorexia nervosa is also people don’t tend to one day be non-not competent, as opposed to psychosis or some of them with episodic illnesses. Often it’s more possibly deterioration over time and often our patients aren’t incompetent. (Emma: registrar psychiatrist, focus group 1)

With the eating disorder, it’s maybe not as sudden a change that they can no longer think for themselves except in your example of medical cognition being affected by a really low weight. (Mandy: intern doctor, one year of clinical experience, focus group 2)

At a low body weight—they’re not rational. (Participant: Amy)

To address this problematic issue, one participant suggested:

You could re-evaluate that and check the decision they’re making is consistent with what they thought a few weeks ago and their rationale for the decision. (Jane: clinical psychologist, focus group 1)

The issue of competency was also discussed in relation to forced treatment. Some participants believed that when a person loses their competency (e.g., is not able to ‘think rationally’), it is justifiable to detain and enforce hospital treatment without their consent. In short, decision-making is not always a rational concept. As a result, the treating team takes on the responsibility for decision-making because they have a duty of care to protect the safety and wellbeing of their patients. Peta (aged 36, social worker with three years of clinical experience) believed that a person who is deteriorating warrants involuntary hospitalisation:

So I think the argument um involuntary treatment is high for people where there’s been an acute deterioration. [making reference to competency] (Participant: Peta, social worker, focus group 1)

If you’re too low a body weight you can’t be rational. And if you deprive yourself—nutrients and glucose, your brain doesn’t work. (Participant: Amy)

My understanding is people become involuntary because they’re either not in a mental or physical state to be able to think clearly and basically stay safe. (Participant: Jo)

Jo later described a time when she lost her competency: ‘I wasn’t thinking like at that stage … oh, my God, I could go into a coma … Like, that’s obviously not me thinking clearly—at that moment’.
Some clinicians expressed a concern that some patients require a ‘medical rescue’, especially when they are acutely unwell. In these instances, the Mental Health Act was used to sanction these patients, but only when the patient was seriously unwell and a danger to others. It was reported that the Mental Health Act was used infrequently:

In many extremes of cases ... literally, no other way and like this person’s life is in danger which is pretty much the reason why they were basically put under the Mental Health Act obviously having met the criteria. (Participant: Jane, clinical psychologist, three years of clinical experience, focus group 1)

People who have been chronically unwell for a long time I think the Mental Health Act is less probable ... it would usually be for resuscitation or something which they can often do in ED or um replacement of electrolytes or something. (Participant: Peta, three years of clinical experience, social worker, focus group 1)

Several participants equated the term ‘competency’ with starvation and explained how this affected their capacity to think clearly:

The other complexity is we’re working with patients that are very unwell and they’ve got very low BMIs so they’re thinking capacity is impaired for quite a period of time ... so maybe as an inpatient it’s not the time to be making this kind of decisions. (Participant: Cindy, general nurse, eight years of clinical experience, focus group 2)

I know when my weight gets low, I can’t think as clearly as other times. (Participant: Mary)

I guess when you’re so malnourished and starved [yourself] you’re cognitive abilities is definitely not probably in the right space to be making decisions about your health. (Participant: Jo)

Competency was defined according to medical and legal parameters, but it was also perceived to be a fluid concept wherein a person’s decisional capacity can fluctuate:

I suppose medical and legally there are defined parameters to assess competence and capacity ... so a person may not be competent to make a decision about their finances but may be competent to decline nasogastric treatment at any stage or something like that. (Participant: Emma, psychiatrist registrar, focus group 1)

Some people change their mind when they’re sick. I don’t remember saying I wanted that, you always change your mind I suppose. (Participant: Amy)
Clearly, the term ‘competency’ has a broad definition; indeed, it may have certain implications for people’s ability to effectively engage in the decision-making process regarding their care.

As mentioned earlier, decision-making was identified as a key issue when ADs were discussed. Perhaps one of the most striking findings in this study was that all participants had no prior knowledge of PADs per se, but they possessed some knowledge (albeit vague) of advance care planning. The term ‘PAD’ was a foreign term that had no relevance and meaning and was often confused with ADs. Thus, most participants believed that ADs had been designed for patients who were terminally ill and were therefore not applicable to patients with severe psychiatric illness.

Tracy (aged 23, psychiatric nurse with two years of clinical experience, focus group 2) asked whether it is ‘like an advance statement under the Mental Health Act?’ She later declared, ‘so this is sort of a new term that when I first read it I wasn’t sure if it’s maybe specific to eating disorders or something … even state-wide we would think of them as advance statements’. Similarly, the patients failed to understand the definition of PADs in the context of their healthcare:

*No. I have heard of it, it’s the same as like the end of [life will] ... I just see it as the same as what the elderly do, or before, you know, their dementia gets worse or anything like that. (Participant: Amy)*

*I’ve always known them as advance statements. (Participants: Tracy, registered psychiatric nurse, two years of clinical experience, focus group 2)*

*I’m surprised that I haven’t really known about that now ... I’ve never heard of it [ADs]. (Participant: Jo)*

*I would be interested to find out a little bit more about it [AD], but it’s actually never [been mentioned]—it’s the first time I’ve ever actually even heard the term. (Participant: Sue)*

Further, clinicians had mixed views about the use and effects of PADs among patients with AN. For instance, Jane (clinical psychologist, focus group 1) believed that PADs are valuable and can be used as ‘a tool that empowers and you know enables choice and allows
decisions to be made’. Tracy (registered psychiatric nurse, focus group 2) supported this opinion:

_I think it’s very positive in that it allows the patient to remain autonomous over what happens to them when they do lose competency and even the process of doing it might give them some sense of relief and trust in the system because they’ve been given the chance to express their opinion and what they want out of their own life._ (Participant: Tracy)

A contrasting view was expressed by Cindy:

_One of the downfalls of having a PAD is if someone has done it in January this year and it hasn’t been reviewed in between [that time]. They might change their view. I mean to say back then they didn’t want the NG [nasogastric] tube but now they’re more accepting of it, or vice versa._

A similar concern was raised by Jane:

_There’s a potential that some things on the PAD may not be met … or only had one thing on my PAD and you didn’t respect that and then that could potentially break the therapeutic alliance I guess._ (Participant: Jane, clinical psychologist, focus group 1)

Tracy had a different view:

_People [patients] might have on their advance statement things that they want or don’t want but I mean at the end of the day they can put that down there but under the Mental Health Act a consultant psychiatrist can go against someone’s advance statement if that’s in the client’s best interests._ (Tracy, registered psychiatric nurse, focus group 2)

There was overwhelming support for the idea of PADs from patients, provided that a person is ‘of a sound mind’ and ‘competent’ to make decisions. The main reason provided was that PADs would give them an opportunity to maintain decision-making control over their medical care. Multiple statements supported this finding:

_Having a choice where I can have a discussion with someone about what medications to use or what ones are best._ (Participant: Jade)

_It’s the comfort in knowing that your decisions are respected, validated._ (Participant: Amy)

_I definitely think that people should have a say in what their treatment is going to look like, or that works for them the most._ (Participant: Jo)
I was competent and of sound mind, I could say in terms of my medical treatment, this is what I would like. This is what I don’t want. I think that’s—I think that is a powerful idea [PADs]. (Participant: Sue)

I think it’s a good idea … I would hope that that would end my life. (Participant: Mary)

The issue of competency was also expressed by focus group members, specifically in the context of the stage of the illness at which PADs should be discussed and implemented. It was generally agreed that it should be done post-hospital admission or towards the end of the hospital stay, when patients are competent:

It might actually make more sense to talk about it [PADs] at the point of stepping down from stepping off at BETRS [Body Image Eating Disorders Treatment and Recovery Service]. They’ve come to the inpatient unit, they’ve done the day program, then they’ve done the step down and then at that point when they’re being discharged from the outpatient service it would make more sense to talk about it then, when they’re probably a lot well, a lot better [competent]. (Participant: Jane, clinical psychologist, focus group 1)

There’s so much going on for the patient that if we did it at the beginning I don’t think they would be receptive to it. So it could be probably done closer to discharge. (Participant: Cindy, general nurse, focus group 2)

All five patients supported the use of PADs and expressed an interest in receiving additional information. Interview answers about treatment preferences were variable, but all responses were related to patient care:

I don’t do nasogastric tubes or anything like that. No medication. I would prefer to be in like an eating disorder clinic … Just the general medical stuff to keep me alive. (Participant: Amy)

Um no ECT, I’ve never had it before but um it’s been mentioned to me before but I never want that. (Participant: Mary)

I’d definitely probably state where I wouldn’t want to be. I would opt for nightly feeds, but feeding throughout the day, um, and then eventually no tube at all. (Participant: Jo)

Like, you know, I don’t do nasogastric tubes or anything like that … no medication … and I would prefer to be in like an eating disorder clinic. (Participant: Amy)

If I had the choice at all, um, the nasogastric tube would definitely be off my list. Being allowed in a setting [clinic] where it’s more of a specialised eating disorder unit, as opposed to just a general medical ward. (Participant: Jade)
Sue reiterated the importance and value of having a PAD. It gave her a sense of comfort and autonomy over her medical care:

*For someone who is chronically ill and potentially facing death, it’s an extremely comforting thing to know that if you do get to the stage where you are unable to make choices and decisions for yourself, that the choices and the decisions that are made are things that you chose.* (Participant: Sue)

She articulated her treatment preferences clearly in the following statement:

*One that is almost a non-negotiable is I would not want to keep on life support. If the only way to keep me living would be through a machine, then that would be a very big no. I don’t think I want anything intrusive. Like, I wouldn’t want shock therapy or anything like that. But I’d—probably would accept medication. I’m not putting through the nasogastric feed.* (Participant: Sue)

One finding that became clear in the data analysis was that family support played an integral role in the care of women with SE-AN, either with or without hospital treatment. The patients defined family support as being accepting of their illness. All participants, with the exception of Mary, identified their parents as being an important source of support, especially during the advanced stages of their illness. In such situations, practical day-to-day support, such as helping them to get dressed, buying groceries and minding their children, were helpful in reducing the burden of living with anorexia, and it also helped to break the isolation that they often experienced.

A couple of participants noted that their parents accepted their illness unconditionally, although it was a topic that was never openly discussed. Sue, who has a European background, explained:

*Both my parents are incredibly supportive, but father has that kind of added dimension where he kind of understands [anorexia].* (Participant: Sue)

*My partner loves and accepts me for who I am, never comments on it. My parents, well they’ve just accepted that that’s just the way I am. So it’s never really talked about it ... I’m just accepted for who I am.* (Participant: Amy)

This finding was also validated in the focus groups, in which family members were encouraged to participate in family therapy and clinical meetings, but with the consent of their
loved ones. This collaborative approach proved to be an important aspect in the delivery and provision of the hospital’s healthcare.

Mandy (aged 27, intern doctor with one year of clinical experience) from focus group 2 stated that, ‘And if there are other people like family members that would like to be involved in that with the patient’s consent then they can also be involved’.

Dianna, a general psychiatric nurse, stated that:

A lot of the time they will want parents or family or partner or, you know, sister or somebody to be involved and invite them in for a family meeting to get them involved in their [patients] care. (Participant: Dianna, registered psychiatric nurse, focus group 2)

Cindy, a general nurse, reinforced this view, stating that ‘Most days we speak to families, whether it’s in the hallway or in the visiting or whether it’s a um formal family meeting or whether it’s phone contact’.

Another finding was that the women described their relationship with nurses and other health professionals as collaborative, supportive and caring in terms of their treatment and recovery. Most participants valued the importance of having a strong therapeutic relationship in which they felt understood, heard, valued and acknowledged by health professionals. This translated into a better experience of inpatient care and was the basis for subsequent voluntary hospital admissions:

I think that point of feeling heard and validated and understood, even when at the end of the day you’re still not getting what you want, I still think that it’s really important then that you are getting that recognition. (Participant: Jo)

It’s still hospital but at least there’s staff that understand and that will talk to me and you know, acknowledge what I’m going through and not just say we don’t know anything about, you know. (Participant: Mary)

I think it is a collaborative approach. And they bring you in on it, and everything, which is helpful as well. (Participant: Jade)

The importance of building trust and developing rapport was a central theme for all participants. Both focus groups reinforced this point. They regarded this as a collaborative approach whereby patients and care providers work together on ‘shared goals’ such as ‘how
long this admission will be and what we’re aiming to achieve’ (Participant: Mandy, intern
doctor, focus group 2). Jane stated that:

*Often how we say—so just to keep that sort of rapport open um and you know sort of build up as best we can. Just being kind and empathetic and um although probably we don’t understand, haven’t walked in their shoes, just sort of being available and caring I think is very helpful, yes.* (Participant: Jane, clinical psychologist, focus group 1)

Dianna, a psychiatric nurse, reported:

*I think they feel a lot more confident if they know who’s coming onto the shift next because you sit with them throughout the meal and you sit them with them in person and we spend so much time with them as nurses ... so I think continuity of care and build a rapport is quite a big deal.* (Dianna, psychiatric nurse, aged 25 with three years of clinical experience, focus group 2)

**8.6 Finding 3: Quality of Life**

The emerging theme of ‘social stigma’ reflects the barrier that prevents women from disclosing their illness and seeking help from professional supports. This had a profound
effect on their quality of life.

**8.6.1 Superordinate theme: Quality of Life**

This theme captures the women’s personal accounts of struggling to live with SE-AN, as well as the debilitating effects that directly affect their physical and psychological functions and quality of life. Figure 8.4 shows the visualisation of these interlinked factors and their effect on a person’s ability to recover from the illness.
Figure 8.4. Subtheme 3: ‘debilitating illness’.

Participants were initially asked to describe their illness. Most of them described it as either a physical or mental problem that required ongoing medical care. This distinction had different meanings to individuals and focus group participants, but they all shared the view that anorexia is a characteristic of both physical and cognitive features. These descriptions included:

*It’s not just a psychological illness. It is predominant part psychological but it affects your social life. It’s behaviour [symptoms] and then physical as well and that all feeds back on itself.* (Participant: Mandy, intern doctor, focus group 2)

*Anorexia nervosa is a mental illness, primarily although it affects every aspect of their life and their physical health and their social health and even like their developmental health.* (Participant: Tracy, registered psychiatric nurse, focus group 2)

*It’s also very much a mental—mental disorder.* (Participant: Joe)

*Sometimes it can be that you start to notice certain slight changes in attitude or changes in behaviour, or changes in thoughts.* (Participant: Jade)

A common theme found in the data, and one that was tied to the patients’ AN identity, was that they felt stigmatised by their diagnosis. Participants reported that clinicians, family and friends treated them differently because of their illness. For example, one participant
stated that people treated her differently: ‘I’m Jo with an eating disorder, I’m not an eating disorder’ (Participant: Jo). Jo felt that she was treated as just another eating disorder ‘case’, which failed to recognise and acknowledge her individual needs. Several participants described the shame and embarrassment of being labelled with AN, which contributed to their poor self-image. All participants knew they had the illness, but they did not disclose their AN identity for fear of being judged or receiving negative reactions from family and friends.

Interestingly, two of the participants (Mary and Sue) had European backgrounds and stated that their families did not understand their condition. They explained that Europeans celebrate and rejoice in food, and it is considered an ‘expression of love’ that brings families together. Indeed, it must be a foreign concept and difficult for their families to understand and witness their daughters struggling with an eating disorder. This undoubtedly contributes to their shame and isolation, which in turn leads to feelings of guilt and blame because of their inability to control their illness. Overall, these factors affected the functional, emotional and social interaction aspects of their quality of life:

*I wouldn’t tell anyone, because I was too embarrassed and didn’t want anyone to worry ... you get looked at and you feel judged and people might say things and point or whatever.* (Participant: Jo)

*Whereas a lot of the time when people are chronically ill, they’re not acknowledged, they’re not validated and—cause they’re deemed as mentally unstable and physically unwell.* (Participant: Amy)

*My parents they don’t acknowledge and would never use the word anorexia, eating disorder; it’s just all sort of I feel like they’re ashamed of it ... Even my brothers and sisters it’s just not talked about ... Like they’re ashamed of me.* (Participant: Mary)

*I didn’t really talk about what I was doing. I was aware of it and I was aware that there was something very, very wrong, but the shame and the guilt that I felt prevented me from actually admitting—I could barely admit it to myself ... I believed strongly that it was my fault ... Your confidence is chiselled away, your friends slowly.* (Participant: Sue)

*I guess there’s a lot of the stigma out there that’s the same. A lot of people feel that mental illness, in general, is, um, I guess something that’s wrong with the person—that they’re in control of it and they should just be able to—you know,*
like depression and stuff like that, that, you know, they should just be able to snap out of it. (Participant: Jade).

The last excerpt highlights the link between a lack of control and living with AN. The irony is that these women felt in control of the anorexia, which gives them a sense of mastery and power—a ‘euphoric feeling’ over their illness. However, the illness consumes them and, as a result, they lose control of managing the illness. An example of this paradox is shown in the following quote:

_But originally the eating disorder has its origins in a form of control ... So, that sense of choice, that sense of control that becomes so important with an eating disorder is suddenly not gradually taken from you; it is ripped out of you. One feels so compelled._ (Participant: Sue)

Social stigma was also related to a feeling of a sense of loneliness and isolation. Several participants discussed how their illness prevented them from engaging in normal activities with friends and family and therefore denied them a decent quality of life:

_Well—it consumed me. I couldn’t participate or do anything, I never had friends, I didn’t go out and socialise, it was just—yeah, it was just the eating disorder all day._ (Participant: Amy)

_I don’t interact with many. I lived in my bedroom for years. I barely leave the house._ (Participant: Mary)

_I might be invited to go out with friends for a night and that would involve me being allowed to have fun and have a good time ... my unhealthy mind would counteract and say that I don’t deserve to go out. I don’t deserve to have fun. I don’t deserve to be happy, basically._ (Participant: Jade)

_Even if I went to a café, I could order a coffee, but I couldn’t eat food. At its worst, I couldn’t even look at food. So here you’re facing every single one of your fears and you don’t have a choice at all ... It takes your entire life from you. It takes your family from you if they don’t understand. It isolates you to the point where you would prefer death._ (Participant: Sue).

To reduce their feeling of isolation and their inability to function, several patients reported instances of suicide attempts and SIBs as a means to maintain a sense of control. Again, the core theme of ‘lack of control’ was intrinsically linked to the patients’ stories about the debilitating nature of living with SE-AN. I was taken aback by their candid descriptions of
suicide. It seemed to me that there was a collapsed sense of ‘hope’ of ever recovering from this insidious disease. The theme of suicide is illustrated by the following statements.

*I’m at the point now where I think I’m ready to die and I just hope that that happens ... and I took some pills and I use laxatives quite severely sometimes. (Participant: Mary)*

*You may not be suicidal in that sense, but you might choose, as I did, to allow the illness to starve you to death. I really believed that that’s what I wanted ... in many ways, it is a form of suicide [She later clarified the term ‘suicide’ in the context of living with SE-AN]. Because you’re starving to death ... so in a sense, it’s not suicide where you actively go out and find a way to kill yourself, but it’s the same result. (Participant: Sue)*

All participants reported significant losses throughout their life, including miscarriages and lost partners, and some conveyed subtle messages about child abuse; however, these claims could not be substantiated for fear of causing further psychological harm and discomfort during the interview. These experiences had a profound effect on the participants’ capacity to cope with life; indeed, it may have prolonged the course of their illness. As Mary explained:

*Things went downhill when my marriage broke down ... my husband basically left me with five very small children and like—I lost a lot of weight in two weeks ... it’s been nine years since my husband left and I’m still not over that and I just don’t think I ever will be.*

*I lost a baby to foetal hydroxy ... and then I miscarried one at eight and a half weeks. (Participant: Amy)*

*It came out in full force during a very, very difficult period of upheaval in my life; ... loss of jobs, loss of a partner, uh, I don’t mind disclosing this. I ... I had, had a, quite an advanced miscarriage ... some difficulties happened and my way of controlling and coping was to go straight back into my eating disorder behaviours. (Participant: Sue)*

*My brother is—has been like an on and off drug addict for quite—well, a long, long—pretty much most of my life. (Participant: Jo)*

As a result of the chronicity of the illness, a number of participants experienced symptoms of depression and anxiety (albeit not all were formally diagnosed) in the context of bereavement, and they found it difficult to function on a day-to-day basis in terms of self-care (e.g., bathing and eating), parenting and maintaining employment and educational pursuits.
Further, they struggled to reach specific milestones in their life, such as completing high school:

*I couldn’t physically do much, so I had to kind of rely on Mum mostly to do a lot of stuff for me, which ... was really hard ... Dad was good ... even having to help me get dressed at times and things like that ... I could hardly walk. I couldn’t dress. I couldn’t dry myself with towels, because they were too heavy.*

*(Participant: Jo)*

*Like self-care aspects that can be like, you know, want to moisturise or something like that, you know, just part of everyone’s general routines. It gets to a point where I just—I can’t do it, because I just don’t feel that I’m worthy enough.*

*(Participant: Jade)*

### 8.7 Finding 4: Healthcare Services

A central theme that emerged from the data was that all participants, including those in the focus groups, supported a person-centred approach in the delivery of healthcare.

#### 8.7.1 Superordinate Theme: Healthcare Services

This subordinate theme comprises two subthemes: limited trained staff and accessing services. These are interlinked with other themes, as shown in Figure 8.4. This subordinate theme emerged when participants were asked about their personal experiences with mental healthcare services. It captures the women’s unique perceptions and insights into the treatment they received, as well as the barriers that impede the delivery of healthcare services to women with SE-AN. Figure 8.4 illustrates the clinical pathways in which patients enter into the healthcare system by means of hospital admission.
The interview data confirmed that all participants had suffered significant medical problems as a result of the chronicity of their illness and therefore had experienced multiple hospital admissions in different healthcare settings and at different geographical locations in Melbourne, Australia. These included general hospital wards (both private and public), ICU and specific eating disorder clinics. Given their wide range of knowledge and experience, the women offered valuable insights into patients’ experiences of the medical healthcare system.

One of the major barriers in seeking medical care for an eating disorder is the lack of specialised eating disorder clinics (SEDCs). All participants reported difficulty in accessing specialised care for the following reasons: there were no existing services in their local area, they lived outside the hospital’s designated catchment area and they were placed on a waiting list because there were no available beds. Two participants lived in rural areas where there were no SEDCs, so they were forced to travel to Melbourne. When there were no services
available, patients were placed in a general medical ward where nursing staff had little or no specialised training in eating disorders. If they were in a critical state and required emergency care, they were placed in ICU to be monitored and kept alive.

Jo, a patient with nine years’ experience in the mental health system, described her experience and highlighted the serious deficiencies in the mental health system:

*I think that’s what’s wrong sometimes in the system, is that one person is treated the same as everyone. So one eating disorder is an eating disorder. I don’t think you can treat one person the same as everyone else ... different types of treatment work for different [types of] people and I don’t think eating disorders should be piled into one basket ... one treatment for all eating disorders ... just another number, just another eating disorder. (Participant: Jo)*

This powerful statement reflects the level of and access to quality of care that is being delivered to patients with SE-AN. Sue summed up her experience by stating that: ‘The underpinning attitude is that we are a waste of a good hospital bed’. The issues described above are validated by the participants’ experiences and connect to the core theme of a lack of control, whereby patients have limited treatment options but have clearly indicated that they want help and support for their illness:

*Lack of um resources ... in our country, you know, in a hospital that doesn’t have a specialised eating disorder unit ... I have been a few times [hospitals] now but usually they just send me to the psych ward in [...] ... they don’t have any clue and they don’t seem to want to care ... they don’t have the staff trained for you know, they don’t know how to deal with eating disorders. (Participant: Mary)*

*Normal hospitals don’t really want you because they [find out that you have an] eating disorder ... and it’s really hard to treat eating disorders, but you’re actually really medically unwell. But you might be too medically unwell to go to a clinic. (Participant: Jo)*

*Just not enough facilities ... I come from [deleted location] and there’s nothing locally for me ... they’re very limited on eating disorder units anyway ... you can only go wherever your jurisdiction is. (Participant: Amy).*

The hospital staff also recognised that there is a shortage of trained staff and specialised care for patients with SE-AN. Some clinicians acknowledged that they have had limited training and were not confident in the delivery of their knowledge and skills to support these patients. During the interviews, many participants revealed that they relied on
the expertise of the senior staff to guide them through the day-to-day operations of the hospital ward and the care of patients. The following statements support this finding:

What is appropriate for these patients, because it’s quite different to all of the other types of people that I’ve dealt with in the past. So, it’s sort of a bit of trial and error and ... you sort of look upon your more senior staff or more experienced staff to see ... a bit of reaffirming that what I’m saying might actually be okay because sometimes I feel like there’s actually a bit of doubt about, you know ... am I being appropriate with these patients? (Participant: Mandy, intern doctor; focus group 2)

I did the CEED (Center of Excellence in Eating Disorders) online training. That was sort of a starting point for me but other than that it’s like I said, more sort of on the job. I’ve got a background in—like in acute psychiatry ... so, that’s how I came to this role. I don’t only work in eating disorders. And yeah, this is so different ... to the general acute psych of course. I just, you know, on my sort of [own]—I just, um, directed by me when I did some extra training. (Participant: Tracy, general nurse, focus group 2)

And then observe—learning through observation I think is the most important as well. (Participant: Mandy, intern doctor, focus group 2)

Participants in both focus groups discussed their lack of control in terms of the limited resources available to patients with eating disorders. A question that was raised to the groups was: What, if anything, would you change about the provision of care for people experiencing anorexia? The responses to this question resulted in a ‘wish list’ that included a ‘wound nurse’, an ‘exercise person’, an ‘inpatient and outpatient setting in the one building’, a ‘physiotherapist’, a ‘peer support worker with lived experience’ and ‘pet therapy’. This wish list reflects the clinicians’ level of understanding of the needs of people with SE-AN, but it also highlights the deficiencies in clinical care.

The patients reported mixed feelings about their treatment. The issue of forced treatment was frequently discussed by participants, either in the context of their current or previous hospital admissions. Some were appreciative of the care and recognised the necessity, but others perceived the treatment to be coercive and unsatisfactory. A common theme in the participants’ narrative was that they felt a sense of a lack of control over their treatment.
Several participants described feeling a sense of powerlessness and of being controlled by the hospital staff regarding their treatment. Specifically, being locked up in a contained environment with supervised meal plans was confronting and challenging for most patients. Two participants felt that their freedoms were taken from them, thereby undermining their autonomy. As Sue explained, ‘The lack of freedom, the lack of independence, the loss of something as simple as your right to get up and walk’. Amy firmly stated, ‘I don’t like the locked ward, I don’t like the lack of freedom’. Mary stated that she had been threatened with involuntary status (which was later enforced) if she did not comply with the treatment program. She discussed her experience: ‘it’s always these constant threats like—so I sort of, they lifted the order but really I—I had no choice, if I said I wouldn’t stay they weren’t going to’. One clinician recognised the restrictive nature of the program, stating that ‘I do feel like most of them find it containing I think when they can’t leave and they need to remain on the ward’ (Participant: Dianna, registered psychiatric nurse, focus group 2).

Several participants spoke about their experience with nasogastric tubing, which is an inpatient hospital practice that compulsory refeeds (liquid food such as Ensure) underweight patients using a tube. The participants described the practice as ‘distressing’ and ‘traumatic’ and explicitly did not want to be tube-fed. Sue said that gastro tubing looks ‘like absolute instruments of torture’. The act of inserting the tube was described as ‘painful’ and was a source of discomfort that caused ‘constant irritation’ to the throat. One participant pleaded with her psychologist to be fed orally rather than tube-fed. However, her request was denied, and she was threatened with the Mental Health Act if she did not comply. This contributed to the women feeling a lack of control over their body and treatment. They agreed that they preferred to be orally fed instead of tube-fed, and this preference was expressed as part of their advance care planning. Overall, the idea of being force-fed increased the patients’
vulnerability to adverse psychological distress and contributed to a heightened sense of mistrust of mental health professionals.

For example, Sue stated that she was forced to ‘drink liquid through a straw’, whereas Jade described being forced (without her consent) to ‘take sleeping medication’, and Mary was forced to take an injection: ‘They basically held me down and gave me the injection’.

Amy offered her point of view:

*People don’t like the control being taken off them. Like, nobody likes to be told what they have to do, nobody likes to ask permission, nobody likes—yeah, when all control is taken away from you, but then they say oh it’s because you’ve done this to yourself, you’re not mentally stable, we have to do this to keep you alive ... If they [patients] don’t have the freedom, you know, and their rights [not] met, you know, it’s not going to—I don’t think it’s going to assist them to get better. I’ve been forced to get better. You know, forced to re-gain weight when I was 16 and 17, it didn’t help. I got out and did the same thing. Played the game while I was in there. So I was one of the smart one—too smart for my own good. Got in there, played the game, did what I had to do, put on the weight, got out. Got back home, did the same thing, ended up back in there. (Participant: Amy)*

The last statement illustrates the chronicity of the illness and supports Dresser’s (1984b) comments about forced treatment: ‘they will manipulate others and “eat their way out” of the hospital’ (p. 321):

*And that’s extremely distressing to someone with an eating disorder. Um, of course, we all want to get better and we have those intentions. But I personally feel like, if you’re [going] to put someone’s fear in their face every single day, but heighten it and heighten it and heighten it and to a point where it’s unmanageable just because you want an admission to be quicker. (Participant: Jo)*

*I think forcing people into hospital settings when they’re not ready can probably be quite traumatic for a lot of people. And I guess it’s probably going to make them quite reluctant to seek out help in the future. (Participant: Jade)*

*It was traumatising. I think it’s been unnecessary [forced hospitalisation] when you agreed. There have been times where I’ve said that I will go but they’ve still made me involuntary. (Participant: Sue)*

*The very first time that I had an involuntary admission I remember I took some laxatives on the ward and started vomiting—it doesn’t usually make me throw up but occasionally it does. The nurse said I had to have an injection for nausea, and I was like well it—it’ll go, you know, I didn’t want the injection and she said you’re involuntary and they basically held me down and gave me the injection—Not with my consent. (Participant: Mary)*
These views were corroborated by the focus group participants, who considered involuntary treatment a necessary measure to ensure the safety of the patients, but recognised that forced treatment can be distressing and traumatising for patients. Interestingly, the focus groups made the distinction between ‘therapeutic’ (more emphasis on psychological care) and ‘rescue’ (weight restoration) hospital admissions. These distinctions determined the type of care that was offered to these patients:

*I think the team has had to make very difficult decisions at times where the distress associated with enforced care wasn’t worth the possible um benefited. And so those decisions do have to be considered because as we know medical rescue isn’t the cure for anorexia nervosa. I think sometimes it can be therapeutic. I think sometimes when patients are deeply ambivalent and distressed and when—and if you can talk it through to them in a way where it’s clear to them that it’s out of care, it can be therapeutic. And they understand that there’s a boundary or containment where you let them be at risk only so much.* (Participant: Emma, psychiatrist registrar, focus group 1)

*So we usually think about the imminence of risk and so we have discharged really unwell patients. A timeframe we would consider would be something like three or four days in terms of the imminence of risk. Um in understanding that, even if we were to put them under the Mental Health Act or a duty of care depending on how they’re presenting, and re-resuscitating then when they walk out the door that’s probably going to continue.* (Participant: Peta, social worker, focus group 1)

In this study, most participants described positive therapeutic relationship experiences when working with the multidisciplinary team. They recognised the professional expertise of the staff and described how they valued being able to talk to the staff and being respected and cared for. This finding was mostly attributed to the person-centred approach adopted by the hospital staff. The participants reported that having a positive relationship with the staff played an important role in their recovery:

*The nurses are lovely ... been really nice. Really supportive ... very approachable. The clinicians, as well, like I don’t know—they’ve each got their certain roles and everything like that, and I think in terms of meeting your needs, you probably rely on certain ones for certain things at different stages and everything like that.* (Participant: Jade)

*As a team, even though at times, you know, you feel challenged; you feel like you’re being pushed too far ... they are quite supportive. And there are quite a lot of different professions, you know, like OTs and social workers.* (Participant: Jo)
There’s staff that understands and that will talk to me and you know, acknowledge what I’m going through and not just say we don’t know anything about, you know. I’ve found the nursing staff here the majority of them really, really good. (Participant: Mary)

Like they tend to focus on, you know, meeting specific goals that you set for yourself, and so it’s a lot more you-driven … [there is] less resistance, less anxiety around the whole situation in general, and you’re probably more likely to seek out help … if you feel like you’re being a little bit more empowered. (Participant: Jade)

To validate the previous theme, the focus groups spoke about the importance of developing a collaborative relationship with patients and their families—a key feature of the hospital’s program. Generally, this was achieved by adopting a person-centred approach to the treatment of people with SE-AN, as well as being inclusive by allowing their families or significant others to participate in their loved one’s care:

So families often come up in psychotherapy and that’s a good avenue for me to introduce them to do some family work. So [deleted name] will run the family meeting here … which are with the consultant, the [psych-reg and the associate nurse unit manager], just to meet the significant other who the patient lives with or who is in their life or some with their families. So we try and bring them in with the patient’s consent. (Participant: Jane, clinical psychologist, focus group 1)

We know that weight restoration alone is not an adequate treatment for um anorexia nervosa. It is inherently a psychological disorder it’s—you know about all the cognitions around food and weight and appearance and that takes a lot of time to address. And if someone is not really—not ready to be open to that in one admission not to push that person too much, just to have a really patient-centred approach, person-centred approach, to where they’re at and meeting their needs at that time and gradually over admissions perhaps building on that. (Participant: Cindy, general nurse, focus group 2)

My own observations, based on the focus group interviews, was that these clinicians conveyed a strong sense of pride in their work in the care of their patients. I also sensed a spirit of comradeship between these health professionals; that is, each had their individual roles and expertise but worked in collaboration to achieve good clinical outcomes:

Like we have psychologists, we have who can do lots of like sensory profiling and things like that with our patients. We have a really good interdisciplinary team. We have the psych reg and, um, a psychiatrist consultant and all those things. Um, and I think that it is kind of a good way to focus on both sides of the illness. (Participant: Tracy, registered psychiatric nurse, focus group 2)
8.8 Summary of Findings

A major finding of this study is that patients living with SE-AN feel that they lack control over their illness. In the qualitative analysis, a number of contextual factors (conditions) were identified that limited women’s opportunities for control regarding their healthcare. This resulted in the women experiencing coercion (consequences) in the following domains: decision-making (e.g., PADs, treatment options, input into or influence over decisions, and competency), choice of treatment services (e.g., patient’s choice of, access to and availability of SEDCs) and the debilitating effects of the illness (e.g., function, social stigma, physical and social). These factors have led to deterioration in the quality of life of these women and may explain the protracted nature of the illness.

For women to reclaim control of ‘self’ over their illness, they must have access to adequate treatment services and be given the opportunity to have a voice in the decision-making process regarding their medical care. This might help to mitigate the iatrogenic effects of coercion and thereby increase the women’s sense of ‘autonomy and choice’ regarding their healthcare. They would then feel more valued and respected in the decision-making process and would be more in control of an otherwise intractable illness.
Chapter 9: Discussion

9.1 Introduction

The focus of this chapter is the interpretation and discussion of the findings of the current study with reference to the extant literature. Common or discrepant findings will be highlighted alongside their significance to the present phenomenon. The results, which are highlighted in Figure 9.1 below, show the processes and conditions of interactions (micro and macro conditions and consequences) between people with SE-AN and health clinicians (Annells, 1996; Charmaz, 2000; Corbin & Strauss, 2014; Creswell, 1998; Strauss & Corbin, 1998). It confirms that there is more than one structural factor to explain the phenomenon of SE-AN. More specifically, it highlights the social relations of power and control that have shaped these relationships (Kushner & Morrow, 2003). To better understand this process, the following analytical categories provide a theoretical framework to link this knowledge and highlight this social process (Bloomberg & Volpe, 2015; Corbin & Strauss, 2014; Holloway, 2005a). There might have been other conditions and consequences that were not identified in the analysis. This chapter concludes with a summary of the clinical implications, recommendations, research limitations and future research directions.

Figure 9.1. Conditional matrix: lack of control.
9.2 Process of Interpreting Qualitative Research

The interpretation and synthesis of qualitative research data is a complex process, and there are no ‘hard-and-fast rules’ (Bloomberg & Volpe, 2008 p. 132) to guide the novice researcher, and ‘there is no single correct’ way to interpret the data (Janesick, 2003, p. 70). This is mainly because data are unique—that is, different data have different meanings and therefore cannot be extrapolated into a set formula to understand their meaning (Berglund, 2001; Denzin & Lincoln, 1998a; Spiggle, 1994; Wolcott, 2009). However, Patton (2015c) believed that interpretation:

> involves going beyond the descriptive data. Interpretation means attaching significance to what was found, making sense of the findings, offering explanations, drawing conclusions, extrapolating lessons, making inferences, considering meanings, and otherwise imposing order on an unruly but surely patterned world. (p. 570)

A further consideration regarding this statement is the need to identify contradictions in participants’ statements—that is, their statements may directly contradict their behaviours. Overall, this quote will provide a general framework for the interpretation of the analysis.

To facilitate this process, Bloomberg and Volpe (2015) developed a set of questions to assist with interpretation and to guide the author’s theoretical thinking. These include: What is really going on here? What is the story these findings tell? Why is it important? What can be learned here? (p. 178). These open-ended questions will help the researcher to draw inferences and conclusions about the data.

The evaluation of the data was performed based on data abstraction—that is, searching for explicit and implicit (hidden) meanings (words and actions of participants) within the data and thereby identifying categories that exert more influence (or information) than others about the social phenomenon (Corbin & Strauss, 2014; Creswell, 1998). In fact, Charmaz (2006) strongly encouraged researchers to use ‘categories as tools to build context’ (p. 161), which can serve as building blocks to explain their findings and interpretations. O’Donoghue (2006)
added that categories can provide the researcher with the language to speak about the phenomenon to illustrate the different meanings found in different contexts. The following major analytic categories were represented in the findings section and were considered the most relevant in understanding the phenomenon of SE-AN (Bloomberg & Volpe, 2008).

Consistent with a GT constructivist approach, it is important to acknowledge that the following interpretations should not be considered claims of ‘truth’ about the phenomenon, but are based on the author’s ‘impressions’, ‘speculations’ and ‘constructions’ of the data and the findings (Barker & Pistrang, 2015; Bloomberg & Volpe, 2008; Charmaz, 2006; Corbin & Strauss, 2014; Denzin & Lincoln, 2008; Thorne, 2008).

This suggests that the researcher is responsible and accountable for providing interpretations that are representative of the realities of the participants, espousing the moral value of ‘veracity’ (Brinkmann, 2017; Henwood & Pidgeon, 1995; Holloway, 2008; Morrow, 2005). Ethically, this can be considered problematic, but it can be achieved by applying Lincoln and Guba’s (1985) principles of trustworthiness (see Section 7.8) (Holloway, 2005b; Riley, 1996).

9.3 Summary of Findings

The core category of ‘lack of control’ explains the main findings of this study and was interlinked with a number of superordinate and subordinate themes that emerged from the analysis, including decision-making, therapeutic relationship, recovery, voluntary care, social stigma and PADs. It is important to note that not all subthemes were discussed, but only those that had more explanatory power to describe the phenomenon of SE-AN. Indeed, some subthemes overlapped and were briefly incorporated into the interpretation of the results. Similarly, different findings had different meanings to different participants; accordingly, they were recorded in their respective subthemes. The aim of this analysis was to explain how a model emerged from the results.
9.4 Category 1: Reclaiming the Self

9.4.1 Subtheme: voluntary care—‘a different frame of mind’

The results of this study support the view that patients with SE-AN want to engage on a voluntary basis in treatment services that are effective and reflective of their needs. This finding is consistent with the current literature and supports the hypothesis that individuals are amenable to coercion when it is delivered in a non-punitive manner (Ayton et al., 2009; Dawson et al., 2014; Tan et al., 2003a; Tan et al., 2010).

Although the patients did not like being forced to do something against their will, they all acknowledged the fact that hospitalisation was necessary to keep them alive. In fact, all participants had multiple hospital admissions—in one case, up to 20 admissions. These data suggest that the women, with the exception of Mary, want to recover from their illness and have a better quality of life (without the illness dominating their life), but they require regular access to psychiatric services. Tierney (2008) found a similar association with young people diagnosed with AN, with all but one acknowledging that treatment was helpful and necessary to ensure their survival. Another study reported that one participant ‘wanted and needed coercion’ before any change occurred relating to her eating disorder (Tan et al., 2003a, p. 703).

In this study, four participants were initially apprehensive about their treatment but came to realise that certain hospital restrictions are necessary to contain their eating disorder behaviours. This finding also corresponds with the ‘thank you’ theory, which postulates that patients may initially be resistant to the idea of hospital care but retrospectively consent to treatment (Griffiths et al., 1997; Guarda et al., 2007; Katsakou & Priebe, 2007; Manley et al., 2001; Tan, Hope, Stewart et al., 2003; Tan et al., 2006). In the present study, four participants were initially apprehensive about their treatment but came to realise that certain hospital restrictions were necessary to contain their eating disorder behaviours. This result could
suggest that the patients struggled to give up their perceived sense of control when deciding the need for a voluntary hospital admission. This theory is supported by Westwood and Kendal (2012), who conducted a literature review of adolescents with AN about their views regarding treatment.

The majority of participants were voluntary patients throughout the course of their hospital stays, were proactive rather than reactive in their treatment and, more importantly, wanted to recover. Therefore, this finding contradicts that of the literature, which finds that patients with a chronic duration of illness are perceived to be ‘treatment-resistant’ with little chance of recovery (Goldner, 1989; Goldner et al., 1997; Griffiths & Russell, 2000; Hay et al., 2012; Strober, 2004; Strober, 2010; Theander, 1992; Yager, 1992). The results of the current study suggest otherwise. This line of thinking is consistent with the literature, whereby patients are requesting voluntary admission to assist with their recovery or to shorten their hospital admission (Beumont & Vandereycken, 1998; Russell et al., 2019).

An explanation for this new trend could be the ‘maturity of experience’ of living with the illness for a long time. As Dawson et al. (2014) explained, people with a longstanding illness reach a ‘tipping point’ whereby they are simply fed up with living with anorexia and want to recover. This agrees with the results of this study, in which most patients had reached their tipping point—or in this case, ‘a different frame of mind’—and requested voluntary hospital admission to support their recovery.

In summary, the findings of this study add to the existing research that shows that the patient’s attitude and motivation (self-determination) towards recovery are important prognostic factors (Fassino & Abbate-Daga, 2013; Nordbø et al., 2006; Nordbø et al., 2012; Redenbach & Lawler, 2003; Scholtz et al., 2010). Four patients out of five had a ‘different frame of mind’ towards recovery and were motivated to improve their quality of life by ‘collaborating’ with eating disorder services on a voluntary basis.
9.4.2 Subtheme: recovery—‘up and down, up and down process’

‘Recovery’ was an important subtheme in the interviews, in which all participants, including clinicians, talked about their experiences in the context of wanting recovery for people with SE-AN.

The results of this study provide evidence to support the theory that negative stressful life events (grief and loss) could be perpetuating factors in sustaining a person’s illness (APA, 2013; Mitchison & Hay, 2014; Nevonen & Broberg, 2000). In this study, all of the women struggled to maintain a degree of recovery post-hospital discharge. They had all experienced periods of remission but remained at risk of having further relapses. A contributing factor was that they had endured significant setbacks in their lives, in some cases experiencing multiple losses. When these setbacks occurred, they reverted to anorexia behaviours and engaged in dietary restrictions, which provided them with a sense of control and perhaps a sense of normalcy. These setbacks were related to the loss of a significant other. Mary lost her husband, Jade lost her ‘sense of self’, Amy lost her baby, Sue had a miscarriage and Jo’s relationship with her brother was tainted by a drug addiction. Similar findings were reported in the literature (Stockford et al., 2018). Although there is little empirical data in the AN literature to support this supposition, it nonetheless provides some scope in understanding the mechanism related to the illness.

An important finding of this research was that all women identified that having a positive therapeutic relationship with their doctors and nurses assisted with their recovery (see Section 8.5). In particular, being understood, heard, valued and acknowledged made a positive difference to their overall care and helped with subsequent voluntary hospital admissions. This theory has been supported by previous studies, which have shown that building rapport with patients can facilitate their prognosis and recovery (Cockell et al., 2004;
Dawson et al., 2014; Espindola & Blay, 2013; Federici & Kaplan, 2008; Ramjan, 2004;
Ramjan & Fogarty, 2019; Russell, 2004; Spinelli, 1994; Turton et al., 2011).

A critical finding of this study was that four of the participants were ready and
motivated to recover from their illness because they wanted a better quality of life. This
finding supports previous research demonstrating that a person’s ‘motivation’ and ‘readiness’
are important positive prognostic factors in recovery (Ayton et al., 2009; Colton & Pistrang,
2004; Darcy et al., 2010; Dawson et al., 2014; Dresser, 1984c; Espindola & Blay, 2013;
Fassino & Abbate-Daga, 2013; Federici & Kaplan, 2008; Guarda, 2008; Hannon et al., 2017;
Hsu et al., 1992; Maine, 1985; Marzola et al., 2019; Serfaty & McCluskey, 1998; Stockford,
2014; Vitousek et al., 1998; Westwood & Kendal, 2012).

Similar to previous studies, recovery was defined by having periods of relapses and
remission, and with no set period for recovery (Bardone-Cone et al., 2010; Couturier & Lock,
2006; Dawson et al., 2014; Dresser, 1984b; Higbed & Fox, 2010; Marzola & Abbate-Daga,
2019). Jade defined recovery as an ‘undercurrent’ and an ‘up and down, up and down
process’, suggesting that recovery is a long, drawn-out process that can affect the patient’s
quality of life. This is in contrast to patients with a shorter duration of illness, whereby
recovery rates are higher (Agras et al., 2004; Geller et al., 2012).

Previous studies have drawn a similar conclusion and shown that recovery from SE-
AN can be long-lasting, characterised by periods of remission and relapses, and can cause
long-term social, physical and psychological sequelae (Bamford et al., 2015; Maine, 1985;
Noordenbos et al., 2002; RANZCP, 2014; Scolan et al., 2013; Stockford et al., 2018; Walsh,
2013). These data confirm and support the current definition of SE-AN (see Section 2.5), in
which all participants were characterised as having periods of ‘persistent illness with possible
periods of remission’ (Lacey & Sly, 2016, p. 203).
These findings suggest that clinicians should consider the type of treatment being offered to SE-AN patients, taking into account the fact that people with SE-AN have different recovery rates and times compared with people with a short or mild form of AN. Not only does this affect their quality of life, but in some cases, treatment regimens could be the only means of allowing people to regain control of an otherwise intractable illness.

9.5 Category 2: Autonomy and Choice

This subsection describes the results of this study in relation to the notion that being excluded from the decision-making process can cause irreparable damage to the therapeutic alliance and increase the patient’s sense of coercion.

9.5.1 Subtheme: decision-making—‘was taken somehow out of your hands’

A major finding of this study was that decision-making was a central theme in participants’ descriptions regarding their care and was linked to the concept of control and the ethical principle of autonomy.

All participants described instances in which they felt excluded from the decision-making process regarding their medical care and believed that their rights had been violated—particularly their autonomy. As a result, the participants reported mixed feelings towards their healthcare providers, felt a lack of control over their illness and were ambivalent about their general care. These negative feelings were more pronounced when they felt coerced (excluded from the decision-making process), but less so when they were actively involved in their medical care. However, in most instances, they would acquiesce to the doctor’s authority despite feeling undervalued and disempowered in the decision-making process (see Section 8.5).

These findings were consistent with the literature review (see Section 5.1.3). A number of authors—particularly civil libertarians—have espoused the theory that the patient’s sense of being coerced increases when their rights and autonomy have been violated. This in
turn causes irreparable damage to the therapeutic relationship, produces poor treatment outcomes and, in some cases, increases the chronicity of the illness (Dresser, 1984b; Katsakou & Priebe, 2007; Lewis, 1999; Matussek & Wright, 2010; Olofsson & Jacobsson, 2001; Schreyer et al., 2016; Selvini-Palazzoli, 1978; Serfaty & McCluskey, 1998; Vandereycken & Beumont, 1998c; Watson et al., 2000; Werth Jr et al., 2003).

Overwhelmingly, the participants in this study wanted to be part of the decision-making process as collaborators rather than acquiescing to their doctor’s wishes. They wanted to decide their own best interests in terms of their care, and not be dictated to by standard hospital protocols. That is, they wanted their autonomy and self-determination to be valued and respected, particularly when they are competent to engage in treatment services.

A number of studies have confirmed this hypothesis and demonstrated that people with AN want to be part of the decision-making process and not be excluded (Darcy et al., 2010; Escobar-Koch et al., 2010; Katsakou & Priebe, 2007; Noble & Douglas, 2004; Ramjan & Fogarty, 2019). Research has shown that engaging patients in the decision-making process can optimise health outcomes, empower them to take responsibility for managing their illness and, more importantly, give control back to the patient (see Section 5.1.6). An example of this is found in the literature on ADs (see Section 4.3), whereby people wanted more control over their healthcare, particularly during periods of incompetency (Atkinson et al., 2003; Davidson & Birmingham, 2003; La Fond & Srebnik, 2002; Ritchie et al., 1998; Swanson et al., 2000).

In contrast to this finding, clinicians were resistant to the idea of involving patients in the provision of care, particularly if there was evidence of incompetency. This decision-making was determined by their duty of care to protect the safety and wellbeing of their patients. However, there were mixed findings in the literature regarding clinicians’ views on decision-making. Some research has shown that decision-making should only be made by health professionals, particularly when the patient is incompetent to provide informed consent.
(Beauchamp & Childress, 2001; Beumont & Vandereycken, 1998; Brock, 1993; Dworkin, 1993; Goldner et al., 1997; Johnstone, 2009; Kitchener, 1984; Tan et al., 2008; Vandereycken, 1998; Widdershoven & Berghmans, 2001).

Others are respectful of a patient’s decision to refuse treatment, even when the decision may seem risky or to the detriment of the patient (Austin, 2008; Bersoff & Koepppl, 1993; Draper, 2000; Giordano, 2003; Johnstone, 2009; Jonsen et al., 1999a; Kitchener, 1984; Oshana, 1998; Roberts & Dyer, 2007; Van Deurzen & Adams, 2010; Vogelstein, 2016; Winick, 1996). This finding was compatible with previous research, which reports that these differences can be attributed to their ethical position—respect a person’s autonomy or support the principle of beneficence (Boddy et al., 2013; Gravel et al., 2006; Jezewski et al., 2003; Sellars et al., 2016; Shields et al., 2014; Van Dorn et al., 2010; Varekamp, 2004).

Another possibility could be related to the power dynamic of the patient–doctor relationship. Perhaps clinicians are not prepared to give up their power and control in the management of their patients. Another hypothesis that was confirmed by this study is related to the inherent belief that the ‘doctor knows best’, which precludes the patient from contributing to the decision-making process—a finding that has been reported elsewhere (see Section 4.2). Both of these possibilities conflict with the concept of ‘participatory medicine’ (Shields et al., 2014; Widdershoven & Berghmans, 2001) and contravene the ethical principles of justice and beneficence (see Sections 3.2.1 and 3.2.2).

These findings have relevance in terms of clinical practice. It can be concluded that involving patients in the decision-making process by making them part of the collaborative alliance reduces treatment refusal, increases treatment adherence and improves recovery rates and the overall quality of the therapeutic relationship.

These outcomes ‘fit’ within the superordinate theme of ‘autonomy and choice’, wherein people want more choice and a collaborative approach in managing their illness. This
conclusion corresponds with the aim of this study (see Section 1.8), whereby clinicians are encouraged to think ‘ethically’ and explore the ethical dimensions of decision-making processes and evaluative aspects when caring for women with SE-AN.

9.5.2 Subtheme: therapeutic relationship—‘definitely building rapport’

The ‘therapeutic alliance’ subtheme emerged from the data based on the participants’ descriptions of their relationships with their clinicians, and it was linked to the superordinate theme ‘collaborative care’.

A major finding of this study, and indeed a consistent finding in the professional literature on anorexia, is that consumers positively respond to a person-centred model of care when they feel cared for and respected by staff. Participants’ descriptions of staff included the following terms: ‘approachable’, ‘supportive’, ‘empowered’ and ‘acknowledged’, and these were reflective of their experiences of their hospital care. This supports the assertion that a therapeutic alliance is an ‘important prerequisite’ to assist patients to recover from their illness, and it is consistent with the literature review (Lemma-Wright, 1994; Maine, 1985; Ramjan, 2004; Ramjan & Fogarty, 2019).

Despite the fact that all participants had experienced acts of coercion (through current or past hospital admissions), they still considered the therapeutic relationship a vital means of support, particularly with regard to their recovery. Three of the interviewees—Jo, Mary and Jade—spoke about the importance of having a positive therapeutic alliance (see Section 8.5). Generally, they appreciated the idea that clinicians were available to talk to, they felt validated when listened to and understood, and they valued the collaborative nature of the patient–doctor relationship.

This result refutes the idea that involuntary care can cause irreparable damage to the therapeutic alliance—a theory that has been postulated by civil libertarians (Dresser, 1984b; Lewis, 1999; Maher & Rosedale, 1993; Matussek & Wright, 2010; Richmond, 2001; Schreyer
et al., 2016; Selvini-Palazzoli, 1978; Serfaty & McCluskey, 1998; Sjöstrand et al., 2015; Watson et al., 2000; Werth Jr et al., 2003).

Rather, the result in this study is in line with the cumulative research that supports the notion that involuntary care does not cause irreparable damage to the therapeutic relationship (Ayton et al., 2009; Carney et al., 2007; Elzakkers et al., 2014; Griffiths et al., 1997; Ramsay et al., 1999; Rathner, 1998; Russell, 2001; Tiller et al., 1993; Werth Jr et al., 2003). Further, it is consistent with the literature that highlights the importance of establishing a strong therapeutic relationship and its positive outcomes in reducing iatrogenic factors associated with inpatient care (Berg et al., 2017; Boughtwood & Halse, 2010; Bruch, 1979; Button & Warren, 2001; Draper, 2003; Federici & Kaplan, 2008; Finelli, 2001; Fox & Diab, 2015; Holm et al., 2012; Madder, 1997; Manley et al., 2001; Matusek & Wright, 2010; O’Brien & Golding, 2003; Sjöstrand & Helgesson, 2008; Tan, Hope, Stewart et al., 2003; Vandereycken & Vansteenkiste, 2009).

In this study, clinicians had mixed views regarding the use of coercion in the treatment of SE-AN patients, but they all agreed that the therapeutic relationship plays an integral role in facilitating a person’s treatment and recovery. The clinicians stated that ‘building rapport’ and ‘being available’ are essential factors in forming trusting relationships, not only with patients, but also with their families (see Section 8.5).

However, the clinicians admitted that the therapeutic relationship could be compromised, particularly in circumstances where forced treatment is administered—a finding that has been reported elsewhere (see Section 5.1.2). This supports the theory that repeated hospital admissions are associated with the development of a poor therapeutic alliance (Button & Warren, 2001; Colton & Pistrang, 2004; Fleming & Szmukler, 1992; Fox & Diab, 2015; Hay & Cho, 2013; Ramjan, 2004; Ramjan & Fogarty, 2019; Tierney, 2008).
The findings reported in this study suggest that adopting a person-centred approach enables clinicians to build rapport and trust with patients and is associated with better patient experiences and satisfaction with hospital treatment. Many patients explained that being supported and acknowledged by staff was important to them and helped them to build trust and respect with the nursing staff. Collectively, these studies demonstrate that building a strong therapeutic alliance and treating patients with respect by including them in the decision-making process (e.g., treatment plans) can reduce the patient’s experience (or perception) of coercion. These findings are comparable with Escobar-Koch et al.’s (2010) study and confirm that people with SE-AN value the importance of a collaborative and client-centred approach to care.

These findings are in line with current clinical practices and guidelines, whereby adopting a person-centred integrated approach to the care of people with SE-AN can increase collaboration between patients and doctors, thereby producing better clinical outcomes (APA, 2006; Geller et al., 2012; Goldner et al., 1997; NEDC, 2010; NICE, 2017; PACFA, 2011; RANZCP, 2014; Strober, 2004; Wonderlich et al., 2012).

9.5.3 Subtheme: psychiatric advance directives—‘I didn’t know this was a thing’

A significant finding of this study was that none of the participants, including the clinicians, had any prior knowledge of PADs. Many responses demonstrated a lack of knowledge about ADs, their relevance and function. This finding is consistent with the literature on ADs (Bogdanoski, 2009; Elbogen, Swanson, Appelbaum et al., 2007; Foti, 2003; McLennan et al., 2015; Srebnik & Fond, 1999) and provides evidence that a ‘lack of knowledge’ remains a barrier in the uptake of ADs for people living with SE-AN.

This discovery is important because it confirms that current methods for overcoming this problem have not been effective (see Section 4.5), thus supporting the development of new methods of information-sharing (Backlar & McFarland, 1998; Perkins, 2000). Further,
this result supports previous research that has shown that health professionals require training in the knowledge of ADs (Boddy et al., 2013; Foti et al., 2005; O’Connell & Stein, 2005; Rhee et al., 2012; Scheyett et al., 2008; Shields et al., 2014).

In the present study, all participants expressed a strong desire to have a PAD and to learn more about them. This suggests that patients want to be more involved in the decision-making process (autonomy) regarding their medical care, and is consistent with previous reports (Bogdanoski, 2009; Collier et al., 2005; Johnstone, 2009; Perkins, 2000; Shields et al., 2014; Srebnik et al., 2003; Swanson et al., 2003; Swanson et al., 2000; Van Dorn et al., 2010; Völlm & Nedopil, 2016). PADs would give them an opportunity to shape and self-direct their treatment care, especially in the event of losing competency or experiencing a relapse. This result supports the argument that people with SMI s have an interest in ADs, and it refutes the assumption that people lack the desire or the ability to formulate an AD.

Overwhelmingly, the participants in this study stated that they would feel a sense of ‘comfort’ if they had a PAD because it would give them greater control and responsibility for their treatment. That is, if they experienced a future relapse or lost competency, they would know exactly what kind of treatment they would receive and under what conditions. Previous studies have reported a similar finding and confirmed that patients’ involvement in the decision-making process is strongly associated with treatment satisfaction and adherence (Atkinson et al., 2003; Coulter et al., 2008; Davidson & Birmingham, 2003; La Fond & Srebnik, 2002; Noble & Douglas, 2004; Ritchie et al., 1998; Swanson et al., 2000).

These studies have emphasised the importance of advocating the ethical principles of self-determination and empowerment to enable people with SMIs to take more responsibility for, and ownership of, their mental health. The literature concerning the issue of consumer rights and responsibilities has also adopted a similar approach, whereby people’s rights are
recognised and are at the forefront of service provision and delivery (Lloyd & King, 2003; Noble & Douglas, 2004).

The results of this study demonstrate strong support for PADs, and all participants were explicit about their treatment preferences and were able to nominate a representative (a proxy) should they lose competency. Interestingly, the responses were mixed when reporting their preferred proxy, but most nominated a family member. This finding is supported by previous studies (Srebnik & Brodoff, 2003) and confirms that the issue of trust plays an important role in supporting people with SE-AN in their treatment and recovery.

Despite the overwhelming evidence in favour of PADs, the clinicians in this study had mixed views about them because the use of PADs would result in a shift in the balance of power between the patient and health professionals towards a more patient-focused approach. This shift could be perceived as a threat to the current status quo, where doctors have traditionally maintained control over decision-making (Lloyd & King, 2003; Ng et al., 2013). The idea of relinquishing professional control and allowing patients to manage their medical affairs in accordance with their wishes and values would be a major shift in public healthcare.

Indeed, this idea has been adopted in the feminist and participatory action research fields, where there is an emphasis on empowering individuals and communities to take action (take part in the decision-making process) to improve their quality of life (Foti, 2003; Kemmis & McTaggart, 2003). It could even be argued that the absence of knowledge about PADs may inadvertently maintain this status quo, thus restricting women’s autonomy and empowerment.

To counteract this problem and increase women’s autonomy in their healthcare, the strategies outlined in Section 4.5 need to be applied to disseminate information and develop better communication pathways among all primary stakeholders. This could be seen as respecting a person’s autonomy as well as developing a collaborative approach towards
restoring the balance of power between health professionals and patients. Previous studies have emphasised the importance of patients taking greater control and responsibility for their health, which is more likely to produce better health outcomes (Darcy et al., 2010; Escobar-Koch et al., 2010; Katsakou & Priebe, 2007; Tan, Hope, Stewart et al., 2003). However, this can only be achieved by providing logistical support and access to information (knowledge about PADs), as well as the skills to enable patients to initiate and formulate a PAD.

In accordance with the principle of veracity, health professionals have an obligation to ensure that people with SMIs have access to information (PADs), which will enable them to make informed decisions (Coulter et al., 2008; Ng et al., 2013). Working collaboratively and sharing information and resources will contribute to helping women with SE-AN to ‘reclaim’ control and responsibility for themselves and their illness.

Based on this evidence, it can be concluded that the absence of knowledge about PADs among all stakeholders is a major barrier that prevents access to, and the use of, PADs. This conclusion is consistent with the literature, which demonstrates a relationship between a lack of communication and knowledge about PADs and their uptake (Anselm et al., 2005; Backlar & McFarland, 1996; Boddy et al., 2013; Golden et al., 2008; Jezewski et al., 2005; Kapp, 1989; Kim et al., 2007; Murphy, 2009; Schickedanz et al., 2009).

9.6 Category 3: Quality of Life

9.6.1 Subtheme: social stigma—‘you are so completely ashamed’

In line with the AN literature, all participants in this study had experienced social stigma, which prevented them from seeking or accepting medical help (Crisp, 2005; Crisp, 1997; Hepworth & Paxton, 2007; Kazdin et al., 2017; NEDC, 2010; Noble & Douglas, 2004; Skårderud, 2007; Troop, Allan, Serpell, & Treasure, 2008).

Four of the five participants expressed concerns about the negative effects of being labelled with AN in the mental health system, and they were particularly concerned about
being rejected by their family and friends. These findings have been reported in previous studies (Crisp, 2005; Escobar-Koch et al., 2010; Federici & Kaplan, 2008; Fox et al., 2010; Hannon et al., 2017) and add credibility to the present findings.

Evidence has shown that being socially stigmatised with a mental illness is a major barrier that prevents people from seeking professional support (Chamberlin, 2005; Johnstone, 2009; NEDC, 2010; Smahelova et al., 2019; Winick, 1994). People living with an eating disorder are ‘fearful of being discriminated against’ (i.e., ‘being treated differently’) and are ‘blamed for their illness’ and made to feel responsible for their condition (Crisp, 2005; Huycke, 2000; Johnstone, 2009; Kitchener, 1984; PACFA, 2011; Vogelstein, 2016). Several studies have confirmed these findings, noting that there is ‘widespread pessimism’ among health professionals. These attitudes have the potential to perpetuate the stigma towards people with eating disorders, thus undermining their attempts to recover (Bamford et al., 2016; Beumont & Vandereycken, 1998; Fleming & Szmukler, 1992; Fox & Diab, 2015; Griffiths & Russell, 2000; Ramjan, 2004; Skårderud, 2007; Tierney, 2008).

The present study revealed that shame is associated with a feeling of denial and is a major subcategory that emerged in the analysis. All participants attempted to hide their illness from their loved ones and friends. It is well documented, and supported by empirical studies, that people with eating disorders engage in secrecy and concealment regarding their illness (Crisp, 2005; Joughin et al., 1991; Mehler & Andersen, 1999; Scholtz et al., 2010; Skårderud, 2007; Smahelova et al., 2019). For example, Sue convinced her family that she had cancer, whereas Jade was afraid to tell her family for fear of being judged as a ‘failure’. Amy did not allow her family, including her children, to visit her at the hospital because she was too ashamed. These reports are consistent with the theoretical constructs of weakness and lapse of self-control that have been widely reported in the literature (Beumont & Vandereycken, 1998; Federici & Kaplan, 2008; Surgenor et al., 2002).
The participants in this study felt that they lacked control to manage their shame, particularly between hospital readmissions. Indeed, the very fact of having repeat hospital admissions fuelled this sense of failure and shame, particularly in relation to letting their family and friends down, but also in terms of disappointing their treating teams such as their doctors and therapists. Two participants felt guilty and blamed themselves. These data confirm that relapses are common among patients with SE-AN and are perpetuated by a culture of shame (Bamford et al., 2016; Dresser, 1984b; Maier et al., 2014).

Although the idea of shame is familiar in the general psychiatric literature (Atkinson, 2007; Roberts & Dyer, 2007), it highlights ongoing questions about social stigma and its negative effects on people’s recovery from mental illness. These patients have little control over their illness, or more specifically, they lack autonomy. The data suggest that these patients want to be in control of their illness so they can lead a fulfilling life, but they are ‘consumed’ by their illness. This finding corresponds with studies by Robinson et al. (2015) and Woodgate (1998).

In this study, social stigma was identified as a strong mediating factor in the relationship between shame and mental illness, as well as a major barrier that prevents people from recovering (Dresser, 1984b; Geller et al., 2001; Maier et al., 2014; NEDC, 2010; Skårderud, 2007). The significance of this finding is that shame was an effective deterrent in helping patients seek professional support for their illness, particularly during episodes of illness exacerbation. This finding corroborates previous research (Mehler & Andersen, 1999; Rance, Clarke et al., 2017; Treasure et al., 2001) and confirms a link between these variables.

The data also support the theory that sociocultural models that promote unrealistic body ideas (i.e., that emphasise thinness) continue to perpetuate shame (APA, 2013; Andersen, 2007; Bruch, 1966; Crisp, 2005; Garner & Garfinkel, 1997; Knauss & Schofield, 2009; Lawrence, 1979; Lemma-Wright, 1994; Midlarsky & Nitzburg, 2008; Stice, 2002;
Striegel-Moore & Bulik, 2007; Thompson, 2004). Indeed, shame has been identified as a perpetuating factor in the maintenance of SE-AN (Skårderud, 2007; Troop et al., 2008). A number of studies have supported this hypothesis (Rance, Clarke et al., 2017; Skårderud, 2007), and further studies into the effects of shame are needed to understand the phenomenon.

Overall, the data in the present study support the notion that shame, denial and social stigma are perpetuating and interrelated factors in sustaining the illness, and they cause significant psychosocial problems for people with eating disorders—particularly for those who want to recover.

9.6.2 Subtheme: psychological—‘it is inherently a psychological disorder’

A significant finding under this subtheme is that all participants described situations in which their illness had caused significant psychological distress. The debilitating effects of living with SE-AN caused isolation and prevented participants from developing friendships, going out, socialising and pursuing life goals. For one participant, it resulted in living in her bedroom for years without interacting with others. Jade described her isolation using a ‘hijack’ metaphor, which implied that it had robbed her of living a normal life. Robinson et al., (2015) used the term ‘constant demands’ to describe the unrelenting demands of living with SE-AN (p. 322). These results could be interpreted as the illness consuming patients’ lives to the point that they were unable to participate in day-to-day living, which affected their quality of life (or otherwise resulted in a loss of control).

That is, the illness becomes a ‘focal point’ which takes precedence over other aspects of the patient’s life—especially academic pursuits, relationships and even their health (see Section 8.6). This was clearly illustrated by Amy, who stated that ‘it was just the eating disorder all day’. This finding is in line with Tan et al.’s (2003a) study, in which several participants acknowledged that AN is the ‘most important thing in their lives’, and they had withdrawn from normal life activities, such as university, to maintain their ‘pursuit of
thinness’ (p. 702). These ideas are consistent with the literature review where women with SE-AN struggle to maintain a reasonable quality of life (see Section 2.4.2.1).

This finding might also suggest that women with SE-AN experienced denial together with other comorbidities such as depression and anxiety, which limited their insights into the illness and prevented them from seeking professional support. This finding has been reported previously (Anderson & Paulosky, 2004; Bruch, 1974; Crisp et al., 1977; Halmi, 2013; Holm et al., 2012; Stice, 2002) and confirms that denial plays an important role in the aetiology of the illness.

However, this study contradicts previous research that shows that comorbidities are common among patients with SE-AN (Bamford et al., 2015; Hannon et al., 2017; Holm et al., 2012). In this study, none of the participants reported that they had been formally diagnosed with comorbidities. This finding is in line with a previous study (Nevonen & Broberg, 2000). This unexpected result could be attributed to the variability in the diagnosis of SE-AN (APA, 2013; Brewerton & Dennis, 2016). Further, comorbidities were not included in the prognostic factors related to patients with SE-AN as described by Lacey and Sly (2016).

The data in this study show that the debilitating effects of living with SE-AN are further exacerbated by social adjustment problems. This result can be best explained by the patients’ inability to maintain long-term relationships with friends and significant others. Two of the participants reported that their partner had left them because of their illness, and all participants identified themselves as ‘currently single’ (see Table 7.1). This result conforms to the literature and demonstrates that people with SE-AN have great difficulty in maintaining social connections (Button & Warren, 2001; Halmi, 2013; Lacey & Sly, 2016).

These characteristics have been reported by previous studies and confirm that SE-AN can cause significant social morbidity and impair function (APA, 2013; Button & Warren,
9.6.3 Subtheme: physical—‘reaching extreme points’

All participants had experienced medical complications as a direct result of starvation. Amy stated that she had oedema, osteoporosis and loss of teeth (replaced by dentures), while Jade described having heart problems (tachycardia) that were complicated by anxiety. Jo had lost the enamel on her teeth and had her gall bladder removed, as well as ongoing liver problems. Mary had heart palpitations and ongoing issues with her potassium levels and electrolytes. Sue explained that she was frequently placed in a coma in ICU to ‘keep her alive’.

These descriptions have been reported elsewhere (APA, 2013; Bruch, 1979; Draper, 2000; Matusek & Wright, 2010; Mental Health First Aid Training & Research Program, 2008; Skårderud, 2007; Stice, 2001; Striegel-Moore & Smolak, 2001) and support the theory that SE-AN is a debilitating illness that requires ongoing medical care. In addition, the data confirm that people with SE-AN are at a higher risk of mortality when compared with other chronic conditions (APA, 2013; Campbell & Peebles, 2014; Crisp et al., 1977; Mann et al., 2018; Wegner & James, 2012).

Several participants acknowledged that they would have died if they had failed to seek medical support, and this was identified as an important motivating factor in their recovery. That is, they considered hospitalisation a protective factor against death. This finding contradicts Tan et al.’s (2003a) study, in which the prospect of ‘death and disability’ from the illness was irrelevant in the eyes of the participants. Instead, they placed a higher value on the illness than on their life. These results support the argument for involuntary care, particularly when a person is medically compromised. At one time or another, all five women experienced life-threatening complications and thus warranted a ‘medical rescue’.
Despite these physical conditions, several studies have reported that people with SE-AN want to rebuild their life and have a good quality of life so they can pursue their goals and interests, but they are preoccupied with the illness and find it difficult to lead a normal life. Although SE-AN is not recognised as a terminal illness, it has psychological and physical features that reduce a person’s quality of life and therefore requires attention. As mentioned previously, there has been a shift from curative treatments to a rehabilitation model of care with an emphasis on the quality of life aspects of living with SE-AN (see Section 2.9). The findings of this study support this view.

Currently, quality-of-life aspects of living with SE-AN are under-reported, and this is a significant gap in the SE-AN literature that requires further investigation (APA, 2000; Bamford et al., 2016; Bamford & Mountford, 2012; Conti et al., 2016; Lock et al., 2013; Marzola & Abbate-Daga, 2019; Robinson et al., 2015; Russell et al., 2019; Wonderlich et al., 2012). Specifically, researchers need to investigate what quality of life means to people with SE-AN and what types of treatments and support they need to improve their quality of life.

Quality-of-life scales and measurements (quantitative and qualitative methods) that are currently used within the general mental illness population can be extrapolated to people with SE-AN (Bamford & Sly, 2010).

Such investigations would, in turn, answer the question presented in Chapter 1: How do clinicians provide humane and dignified treatment without undermining the principle of respect for patient autonomy?

9.6.4 Subtheme: suicide—‘I’m ready to die with anorexia’

A significant finding of this study was that suicide affected the lives of two participants. One acknowledged that their eating disorder (the effects of starvation) was a form of suicide: ‘in many ways, it is a form of suicide’. The other stated that she did not want to live because life was intolerable (she was grief-stricken because her husband left her) and
she was ‘ready to die with anorexia’. These findings contradict the results from Tan et al.’s (2006) study, where two participants denied suicide ideation in the context of their eating disorder. Rather, they had a low opinion of themselves, which was attributed to their depressive symptoms.

However, the results in this study support the view that suicide ideation places people with AN at greater risk of mortality (Agras et al., 2004; APA, 2013; Ayton et al., 2009; Bulik et al., 2008; Lilenfeld, 2016; Radu et al., 2016; Selvini-Palazzoli, 1978; Steinhausen, 2002).

The two participants in this study expressed their need to manage their emotional pain through acts of SIBs such as excessive usage of laxatives and deliberate starvation. These findings are in accordance with the literature review, which found that suicide has been contextualised as overt or covert acts of suicide (Ayton et al., 2009; Bulik et al., 2008; Lilenfeld, 2016).

Further, this finding supports the theory that suicide ideation is an attempt to self-regulate the negative emotional aspects of living with the illness—for example, to ‘numb the pain’ through acts of self-harm (Brewerton & Dennis, 2016; Lacey & Sly, 2016; Manley & Leichner, 2003; Smithuis et al., 2018). Indeed, it has been reported that SIBs are the patient’s attempt to regain control over their life (Berg et al., 2017; Bruch, 1974; Crisp, 1995).

Although these participants expressed the intent to die as a result of their eating disorder, they are still receiving hospital care, suggesting that they might be holding onto hope that recovery from anorexia is possible. This was supported by the fact that one clinician stated that ‘we do have recovered people come back and talk to us as well, which instils a lot of hope’. Therefore, this supports the hypothesis that it is a misconception that people with AN want to end their life through suicide or self-harm (Bruch, 1974; Carney, 2009; Fost, 1984; Geppert, 2015; Giordano, 2010; Melamed et al., 2003; Rathner, 1998; Selvini-Palazzoli, 1978; Tiller et al., 1993). Rather, suicide is a reflection of people’s suffering
(despair) and a loss of hope of recovery, especially during periods of instability (Manley & Leichner, 2003). There are two possible reasons for this occurrence. First, the quality of life for these women has been diminished by their eating disorder. Second, they have been ‘consumed’ by the illness to the point that they have lost control; therefore, they believe that life with anorexia is not worth living.

However, in contrast to the above, one patient (Mary) was explicit in her desire to die because she found life intolerable and believed that it offered no meaning or fulfilment apart from the hope that she could end her life. Mary’s story highlights that there are increasing numbers of people with SE-AN who simply do not respond to conventional therapies and thus have relinquished hope of ever recovering. A number of authors have reached a similar conclusion and have advocated ‘a different paradigm of management’ (Strober, 2004, p. 251) that emphasises improving the quality of life of people with SE-AN (Bamford et al., 2016; Bamford & Mountford, 2012; Calugi et al., 2017; Conti et al., 2016; Goldner, 1989; Lock et al., 2013; Robinson et al., 2015; Russell et al., 2019; Strober, 2004; Tierney & Fox, 2009; Touyz & Hay, 2015; Wonderlich et al., 2012).

Stories like Mary’s experience of SE-AN are a growing concern among health professionals and support the argument that curative treatments may not necessarily match the values or beliefs of patients who are competent to refuse treatment and who have decided to end their life (Campbell & Aulisio, 2012; Coggon, 2014; Davies et al., 2012; Fost, 1984; Giordano, 2010; Hebert & Weingarten, 1991; Maher & Rosedale, 1993; Melamed et al., 2003; O’Neill et al., 1994; Selvini-Palazzoli, 1978; Tiller et al., 1993; Wang, 2015).

These findings raise the question of whether the ethical principle of beneficence should be enforced to preserve the life of these patients. This debate is complex, with mixed views (see Sections 5.1.2 and 5.1.3). However, the data in this study confirm that most (four out of five) participants were in favour of the ethical principle of beneficence to preserve life,
but only under extenuating circumstances. This includes evidence of a loss of ‘competency’—that is, when the patient is deemed ‘not of sound mind’ (see Section 8.5). Conversely, it could be argued that the participants supported the patients’ choice to end their life when competency was demonstrated. This finding therefore supports the view that mental illness does not necessarily prevent a person from being competent (Giordano, 2005; Halpern & Szmukler, 1997; Winick, 1996).

In summary, the results showed strong support for the ethical principle of beneficence to breach a person’s autonomy when there is evidence of incompetency. This finding is comparable with the literature (Carney et al., 2007; Dresser & Boisabuin Jr, 1986; Griffiths & Russell, 2000; Richmond, 2001; Schreyer et al., 2016) and therefore supports the clinicians’ ethical duty of care (beneficence) to impose paternalistic (e.g., Mental Health Act) treatment (see Section 8.5) to protect the safety and wellbeing of patients who present with self-harm or suicide ideation. This finding also supports current ‘best practice’ in terms of encouraging clinicians to screen their patients for suicide ideation and self-harming behaviours, particularly during the initial baseline assessment (APA, 2013; Appelbaum & Rumpf, 1998; Bulik et al., 2008; Goldner et al., 1997; Lilenfeld, 2016; Smith et al., 2018; Strober, 2010; Westmoreland & Mehler, 2016).

9.7 Category 4: Healthcare Services

9.7.1 Subtheme: limited trained staff—‘just another number, just another eating disorder’

A key finding that emerged from this study was a lack of trained staff, which was identified as a major barrier that prevented patients from receiving an adequate standard of care, and as a result, all participants had been subjected to coercion. This is a common problem that has been cited in several studies, and it confirms that a lack of staff trained in eating disorders was associated with a higher risk of coercion (Fox & Diab, 2015;
Noordenbos et al., 2002; Palmer & Treasure, 1999; Reid et al., 2008; Scholtz et al., 2010; Tierney, 2008).

All participants discussed their experiences of hospital care with a focus on physical symptoms. This suggests that there was too much emphasis on weight restoration, with little attention focused on psychological needs. One participant highlighted this point by stating that ‘sometimes they [staff] have a view that people come in [ward], let’s get the weight on, let’s get them healthy, and let’s just get them out the door’.

Many studies have reported a similar finding and concluded that participants want a more holistic approach towards addressing the psychological and physical aspects of the illness (Bell, 2003; Button & Warren, 2001; Cockell et al., 2004; Colton & Pistrang, 2004; Dresser, 1984b; Escobar-Koch et al., 2010; Federici & Kaplan, 2008; Ramjan & Fogarty, 2019; Rance, Clarke et al., 2017; Reid et al., 2008; Scholtz et al., 2010; Williams & Reid, 2010).

Treatment often involves acts of coercion such as force feeding (i.e., nasogastric tubing), forced medication, restricted movement on the ward (i.e., bed rest) and complying with meal plans to increase BMI levels. Most participants reported that these acts mainly occurred in general hospital wards and were administered by untrained staff. These results could be best explained by the fact that there is no clear consensus in the literature on the treatment of SE-AN. Further, there is no agreement regarding what constitutes ‘good care’ for this group of patients (Ciao et al., 2016; Dresser, 1984b; Lacey & Sly, 2016; Marzola & Abbate-Daga, 2019; NICE, 2017; RANZCP, 2014; Tierney & Fox, 2009; Treasure et al., 2015).

In addition, it could be argued that some clinicians blame patients for their illness and believe that they do not deserve to be cared for as seriously as patients with other medical conditions. This was exemplified by a participant’s statement that ‘the underpinning attitude
is that we are a waste of a good hospital bed’. The literature supports the argument that the pessimistic attitude of clinicians could have a negative effect on the delivery of services and undermine the overall quality of care provided to patients with SE-AN (Agras et al., 2004; Beumont & Vandereycken, 1998; Espindola & Blay, 2009; Fox & Diab, 2015; Ramjan, 2004; Rance, Moller et al., 2017; Yager, 1998). This finding was reported in a study that found that nursing staff treated adolescent patients with AN with a pessimistic attitude, as if they were another ‘case’ to be treated rather than an ‘individual within the condition’ (Tierney, 2008, p. 371). For this reason, many participants reported a lack of connection with the nurses and consequently dropped out of care.

The literature review supports this conclusion. Evidence has shown that there is a high treatment dropout rate among patients with AN (Halmi et al., 2005; Surgenor et al., 2004; Vandereycken & Vansteenkiste, 2009; Winkler et al., 2017; Wonderlich et al., 2012), and this study supports the theory that inadequate staff training in AN treatment—particularly among general nurses—combined with a poor therapeutic relationship are contributing factors to this dropout rate. This may also explain why patients have repeated hospital admissions, view general hospital care as punitive and have difficulty trusting the mental health system—findings that have been reported elsewhere (Darcy et al., 2010; Dresser, 1984c; Ramjan & Fogarty, 2019; Richmond, 2001; Tan, Hope, Stewart et al., 2003; Verkerk, 1999; Wyder et al., 2013).

Given that most participants have described their experience as overwhelmingly negative when receiving generalist hospital care, it seems reasonable to conclude that better training and support is needed for generalist nursing staff. This recommendation has been supported by a number of eating disorder guidelines (NEDC, 2010; NICE, 2017). This supports the theory that inpatient treatment should focus on both the physical and psychological aspects of the illness. Developing expertise in eating disorders and ensuring a
strong therapeutical alliance, with an emphasis on compassion and understanding to support people with eating disorders, would make a significant difference towards patients’ recovery during or post-hospital discharge (Marzola et al., 2019).

9.7.2 Subtheme: limited specific services—‘just not enough facilities’

A significant finding in this study was that all participants had difficulty accessing specialised eating disorder treatment programs. The participants felt frustrated in their efforts to access SEDCs and were subsequently shunted off into general medical wards where nursing staff were not familiar with the condition of anorexia. This finding has been reported elsewhere (Button & Warren, 2001; Escobar-Koch et al., 2010; Rance, Moller et al., 2017; Tierney, 2008) and confirms that limited eating disorder services are available to accommodate the needs of people with SE-AN. This raises questions regarding what type of patient is likely to gain access to services and whether eating disorder services are effective in meeting the needs of all patients with eating disorders. Similar concerns were expressed by Rance et al. (2017).

It was discovered through this research that geographical location is a significant barrier that prevents women from accessing specialised care. The participants in this study reported that most eating disorder services were located in metropolitan areas, and there were no formal services in rural and regional areas. In addition, these services have designated catchment areas, which limit women’s treatment options because they cannot nominate a particular hospital, doctor or type of treatment. This finding was comparable with similar studies that reported on eating disorder services (Escobar-Koch et al., 2010). As a result, they cannot access services that are close to their home or family, as well as other important support such as local doctors and allied health workers. These primary healthcare supports are integral to patients’ care and recovery, particularly when they are feeling vulnerable (William,
This supports the argument that restricting services could potentially compromise patients’ health and wellbeing.

This finding has been frequently reported in the AN literature and is a major concern for health professionals, researchers and consumers. Research shows that early diagnosis and adequate access to healthcare services can reduce the morbidity and mortality of AN and reduce overall prevalence rates (Errichiello et al., 2016; Garner, 1985; Holm et al., 2012; Jarman et al., 1997; Joughin et al., 1991; Lähteenmäki et al., 2014; Linville et al., 2010; Mehler & Andersen, 1999; Mental Health First Aid Training & Research Program, 2008; Mitchison & Mond, 2015; Murray et al., 2011; Noordenbos et al., 2002; RANZCP, 2014; Redston et al., 2014; Steinhausen, 2002; Tan et al., 2008).

The results from this and other studies suggest that patients who cannot access specialist care services have relied on mainstream services, where the quality of care can be poor and inadequate in addressing the patients’ complex needs (Escobar-Koch et al., 2010; Rance, Moller et al., 2017; RANZCP, 2014; Tierney, 2008).

When entering a general medical ward, patients are often exposed to a higher level of coercion and imposition. Most participants described their experiences as ‘traumatic’ and ‘terrifying’, and they were often subjected to punitive treatment. It can be safely assumed that patients (first-timers) transitioning from a general ward into a specialised eating disorder ward would expect a similar experience. Overall, the data suggest that women with SE-AN do not want to be treated within a general medical ward, but rather in a specialist eating disorder clinic. This finding is supported by Bamford et al. (2016) and Tierney (2008) and has been attributed to the structured treatment program in the eating disorder clinic.

The participants valued an integrated multidisciplinary team-based approach to their care, whereby their psychological and physical needs were met and they felt understood by the clinicians. All participants found ‘comfort’ in the idea that there were different clinicians
who could address both their physical and psychological symptoms. They also valued the idea that staff were trained to recognise and deal with their disorderly eating behaviours such as hiding food and restricting food intake. Many participants valued the program’s consistent approach to their care—for example, conducting regular catch-up meetings with the same clinicians as opposed to one-off meetings with different clinicians. Participants’ descriptions also showed that they want empathetic understanding from clinicians—especially those from generalist medical hospital wards. This approach would foster positive relationships and challenge existing negative perceptions among nursing staff.

Similarly, Van Ommen et al. (2009) reported that participants valued a ‘structured’ treatment program that enabled them to ‘normalise’ and take ‘responsibility’ for their eating behaviours. Participants also recognised that nurses’ attitudinal and empathic support were important factors in facilitating their recovery. This result, together with the findings of the present study, confirms the theory that inpatient care in the form of a ‘structured treatment program’ can be beneficial to patient care and, in some cases, be a life-saving device for these patients (Ayton et al., 2009; Gutheil & Appelbaum, 1982; Melamed et al., 2003; Tan et al., 2010; Verkerk, 1999).

This study has identified that there is a lack of assessable specialised eating disorder services for people with SE-AN. Addressing this gap in service provision would provide these patients with the necessary resources to assist them in their recovery efforts, and it would help them to self-direct their care according to their individual needs and goals.

The main findings, interpretations and conclusions of this study can be found in Table J.1 in Appendix J. The purpose of this table is to help the reader conceptualise the data (Corbin & Strauss, 2014; Glaser, 1967).
9.8 Conclusion

A ‘lack of control’ was the dominant theme that emerged from this research. All participants described a feeling of not being in control. This was contextualised and understood in relation to their perceptions of one another based on their interactions within an acute hospital ward. In addition, participants’ personal accounts of living with SE-AN generated different meanings and feelings in relation to the phenomenon.

As described in Chapter 5, SI was applied to the research problem to understand the phenomenon, and this provided the theoretical lens through which to interpret the data. This study explored the interaction between the hospital staff and patients to understand the conditions and processes that influence coercion.

The results showed that the use of coercion in psychiatric care was confirmed by the individual experiences of women and therefore remains a moral and ethical problem. The central concern of all individual participants was that they lacked control over the illness, specifically relating to all four domains: the provision (or lack) of care, the decision-making process, living with the debilitating effects of SE-AN and the absence of knowledge about PADs.

The subthemes provided further insights into the consequences and conditions that have influenced the phenomenon of SE-AN. All subthemes were related to the core theme of ‘lack of control’ and were representative of the barriers that prevent women from recovering. For example, they were forced to deal with the negative effects of social stigma, the iatrogenic effects of inpatient care, the lack of involvement in shared decision-making, the negative psychological and physical effects of living with SE-AN, and ongoing difficulties in accessing appropriate specialised services and trained staff.

Despite these barriers, the data revealed that most participants were determined to recover, but they needed a strong therapeutic alliance, a holistic approach to the delivery of
treatment services, regular access to trained staff, participation in decision-making and to be informed about PADs. Collectively, this support would promote patient autonomy and self-determination and empower them to overcome these barriers to maintain a reasonable quality of life. An important message from this discussion is that collaborative relationships can be built with patients by adopting a person-centred approach. This in turn will mitigate the iatrogenic effects of hospital treatment and assist in patients’ recovery from SE-AN. Adopting this approach will provide an answer to the complex question raised in Section 1.4.

9.9 Clinical Implications for Practice

The purpose of this section is to identify and discuss the clinical implications of the findings—specifically in relation to the health needs of people with SE-AN and to the clinical practices of health professionals. This section aims to provide future clinical guidance for eating disorder specialists, review existing policies relating to standards of care and minimise the iatrogenic effects of treatment.

9.9.1 Collaborative decision-making

The findings demonstrated that women with SE-AN want to collaborate with their health professionals in the decision-making process regarding their treatment. This has important implications for self-determination and autonomy. For example, denying women the chance to participate in decision-making resulted in them feeling disempowered and coerced, and it limited their autonomy and reduced the likelihood of recovering. Conversely, encouraging participation increased their self-esteem and confidence, improved the therapeutic relationship, reduced hospital admissions and reduced the dropout rates.

All participants except Mary wanted a more inclusive and collaborative service delivery that would enable their family and significant others to participate in their care. According to the research findings, families and significant others provide valuable support in the lives of these women. This has important clinical implications, because involving the
patient’s family and significant other in their care would enable health professionals to obtain current and historical information about the person’s illness, as well as an understanding of their individual interests and needs. It is also an opportunity for health workers to identify treatments that have worked (or not) in previous hospital admissions (Henderson et al., 2010; Swanson et al., 2000). Not implementing this process may reduce a person’s motivation to engage in treatment services, decrease their chances of recovery and may be perceived as a form of coercion. Therefore, clinicians are encouraged to provide opportunities for their patients to participate in all areas of their care.

9.9.2 Psychiatric advance directives

A finding of this study was that participants had ‘no prior knowledge’ of PADs. The implication of this finding is that women’s preferences for treatment were limited, which further undermined their responsibility for and ownership of their health. These concerns could be addressed by incorporating the mechanisms outlined in Section 4.5. These mechanisms could be used as a template to develop a policy that deals with the promotion of and training for PADs, and the provision of a person (e.g., social worker, nurse or psychiatrist) whose role is to provide information and discuss this issue. The policy would not only increase the uptake of PADs, but also improve quality of care.

This study identified that PADs offer a solution to increase collaborative decision-making between patients and healthcare workers, and they have the potential to reduce the iatrogenic effects of psychiatric hospital care. Most participants believed that that PADs can increase a person’s autonomy (gain control) and self-determination.

Overall, these results suggest that developing PADs with the involvement of families, significant others and health workers is a means of achieving collaborative care and enhancing service delivery, thus reducing the iatrogenic effects of psychiatric care. Failing to
provide information about PADs to people with eating disorders could limit their ability to control and manage their illness, which could in turn jeopardise their future healthcare.

9.9.3 Debilitating effects of shame and social stigma

The findings of this study confirmed that shame and social stigma prevent women from seeking professional support, and this has important clinical implications for service delivery and provision.

To reduce stigma and shame, GPs and nurses—particularly those working in general medical wards—need better training to develop their skills and knowledge concerning the psychopathology of eating disorders. This, in turn, will enable them to detect and identify symptoms of the illness and engage in discussions with their patients about suspected eating disorders. However, without adequate training of staff, shame and social stigma will remain social barriers that prevent women from seeking medical support that is potentially lifesaving.

A disturbing finding of this study was that shame was perpetuated by health professionals, either by words or actions, when offering hospital care to patients. For example, Sue felt ashamed when she was forced to pick up crumbs from the table with her fingers in front of nursing staff and other patients. Similarly, Jade described an incident in which she was forced to have a tube inserted into her nose because the nurses thought she was not complying with the meal plan. This provoked feelings of shame and embarrassment. The conclusion that can be drawn from this is that clinicians should reflect on whether their actions and words have a negative effect on the psychological welfare of their patients—specifically, whether they induce feelings of shame and embarrassment. A further implication is that this could damage the therapeutic relationship.

Two studies reported a similar finding about the iatrogenic effects of shame and stigma within psychiatric care (Skárderud, 2007; Tierney, 2008). These studies provide
further evidence to support the inclusion of training for eating disorders staff to minimise the risk of further stigmatisation for people with eating disorders.

**9.9.4 Provision of care**

This study confirmed that there was a significant lack of trained staff and specific eating disorder services to accommodate the complex needs of people with SE-AN. The research results showed that staff lacked ‘sufficient knowledge’ about eating disorders and ‘relied on senior staff’ for clinical guidance and support. The implication of these findings is that patients were subjected to acts of coercion. They were forced to accept treatments that were not consistent with their wishes, they were subjected to negative pessimistic attitudes and they were treated with indifference by generalist nursing staff. This could have been ameliorated by providing ongoing supervision and training for staff. Failing to do so could result in further exposure to coercion and impede the person’s recovery.

The findings of this study identified the need for increased access to, and development of, specialised eating disorder services in regional and rural areas to provide easier access to quality care for people with eating disorders. This could result in reduced mortality rates, a reduced burden of care and lower waiting lists in metropolitan hospitals. In addition, it would ensure that people with SE-AN, as well as their families and friends, could access and receive professional services in their local area. Both federal and state governments can play a key role in financing this reform.

**9.10 Conclusion**

Overall, the study results support previous research that showed that patients and clinicians who develop collaborative relationships can minimise the iatrogenic effects of hospitalisation. A lack of integrating the above suggestions into clinical practice may result in further acts of coercion, leaving women feeling powerless and not in control of their illness. To address this concern, clinicians are encouraged to think ethically and explore the ethical
dimensions of decision-making processes and evaluative aspects when caring for women with SE-AN (see the research objective in Section 1.8).

9.11 Recommendations

Table 9.1 summarises the key recommendations that emerged from the research findings. They provide a framework to guide clinical decision-making by health professionals in reducing patients’ experiences (or perceptions) of coercion when receiving psychiatric care. Some of these have already been cited in the medical literature and are therefore familiar, but they were nonetheless reiterated by the participants in this study.

The importance of listening to people’s ‘voices’ in the delivery of healthcare services has been reported elsewhere in the mental health literature (Gallagher, 1998; Winick, 1997) and is an integral component in helping people to recover from SE-AN (Dawson et al., 2014; Pettersen & Rosenvinge, 2002). Providing opportunities to allow patients with SE-AN to participate in all decision-making processes (e.g., the use of PADs) enables them to feel part of the process and the solution, thereby promoting an ethos of client empowerment and self-determination (Matusek & Wright, 2010). These recommendations might help to reduce patients’ experiences (or perceptions) of coercion in psychiatric services and encourage patients to engage in treatment services on a voluntary basis.
<table>
<thead>
<tr>
<th>Respect for autonomy</th>
<th>Clinical practices</th>
<th>Treatment</th>
<th>Share decision-making</th>
<th>Uptake of PADs</th>
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<tr>
<td>Listen to patients’ voices and their maturity of experience</td>
<td>Limit the use of the <em>Mental Health Act</em> and Community Treatment Orders</td>
<td>Recommend alternative non-adversarial treatment options (e.g., outpatients)</td>
<td>Work collaboratively with patients and their families in the decision-making process</td>
<td>Provide information to healthcare professionals and consumers about the utility of PADs</td>
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<tr>
<td>Respect patients’ values and beliefs</td>
<td>Provide appropriate referrals to eating disorder specialists and services</td>
<td>Modify standardised treatment programs to accommodate the needs of SE-AN patients</td>
<td>Inform patients of their right to formulate a PAD</td>
<td>Provide logistical support to assist patients to formulate a PAD (e.g., consumer advocate)</td>
</tr>
<tr>
<td>Develop a strong therapeutic alliance</td>
<td>Provide specific training about eating disorders to generalist nurses through the Australian Centre for Eating Disorders or comparable approved training programs such as the ‘Child and Adolescent Mental Health’, a course that is offered by most Australian universities (Ramjan, 2004)</td>
<td>Less emphasis on weight and more emphasis on the psychological needs of patients</td>
<td>Multidisciplinary team should initiate conversations about PADs with patients before hospital discharge</td>
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<td>Ethical Considerations in Collaborative Care in SE-AN</td>
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<td>Instil hope that recovery is possible</td>
<td>Coordinate health services in general and specialised eating disorder services</td>
<td>Consider community-based treatment programs as a least restrictive alternative to the traditional medical model</td>
<td>Avail adopting an adversarial or punitive approach to treatment that could damage the therapeutic relationship, reduce treatment adherence and ultimately affect the patient’s recovery</td>
<td>Service providers should make services more accessible to patients and their families, both financially and geographically</td>
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<tr>
<td>Conduct suicide risk assessments to determine a patient’s intent to die and their level of competency to make informed decisions</td>
<td>Avoid adopting an adversarial or punitive approach to treatment that could damage the therapeutic relationship, reduce treatment adherence and ultimately affect the patient’s recovery</td>
<td>Refer patients to SEDCs or allocate an eating disorder nurse to a generalist ward; by providing the least restrictive principle of care, these approaches might reduce patients’ experiences (or perceptions) of coercion</td>
<td>Refer patients to SEDCs or allocate an eating disorder nurse to a generalist ward; by providing the least restrictive principle of care, these approaches might reduce patients’ experiences (or perceptions) of coercion</td>
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9.12 Limitations of the Study

To inform future research, it is standard research practice to list the limitations and acknowledge the strengths of a study (Hess, 2004; Marshall & Rossman, 2010; O’Leary, 2014).

The first major strength of this study was the research design. The research methodology (GT, SI, social constructivism, semi-structured interviews and focus groups) proved to be effective in developing a deeper understanding of the issues and inductively creating an ethical decision-making model. Further, the study was successful in recruiting a diverse group of participants (clinicians and patients) with varying experience and roles to capture multiple perspectives to better understand the phenomenon of SE-AN.

The second strength was the location of the study. It was conducted in a ‘real clinical setting’ (i.e., an acute general psychiatric hospital ward) in which participants had first-hand knowledge of the illness and the conditions that contribute to the research problem. In addition, the study provided a ‘real’ opportunity for those experiencing SE-AN to share their story with others in the hope that it might help them in the future (Corbin & Morse, 2003; Timmerman, 1999).

There were a number of limitations to this study. First, this was a naturalistic study that consisted of a small homogenous size, which limited the generality of the findings and their potential relevance to other clinical settings (Barker & Pistrang, 2015). Another limitation was that the study was conducted at only one acute care psychiatric hospital. Further, the sample was biased towards Caucasian adult women who were receiving specialised hospital care (Dresser, 1984b). Therefore, these results may not be applicable to those who have the same eating disorder but who are male, from a different culture or in a younger age group. In addition, all participants were critically unwell and had reached the ‘severe end of the illness spectrum’ (Whitney et al., 2005, p. 448). Therefore, these findings
cannot be generalised to those who have not reached the same stage of illness severity (Whitney et al., 2005). For example, some patients with a diagnosis of SE-AN may never reach a stage where they require inpatient care or even access health services (Keski-Rahkonen et al., 2007). Consequently, this small sample group may not be typical of women with SE-AN.

Unfortunately, this study did not recruit carers. The snowball method of sampling (a non-random method) was used to recruit carers (Bryman, 2012; Padgett, 2008; Patton, 2015b). However, it became apparent that patients with SE-AN could not identify a carer. This may have been because of their demographics, age, independent living or the study design. It might have been more effective to recruit carers through alternative methods such as surveys or a self-administered questionnaire distributed through services such as the Butterfly Foundation and Eating Disorders Victoria.

The perspective of carers would have increased the strength of the study—specifically, their views on PADs (i.e., whether they have any value), the efficacy of hospital inpatient care and their role in supporting people with SE-AN might have broadened our understanding of the complex needs of people with SE-AN.

The research team had limited success in recruiting males for both focus groups and individual participants, so all participants were female. There were several reasons why this might have been the case. As mentioned earlier, prevalence rates of male eating disorders are significantly lower among males compared with females; therefore, it was not feasible to include them in the study. Further, there was a limited number of male nurses in the eating disorder clinic, and those who were invited to participate declined. This could have been due to a lack of willingness to discuss or express their opinions about a problem that largely affects females. The male perspective might have offered new insights (e.g., different
attitudes and beliefs) regarding the ethics of forced treatment of females, and it might have changed the matrix of the evolving model.

Most of the clinicians in this study reported that they lacked clinical experience when working with eating disorder patients. This is largely because they came from other fields, such as general nursing, where they received no specific training in eating disorders.

Therefore, it could be argued that their responses cannot be generalised to more experienced clinicians (Hilden et al., 2004). Clinicians with more clinical experience and training might have resulted in a different set of findings and provided more in-depth responses regarding the care of people with SE-AN. Further, these responses might have influenced the emerging matrix of the model.

This study did not use the GT theoretical sampling technique because the clinicians selected the clients. However, this constraint did not appear to be critical because the generated data were rich and informative enough to enable the researcher to develop a model. It is standard practice in qualitative research, especially GT, to conduct follow-up interviews to validate the findings (Bryman, 2012). However, this would have been difficult because the patients had been discharged by the time this phase of the research occurred.

A further limitation was related to my gender, which might have prevented female patients from sharing their experiences in an authentic, open manner. The assumption behind this statement is that female participants might feel uncomfortable and be less likely to disclose details about their experiences, which might not be the case if they were interviewed by a female researcher (Berger, 2015; Pérez, Mubanga, Aznar, & Bagnol, 2015).

It is important to highlight the strengths and limitations of this study. These considerations should be taken into account by future researchers who want to pursue a similar study. To facilitate this, I have outlined a number of possible future research directions below.
9.13 Future Research Directions

To contribute new knowledge about SE-AN, this research has identified a number of research gaps that warrant investigation (Hess, 2004), as outlined in this section. First, the proposed ethical decision-making model needs to be empirically tested. This can be achieved by conducting surveys and statistically analysing the data (Marks & Yardley, 2004).

A mixed-methods approach involving both qualitative and quantitative studies is needed to determine the utilisation of PADs in mental health settings in Australia. Second, future studies should investigate voluntary and involuntary cohorts to determine the frequency and duration of hospitalisation for patients with SE-AN. These data might support or refute the hypothesis that patients with SE-AN are treatment-resistant. It will also provide valuable data about patients’ perceptions of coercion and its effect on treatment outcomes.

Researchers might want to consider exploring remission rates, treatment adherence rates, attrition rates and adherence to protocols between voluntary and involuntary patients with SE-AN. This information might help to explain whether there are any differences or similarities that could be attributed to hospital care.

There is limited research on the mortality rates of people with SE-AN who die in hospital care (Carney et al., 2019; Robinson, 2012; Robinson & Jones, 2018). Future researchers should examine the incidence rate and probable causes (Robinson, 2012). It would be interesting to gather data of such deaths (including statistical data on the frequency of hospital readmissions). This might provide new evidence on the efficacy of involuntary treatment and might prompt health professionals to modify their clinical practices or investigate alternatives.

An important area for future study is to explore how families and carers can play a more active role in the delivery of the medical care model. A number of collaborative care
models have advocated this approach, but with little direction on how to implement the recommendation (Wonderlich et al., 2012; Woodside et al., 2016; Yager, 1992).

Another area of investigation is the phenomena of shame and social stigma and their effect on people living with SE-AN. Both qualitative and quantitative methods can be used to develop knowledge about mechanisms to prevent the negative effects of shame and social stigma.

As mentioned earlier, investigating patients’ views on palliative and end-of-life care warrants attention. Mary’s story exemplifies the need for this type of research. One approach is to use narrative life-story interviews, which can provide rich data on the sociocultural factors that influence people’s views of palliative care (May, 2001; Plummer, 1995).

A question that needs to be addressed in future studies is how or who should implement the model. Feasibility trials such as pilot programs could be an effective means of testing and evaluating the model (Arksey & Knight, 1999). Future researchers could conduct a number of small pilot programs in various healthcare settings to identify potential barriers and solutions in relation to implementing the model. These pilot programs should be representative of all stakeholders and consist of a small number of participants. The data may reveal that different individuals (e.g., psychiatrists and social workers) or the entire multidisciplinary team may want to implement the model.

Recruiting participants from a cross-section of the eating disorder population (e.g., younger patients, males, patients with different eating disorders, with a milder form of illness and those from different cultural backgrounds) could yield different data responses and may change the matrix of the shared decision-making model in terms of transferability and generalisability to other settings and cohorts. Future researchers should investigate these differences so that the model can be tailored to meet the needs of these groups. Finally, future studies should attempt to validate or refute the findings of this study. To contribute new
knowledge regarding SE-AN, researchers should pursue these areas of interest for further study.
Chapter 10: A Collaborative Care Model for Severe and Enduring Anorexia

10.1 Introduction

This chapter outlines the development of the ethical decision-making model. The construction of the theoretical model was based on the lived experiences of five women with SE-AN and includes the responses from health professionals. GT was used to develop a substantive theory that can best explain the conditions and processes that influenced the phenomenon. A brief overview of the model’s key aspects has been provided to enable the reader to conceptualise the model’s structure and purpose. The discussion will be framed in accordance with the ethical principles outlined in Chapter 3. This chapter concludes with a final statement and a discussion of this study’s contributions to new knowledge.

10.2 Overview of the Parameters of the Ethical Decision-Making Model

Consistent with the aims of this research (see Section 1.8), this thesis has identified a significant gap in the professional literature of anorexia relating to the knowledge of decision-making and the use of ADs in the care of adult females with SE-AN. Based on the research findings, this study demonstrated (and justified) the need to develop an ethical decision-making model, framed under the auspices of ADs, to guide health professionals to resolve ethical issues, give a ‘voice’ to women in decision-making and reduce the iatrogenic effects of hospitalisation for people with SE-AN. In addition, the model was designed to maximise patients’ autonomy, increase the uptake of PADs and reduce the need for involuntary hospital admissions. A fundamental component of this ethical model is based on collaboration, whereby all stakeholders (family members, health providers and patients) have an opportunity to contribute to meaningful decision-making. This feature is also found in other ethical decision-making frameworks involving eating disorder patients (Davis, 1997; Goldner et al.,
This model is underpinned by a social constructionist framework that explores the social aspects of decision-making—that is, people’s meaning and interpretations—from both a cognitive and an emotional viewpoint (Corey, Corey, Corey, & Callanan, 2014; Cottone, 2001). The purpose of this model is to ‘promote awareness’ and ‘contextual understanding’ of the ethical dimensions of decision-making processes and evaluative aspects when caring for people with SE-AN (Warren & McGee, 2013).

A basic tenet of this model of care is to remove any perceived hierarchical power structures that could impede decision-making. This can be achieved by restoring the power (control) imbalances through supported and substitute decision-making and by adopting a patient-centred approach (Alharbi et al., 2014; Coulter et al., 2008; Ng et al., 2013). This study identified the underlying social processes that contributed to women’s experiences (or perceptions) of coercion—that is, a lack of control (core theme)—especially in the decision-making process. Therefore, the results of this study support the ethical principle of respect for patient autonomy to increase decision-making participation through the use of PADs (Backlar & McFarland, 1998; Bogdanoski, 2009; Farrelly et al., 2014; Gallagher, 1998; O’Connell & Stein, 2005; Scheyett et al., 2008).

This model of care does not advocate the use of paternalism, whereby decisions are made without the consent of the patient (except in exceptional circumstances), and treatment should not be regarded as being punitive and demoralising (Coulter et al., 2008; Dresser, 1984b; Goldner, 1989; Thomasma, 1983). Instead, the model aims to promote autonomy and support collaborative decision-making while aiming to improve the quality of care for patients with SE-AN in the least restrictive environment possible (RANZCP, 2014).
Further, the model is not designed to resolve ethical dilemmas relating to paediatric patients (i.e., children and adolescents with EDs) where developmental (e.g., emotional regulation) and cognitive factors may affect the patient’s capacity to engage in informed treatment decision-making (Dresser, 1984b; Manley et al., 2001; RANZCP, 2014). Equally, the model is not designed for acute medical rescue when a patient is at imminent risk of danger. Rather, it is designed to address the AD issues that might arise before hospital care so all stakeholders can negotiate and achieve consensus in decision-making (Manley et al., 2001).

Given that most of the participants in this study were voluntary patients, this model is best suited to patients who are competent, not resistant to treatment, not on involuntary orders, not first-timers (hospital admission) and committed to recovery. Typically, this group of patients requires periodic care, either in the context of a short medical or therapeutic hospital admission, or a combination of other treatment interventions such as outpatient care (Bamford & Mountford, 2012; Geller et al., 2001; Robinson et al., 2015; Woodside et al., 2016).

The aim of this approach is to reduce the risk of having a severe prolonged episode of AN, reduce the frequency of hospital admissions, prevent an acute medical crisis, reduce the need for paternalistic measures, encourage voluntary treatment, improve quality of life and promote autonomy (APA, 2000; Bamford & Mountford, 2012; Conti et al., 2016; Dresser, 1984c; Geller et al., 2012; Lock et al., 2013; Marzola & Abbate-Daga, 2019; Srebnik et al., 2003; Wonderlich et al., 2012). This model of care is designed to support this treatment approach through the use of PADs.

Corey et al. (2014) stated that there is no one model that is effective and ‘fits’ within the experiences of all individuals. Rather, there is variability in their application requirements. This model is no exception. It offers flexibility in its application because it can be applied to a
diverse range of populations and in various contexts and cultures (see Section 7.8.4). It is a problem-solving model—*develop* (relationships), *identify* (safeguards), *engage* (decision-making), *improve* (quality of life) and *evaluate* (outcomes)—that is designed to be used in a systematic way and possibly in conjunction with other models (Fry & Johnstone, 2008).

A potential intermediary step that can be incorporated into the model to improve its design is the *implementation* phase. Future researchers could develop this step using quantitative methods and thereby increase its application and generality into other clinical environments (see Section 10.8).

However, there are limitations in using the model. Not every aspect of the model can be used and will vary according to legal, clinical and ethical considerations. For example, step 2 cannot be applied to those with severe physical or psychiatric conditions when ‘decisional capacity’ is limited or impaired and therefore prevents informed consent (Buchanan & Brock, 1989; Jonsen et al., 1999b). Step 3 may not be implemented because ADs may or may not be legally recognised in certain jurisdictions or countries (Atkinson, 2007; Dworkin, 1993; Scheyett et al., 2008; Schüklenk et al., 2011; Tamayo-Velázquez et al., 2010). Similarly, step 4 may not be applicable in countries where the right to die with dignity is prohibited, but it can be applied in countries (e.g. Switzerland, Netherlands, Europe, certain US states, Canada, Colombia, and of course, Victoria, Australia) where people have the right to choose to end their life (Hodel et al., 2019; Russell et al., 2019).

For each of the following steps, I will present an ethical dilemma based on the research findings and identify the relevant ethical principles (Forester-Miller & Davis, 1995; Roberts, 2002). Table 9.1 presents a list of recommendations to assist with problem-solving. Figure 10.1 illustrates how these steps are interrelated with each other. It is designed as a sequential model that consists of five simple steps to emphasise the collaborative nature of decision-making between stakeholders.
10.3 Ethical Decision-Making Process

10.3.1 Step 1: develop collaborative relationships

There is widespread recognition among health professionals that demonstrating the values of fidelity and veracity will help to build a strong therapeutic alliance with people with SE-AN, and it is a predictive factor in producing positive treatment outcomes such as reducing the symptoms of the illness (Ciao et al., 2016; Escobar-Koch et al., 2010; Hay & Cho, 2013; Ramjan & Fogarty, 2019; Yager, 1992). Although there is little empirical data to support this hypothesis (Marzola et al., 2019; Stiles-Shields et al., 2013; Zugai et al., 2018), the results of this study suggest otherwise.

It is a fiduciary requirement for health professionals to act in good faith towards their patients to develop a collaborative relationship (Beauchamp & Childress, 2001). This approach is underpinned by the principle of informed consent, whereby people’s rights and choices (i.e., the right to accept/refuse or withdraw from treatment) are respected in the decision-making process (Backlar, 2004; Buchanan & Brock, 1989; Capron, 1991; Charles et
al., 1997; Le Boutillier et al., 2011; Ouliaris & Kealy-Bateman, 2017; Rhee et al., 2012; Shields et al., 2014; Thornicroft et al., 2013; Weller, 2010; Zelle et al., 2015).

All major eating disorder clinical guidelines have endorsed this approach and advocated that building a secure and supportive therapeutic alliance between patients and doctors is a major contributing factor in helping people to recover from AN and reducing treatment refusal (APA, 2006; Geller et al., 2012; Goldner et al., 1997; NEDC, 2010; NICE, 2017; PACFA, 2011; RANZCP, 2014; Strober, 2004; Wonderlich et al., 2012). However, several studies have reported that a patient’s perception of coercion could significantly affect the building of a collaborative relationship with their doctors, thereby affecting their treatment and subsequent recovery (APA, 2000; Charles et al., 1997; Griffiths & Russell, 2000; Manley et al., 2001; Matussek & Wright, 2010; Mitrany & Melamed, 2005; Selvini-Palazzoli, 1978; Serfaty & McCluskey, 1998; Stirling et al., 2012; Tan et al., 2010; Werth Jr et al., 2003).

According to the literature review, developing a therapeutic relationship can lead to better healthcare outcomes for people with SE-AN. These include reducing their experiences of coercion, feeling more empowered, reducing feelings of treatment ambivalence and taking more responsibility for their recovery (APA, 2000; Colton & Pistrang, 2004; Dawson et al., 2014; Elzakkers et al., 2014; Offord et al., 2006; Ramjan & Fogarty, 2019; Sallas, 1985; Van Ommen et al., 2009). The findings of this study provide data to support this view. Patients want to build collaborative and trusting (fiduciary) relationships with health professionals to assist them in their recovery and reduce the need to use coercion (see Sections 8.7 and 9.3). They also appreciate the function of a multidisciplinary team approach and its benefits (see Section 8.7).

For the patient–doctor relationship to be successful and have therapeutic value in the care of patients with SE-AN, a number of relationship characteristics were identified as being important. In this study, participants reported that skills involving listening, maintaining a
non-judgmental attitude, empathy, respect and general psychological support (with less emphasis on the physical aspect of the illness) were important factors and were associated with an increase in patient satisfaction with hospital care (see Sections 5.1.5 and 8.5).

Based on these findings, this model recommends that health providers pay special attention to these skills to effectively engage and communicate with patients and their families. This will not only facilitate collaboration between stakeholders, but will also help to shift the focus from curative medical interventions to a more patient-centred focus.

This study also found that health professionals exhibited negative attitudes towards patients with SE-AN, which had a negative effect on the therapeutic relationship and treatment outcomes (see Sections 8.6 and 9.5). To overcome this pessimism, this model recommends that health professionals engage in regular training and education in relation to AN so they can be properly informed and be aware of possible prejudices that might compromise the therapeutic relationship (Geller et al., 2012). An experienced eating disorder specialist, such as a senior nurse or a consultant psychiatrist, could supervise and provide on-the-job training of new staff.

A number of studies have found that too much emphasis on the physical aspects of the illness, and not enough on the psychological aspects of care, have contributed to the development of a poor therapeutic relationship (Bell, 2003; Button & Warren, 2001; Cockell et al., 2004; Colton & Pistrang, 2004; Escobar-Koch et al., 2010; Federici & Kaplan, 2008; Noordenbos et al., 2002; Rance, Clarke et al., 2017; Scholtz et al., 2010; Williams & Reid, 2010).

This finding was reflected in the results of this study (see Section 9.4) and supports the ethical argument that too much emphasis on the physical aspects of the illness (i.e., forced feeding) compromise the therapeutic relationship and deter patients from seeking support in the future (Dresser, 1984b; Lewis, 1999; Matusek & Wright, 2010; Schreyer et al., 2016;

This study has shown that a collaborative patient–doctor relationship is associated with an increase in patient satisfaction with hospital care, as well as a decrease in the perception of coercion. Conversely, the pessimistic attitude of staff towards patients and their lack of psychological support results in an increase in the perception of coercion and a decrease in patient satisfaction and quality of care. For this model to be effective, a collaborative relationship between health professionals and patients is essential to assist patients with their treatment and recovery from SE-AN.

**10.3.2 Step 2: engage in respectfully shared decision-making**

This model is supported by the findings, whereby a person-centred informed decision-making approach was the preferred treatment for people with SE-AN (NEDC, 2012; RANZCP, 2014). While medical paternalism (‘doctors know best’) exists in clinical practice, particularly with highly complex at-risk patients (including anorexia), there is a growing body of evidence supporting a shared decision-making model of care (Breeze, 1998; Caplan, 2006; Charles, Whelan, & Gafni, 1999; Dworkin, 1986; Gillick, 2006; Lammers & Happell, 2004; Lloyd & King, 2003; Ouliaris & Kealy-Bateman, 2017; Patel & Bloch, 2009; Peto et al., 2004; Ritchie et al., 1998; Silber, 2011; Tamayo-Velázquez et al., 2010; Thompson et al., 2003). Thus, this thesis contributes to the existing body of research.

Respecting a person’s autonomy is instrumental in the success of the model. Therefore, this model incorporates the principle of ‘respect for autonomy’, whereby patients’ views and choices are respected and they have sovereignty over their medical care (Breeze, 1998; Caplan, 2006; Charles et al., 1999; Dworkin, 1986; Gillick, 2006; Lammers & Happell, 2004; Lloyd & King, 2003; Ouliaris & Kealy-Bateman, 2017; Patel & Bloch, 2009; Peto et al., 2004; Ritchie et al., 1998; Tamayo-Velázquez et al., 2010; Thompson et al., 2003). Thus,
they can choose whether to participate in shared decision-making (Charles et al., 1997; Coulter et al., 2008; Waterworth & Luker, 1990; Weinryb, 1995).

It has been strongly debated in the literature whether respecting a patient’s treatment preferences is more beneficial than forced treatment for their recovery from anorexia in the long term (Dresser, 1984c; Dresser & Boisaubin Jr, 1986; Jonsen et al., 1999b; Silber, 2011). There is strong empirical evidence to support this assertion (see Sections 5.1.6 and 8.5). Thus, when there is an emphasis on the patient’s treatment preferences and goals, and when they have the opportunity to participate in the decision-making process, patients feel valued and respected, less coerced and have a propensity to seek help regarding their illness (Goldner et al., 1997; La Fond & Srebnik, 2002; Winick, 1999).

In contrast, when patients are not included in the decision-making process, especially in clinical ward rounds, they feel a sense of disempowerment and a lack of control in managing their illness and are reluctant to engage in the treatment program (see Section 8.5). Clinical ward rounds are one of the few opportunities for patients and their clinical team to interact and build rapport by sharing information and asking questions. However, this was not the case for many of the participants in this study. They felt left out of the decision-making process and questioned whether there was any point to the ward rounds at all. Not only does this reduce the effectiveness of the ward rounds, but it reduces the patient’s sense of control and confidence in the decision-making process (see Sections 5.1.6 and 8.5). This finding also confirms that power differentials exist and remain a barrier for many women to take control of their medical care.

The debate regarding beneficence versus respect for autonomy often depends on a person’s competency (see Section 5.1.8). This model has developed a number of built-in strategies to address this key concern. For example, if a person has an existing PAD, it is recommended that their treatment preferences be carried out and honoured. Indeed, this would
be considered an act of respecting a person’s autonomy—an outcome that has been supported by previous studies (Backlar, 1999; Backlar et al., 2001; Kim et al., 2007; Srebnik et al., 2003; Swanson, Swartz, Elbogen et al., 2006). The respondents in this study supported the provision of a PAD in the event of losing their ability to make informed choices (see Section 8.5).

In addition, the ethical model has the provision that a person’s PAD can be revoked. However, before revoking a person’s PAD, it is recommended to integrate Goldner’s (1989) treatment refusal principles (see Section 5.1.7) to negotiate with the patient (and the patient’s family) until there is a consensus that the patient is not at risk of harm.

Based on the participants’ descriptions, if a person is presenting as incompetent—that is, is ‘not of sound mind’—and wants to change an existing PAD to their detriment (e.g., withdraw from hospital care), breaching their autonomy is justified to prevent possible harm (see Section 8.5). This finding coincides with Tan et al.’s (2010) study, in which 29 patients and their parents agreed that treatment refusal should be overridden if a person’s life is at stake. Similarly, a number of models of care support the doctrine of treatment imposition when a patient’s life is at risk (Goldner, 1989; Woodside et al., 2016; Yager, 1992).

Protecting a person’s safety (beneficence) outweighs the potentially harmful effects on the person (breaching their autonomy) when forced medical treatment is necessary (Maher & Rosedale, 1993). Therefore, it could be assumed that this finding supports the ‘thankyou theory’, in which a person retrospectively agrees that forced hospitalisation was justified (see Section 3.3.1) to save their life. This finding correlates with previous studies (Appelbaum & Rumpf, 1998; Faith, 2002; Tan et al., 2010; Watson et al., 2000), which found that coercion was justified to protect patients’ best interests. The APA (2006) has also endorsed involuntary civil commitment to intervene ‘respectfully with patients whose judgment is severely
impaired by their psychiatric disorders when such interventions are likely to have beneficial results’ (p. 16).

Some concerns have been raised about overriding a person’s PAD. Previous studies have shown that not honouring a person’s AD is considered a major disincentive for those wishing to complete an AD (Backlar, 2004; Henderson et al., 2008; Kim et al., 2007; Scheyett et al., 2007; Sellars et al., 2016; Srebnik & Fond, 1999; Swanson et al., 2000). This would undermine a person’s dignity and trust in the mental health system, and it underscores the importance of legal protection within the human rights context of having a PAD (Weller, 2010). Despite these concerns, overriding a person’s PAD is legally permissible in the state of Victoria under the Mental Health Act; indeed, it is supported by retrospective consent (Griffiths et al., 1997; Guarda et al., 2007; Katsakou & Priebe, 2007; Manley et al., 2001; Tan, Hope, Stewart et al., 2003; Tan et al., 2006).

Respectful shared decision-making involves engaging with other relevant stakeholders, particularly family members (including caregivers) and significant others, which is in line with previous studies (Campbell & Peebles, 2014; Commonwealth of Australia, 2013; Geller et al., 2012; Ho, 2008; NICE, 2017; RANZCP, 2009; Silber, 2011; Wonderlich et al., 2012).

The rationale behind this approach is to capture a broad range of views about a person’s circumstances in both current and historical contexts (e.g., identify treatment strategies that have previously worked or not worked), especially during periods of instability, when a person’s competency has been compromised (Atkinson, 2007). The advantage is that a proxy (friend or family member) can provide assistance and negotiate on the patient’s behalf during the assessment and treatment process (RANZCP, 2014; Russell, 2001) and therefore make substitute judgments or best-interest medical decisions (see Section 3.3) (Atkinson, 2007).
The results from this study support the inclusion of family members and others, either directly or indirectly, in the decision-making process (see Section 8.5). Therefore, this model recommends that health professionals provide decision-making opportunities for patients and their family members during hospital care. This can be achieved through participation in ward rounds, decision-making aids such as PADs and treatments plans, and conducting informal conversations with healthcare workers.

Further, it is imperative that health professionals provide sufficient time for each patient so they can discuss their personal concerns and receive answers to questions regarding their medical care. In fact, in the literature on PADs, ‘lack of time’ has been identified as a barrier in the uptake and implementation of PADs (see Section 4.4.3), and this fact needs to be acknowledged when using this model, particularly when determining a suitable time to introduce PADs (see Section 8.5).

This section concludes that providing opportunities for patients and their families to participate in the decision-making process will increase collaboration between stakeholders and provide patients with a greater sense of control and confidence in their recovery. Further, it will reduce the power differentials that have inherently shaped the patient–doctor relationship, thereby providing a more level playing field in the decision-making process.

10.3.3 Step 3: identify safeguards to optimise the quality of patient care

This model has identified a number of safeguards, framed under the ethical principle of nonmaleficence, to reduce the iatrogenic effects (coercive interventions) of hospital care and improve the quality of care for people with SE-AN (see Section 8.6).

In this study, all five women have endorsed and supported the use of PADs to safeguard their ‘best interest’ and reduce the risk of coercion. For example, all participants preferred to be placed in a specialist eating disorder unit rather than a general medical hospital
ward, where they were subjected to a higher level of coercion and were stigmatised and judged differently on the basis of their illness (see Section 8.6).

To reduce the risk of stigma and discrimination in healthcare settings and improve patients’ wellbeing, this model of care recommends referring SE-AN patients to specialised eating disorder facilities. This accords with the ethical principle of justice whereby people should have access to treatment and support services free from discrimination, and that meet their individual needs (Roberts & Dyer, 2007). The NEDC’s (2012) practice principles have endorsed this approach to treatment: ‘People have access to treatment and support services when and where they are needed, early in the illness and early in each episode of illness’ (p. 22). Similarly, the NICE’s (2017) general principles of care state:

Ensure that all people with an eating disorder and their parents or carers (as appropriate) have equal access to treatments (including through self-referral) for eating disorders, regardless of: age gender or gender identity (including people who are transgender), sexual orientation, socioeconomic status, religion, belief, culture, family origin or ethnicity, where they live and who they live with, any physical or other mental health problems or disabilities. (p. 5)

Another safeguard to protect patients from acts of coercion and optimise the quality of care is to implement their PAD as part of their treatment plan. All participants, including focus group members, recognised that PADs can provide a range of healthcare benefits and can be used as a tool to enhance collaboration between patients and their multidisciplinary team. These benefits were highlighted in the findings chapter and are in line with previous studies (see Sections 4.3 and 8.5).

Perhaps one of the most effective strategies to apply to lessen the risk of professional coercion and to reduce the severity, duration and impact of the illness, is to develop early intervention and educational programs—a point that has been reiterated in the AN literature (Agras et al., 2004; Elzakkers et al., 2014; Geller et al., 2012; Natt, 2018; NEDC, 2012; NICE, 2017; Steinhausen, 2002; Turrell et al., 2011; Walsh, 2013).
For example, educating family members, caregivers and adolescents (especially those aged 15–19) about the benefits of early detection and diagnosis, the factors that cause and maintain the illness, and the medical consequences and its long-term effects (e.g., mortality) can assist in breaking down barriers (e.g., shame and denial) and stereotypes and can help with recovery (Campbell & Peebles, 2014; Crisp, 2005; Geller et al., 2012; NEDC, 2010). Strober (2004) adopted a similar approach in his model of care.

Similarly, providing educational training for health professionals, especially GPs and nurses (Linville et al., 2010; Newton et al., 1993; Noordenbos et al., 2002), could lead to a better understanding of the psychological and physical risk factors of the illness and therefore assist in the early detection of AN. It could also reduce negative attitudes and pessimism towards patients with SE-AN. A number of studies have reported that specialised training for eating disorder staff is required to effectively manage patients during all stages of the illness (Geller et al., 2012; Jarman et al., 1997; NEDC, 2012). The NEDC (2012) recommended that ‘training includes the development of attitudes and practices that support early identification and intervention and a person-centred and recovery-oriented approach’ (p. 75).

The findings of this study support this conclusion. Many of the focus group participants had little or no training in treating eating disorders and relied on senior staff to provide guidance and direction. Similarly, participants (patients) described instances in which they had contact with doctors and nursing staff who had little understanding of their condition (see Section 8.7).

This model suggests that eating disorder services should be more flexible in their approach to the management of people with eating disorders, especially among individual subgroups, and not assume that people’s needs are the same simply because of their diagnosis. That is, there is no ‘one-size-fits-all’ treatment when providing general psychiatric care. These recommendations are consistent with the findings of previous studies (Escobar-Koch et
al., 2010; Ramjan & Fogarty, 2019). The NICE (2017) expressed a similar concern and recommended the following:

*Children, young people and adults with an eating disorder who are admitted today for inpatient care should be cared for in age-appropriate facilities (for example, paediatric wards or adolescent mental health services). These should be near to their home and have the capacity to provide appropriate educational activities during extended admissions. (p. 32)*

Therefore, patients should not be limited to a certain type of treatment approach but should be offered a range of treatment options that will suit their individual needs (see Section 2.9). This sentiment was echoed by the NICE (2017), which stated that health professionals should ‘explain to the person what the treatments involve to help them choose which they would prefer’ (p. 41). Adopting this approach would give the patient a sense of control over their medical care and help them feel part of the decision-making process. Based on the research findings of this study, patients generally know what works and what does not work regarding their medical care and treatments, and this has largely been attributed to the maturity of their experience (see Section 8.4). This accords with Yager’s (1992) model of care.

In summary, health providers have a responsibility (duty of care) to maintain a competent standard of practice (training) to ensure that an adequate standard of care is being provided to people with SE-AN.

**10.3.4 Step 4: improve the quality of life for people with SE-AN**

In the literature concerning PADs, the most commonly presented justification against their use is that a person could use them as a tool to refuse future treatment (Appelbaum, 2004; Backlar, 2004; Backlar et al., 2001; Elbogen et al., 2006; Farrelly et al., 2014; Geller, 2000; Henderson et al., 2008; Kim et al., 2007; Scheyett et al., 2007; Srebnik & Brodoff, 2003; Vuckovich, 2003). The following analysis will reveal the extenuating circumstances in which this attitude is appropriate and justified. Currently, most ethical models of care relating
to eating disorders focus on the preservation of life (Goldner et al., 1997; Manley et al., 2001; Matusek & Wright, 2010; Melamed et al., 2003).

However, the model in the present study supports and acknowledges a person’s right to consent to or refuse treatment in whatever form (Campbell & Aulisio, 2012; Draper, 2000). The justification for this is that it allows the patient to be in control of the decision-making (when there is evidence of competency). Further, it reduces treatment resistance (Draper, 2000; Goldner, 1989; Strober, 2004; Strober, 2010).

The AN literature has established that curative treatments have not been successful in improving health outcomes for people with SE-AN (Geller et al., 2012; Kendall & Hugman, 2014; RANZCP, 2014). More recent research has suggested that a focus on improving quality of life, combined with a supportive milieu, is more conducive to supporting the needs of people with SE-AN (Andersen et al., 1997; Conti et al., 2016; Geller et al., 2012; Goldner et al., 1997; Lock et al., 2013; Stockford et al., 2018; Strober, 2004; Williams et al., 2010; Wonderlich et al., 2012). Therefore, this model of care advocates the use of alternative approaches such as palliative care, framed under the auspices of PADs, to improve quality of life when other methods of care have failed and offer no relief to those experiencing SE-AN (Draper, 2000; Sjöstrand et al., 2015).

The WHO Quality of Life (WHOQOL Group) (1998) defined quality of life as an individual’s ‘perception of their position in life in the context of the culture and values systems in which they live and in relation to their goals, expectations, standards, and concerns’ (p. 551). One such concern is the issue of treatment refusal. Many patients who have endured a life-threatening illness, including anorexia, and who have experienced all types of treatments (inpatient and outpatient treatment care, medications and psychotherapy) and found them to be unsuccessful, reach a point in their life where their life is not worth
living, and they make a conscious decision to withdraw from treatment (Campbell & Aulisio, 2012; Kaplan & Strober, 2019).

In this study, one participant adamantly stated that she did not want to continue with treatment: ‘I would want no treatment and I would hope that that would end my life’, but her request was denied in the context of suicide ideation and she was subsequently placed on an involuntary order (see Section 8.7). Suicide ideation is considered by many a moral justification for imposed involuntary treatment, but it remains a contentious issue (Cutcliffe & Links, 2010; Maher & Rosedale, 1993; Sjöstrand et al., 2015). While some scholars may be quick to defend and support this justification (Fost, 1984; Lopez et al., 2010; Melamed et al., 2003), many libertarians would consider it a violation of a person’s autonomy, choice and their right to bodily integrity (Boyle, 2019; Draper, 2000; Lewis, 1999; Loewy, 2004; Schüklenk et al., 2011; Yager, 1992). One qualitative study reported that suicide may be ‘rational’ to end one’s suffering from a psychiatric illness (Sjöstrand et al., 2015, p. 8), while another reported that suicide could be justified for ‘humanitarian reasons’ (Barker & Ritter, 1998, p. 64). Westmoreland and Mehler (2016, p. 318) described suicide as an act of ‘compassion’, and the results of this study support this view (see Section 8.6).

Mary has a 10-year history of SE-AN, experienced multiple hospital admissions including ICU (20 in total) and endured all forms of treatment, including nasogastric and forced medications (i.e. Depot), but has failed to respond to the treatments and has expressed a wish for no further medical intervention. She has five children in total, including a set of twins. Her husband abandoned her shortly after the twins were born, and she has a family history of anorexia, with two cousins experiencing longstanding eating disorders. Mary feels that she has ‘ruined her kid’s lives’ and does not think that she ‘deserves to be healthy and well and have a good life’. She believes that she is in the final stages of her psychiatric illness (see Section 8.6).
This case is similar to the scenario presented by Gans and Gunn Jr in Chapter 1, in which the patient (Mrs Black) had exhausted all treatment options and finally reached the end stage of her illness when her life was unbearable to live and she decided to withdraw from further treatment. In both cases, the Hippocratic Oath to do no harm was applied to ensure the preservation of human life, despite the fact that both patients were ‘of sound mind’ to make an informed decision to refuse medical treatment. However, there is an important difference between the two cases. Mrs Black was eventually granted the right to refuse treatment, but this was rejected in Mary’s case. Sadly, there are many people like Mary who have not been granted the right to refuse treatment and therefore remain ‘in limbo’ to this day (Woods et al., 2008). In these cases, it is fair to say that social paternalism has overridden the person’s autonomy on the grounds of beneficence (Beauchamp, 2019).

In the medical literature, it appears that those with physical illnesses—as opposed to psychiatric illnesses—fare much better in obtaining the right to refuse treatment, supported by the principle of ‘best interest’ (Boyle, 2019; Campbell & Aulisio, 2012; Draper, 2000; Geppert, 2015; Halpern & Szmukler, 1997; Hodel et al., 2019). For example, Jehovah’s Witnesses can refuse a blood transfusion or refuse artificial nutrition that might otherwise prolong their life (Atkinson, 2007; Caplan, 2006; Draper, 2000; Dworkin, 1986; Gillick, 2006; Shields et al., 2014; Swanson et al., 2000). Similarly, cancer and dialysis patients are able to exercise their right to terminate their treatment and consciously decide to end their life (Lopez et al., 2010; Yager, 1992; Yager et al., 2016). People who experience protracted periods of suffering—especially those with a neuropsychological illness such as Parkinson’s disease—and those with profound physical disabilities (e.g., haemophilia, cystic fibrosis and cerebral palsy) can choose to end their life in countries where assisted suicide is legalised (Giordano, 2010; Hodel et al., 2019). Starzomska (2006) even suggested that prisoners (while
competent) have the right to refuse food (hunger strike), knowing that they will die as a result of their starvation.

In contrast, people with severe psychiatric disorders (not all, of course) and who are frequently hospitalised because of their mental illness are not able to refuse treatment, even when they have demonstrated full decisional capacity (Brock, 1993; Draper, 2000; Miller, 1998; Shields et al., 2014). This stems from the ethical imperative of beneficence in which all lifesaving measures should be employed to keep a person alive despite their suffering (Fost, 1984). A point in case is anorexia, which is viewed by the medical profession (endorsed by the DSM) as a ‘reversible and treatable psychiatric condition’. This view firmly states that people with psychiatric disorders do not suffer from a terminal illness (Melamed et al., 2003), which precludes them from withdrawing from medical care (Draper, 1998; Lopez et al., 2010). Further, this attitude perpetuates a social stigma and isolates patients whose condition requires holistic care that is beyond the scope of traditional lifesaving medicine (Campbell & Aulisio, 2012; Draper, 2000).

Gans and Gunn Jr (2003) offered a different view. They argued that there are unique circumstances in which a person’s right to refuse treatment is permissible based on the following criteria: evidence of a ‘long chronic illness, multiple treatment failures, poor quality of life, and possible irreversible medical complications’ (p. 684). These criteria rely on the patient retaining competence to refuse treatment (see Section 5.1.8). Of course, if there is any doubt about a person’s ability to understand the consequences of their decision to refuse treatment, then all precautions should be taken to avoid unnecessary loss of life (Giordano, 2010).

There are numerous case studies in the AN literature where people with SE-AN have endured years of medical treatment without symptom relief and have pleaded with their health providers to refuse treatment, but their requests were denied, despite having competence
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(Campbell & Aulisio, 2012; Coggon, 2014; Fost, 1984; Giordano, 2010; Hebert & Weingarten, 1991; Maher & Rosedale, 1993; Melamed et al., 2003; Wang, 2015). Dally (1969) believed that people who have had an illness for more than seven years and experienced multiple hospital admissions often lead ‘miserable semi-invalid lives’ (p. 53) with a reduced quality of life. This was echoed by Nordbø et al.’s (2006) study, where two participants wanted to die. They recognised that their eating disorder was an expression of suicide (starving oneself to death) and described their lives as unbearable.

This invites the question: Is Mary any less deserving of respect and humane treatment simply because she has a psychiatric illness in which her burden of symptoms may not be comparable with those across other patient groups who have also suffered a protracted period of suffering? Further, how does the arbiter (e.g., family members, friends or clinicians) determine a person’s degree of ‘suffering’ (physical or psychological)? Moreover, what does this look like for the sufferer, to enable the arbiter to make an accurate appraisal (ethical, legal or clinical assessment) of a patient’s quality of life to either withdraw or withhold medical treatment? Kaplan and Miles (2016), and Russell et al., (2019) suggested that the way to mitigate any potential biases is to seek the assistance of independent (medical) ethicists to determine the validity of these appraisals. Indeed, such an approach would allow more scope for objective decision-making and ensure that the person’s wishes and values are respected.

Giordano (2010) asked: Should anyone (while competent) be forced to continue to ‘live in agony’ despite their preference to end their life? She defended the argument that being terminally ill or suffering unbearable pain where there is no remedy can be a moral and ethical justification for allowing a person to end their life according to their values and wishes. Draper (1998) made the distinction between ‘prolonging life and saving it’ (p. 5). She asserted that there are those who respond to curative measures and eventually recover, but for others (a small group of incurable patients), the prolonging of life has no bearing on their
quality of life, and they will never be grateful or thank those who have forced medical
treatment upon them. Even the European Convention on Human Rights recognises that:

Forcible feeding over a long period of time against her clearly expressed wishes,
most especially with the use of physical restraint, is likely ... to amount to
inhuman or degrading treatment, [and] certainly it would amount to severe
interference with her life and personal autonomy. (Wang, 2015, p. 875)

To improve the quality of life for adult women with SE-AN, this model supports and
respects a woman’s right to withdraw from treatment when she has the capacity to make
collaborative decisions with her treating team, her family or her significant other. Indeed,
such a stance can be viewed as supporting a person’s self-determination and autonomy and
accords with their values and life plans (PADs), and it gives her a sense of self-worth, dignity
and, more importantly, control (Campbell & Aulisio, 2012; Dresser, 1984b; Dresser &
Boisaubin Jr, 1986; Geller et al., 2012).

Mary’s situation highlights the juxtaposition between the ethical principles of
beneficence and self-determination (Maher & Rosedale, 1993; Scolan et al., 2013; Woods et
al., 2008; Yager, 1992). This case highlights the ethical challenges (i.e., duty of care v.
autonomy) faced by many health professionals when providing healthcare to patients who
want to die. Conversely, it also shows the difficulties faced by patients when entering into a
healthcare system that is designed to provide life-preserving treatment, which contributes to
their sense of a lack of control (Davies et al., 2012; Woods et al., 2008). One wonders how
long it will take and how much suffering Mary will endure before she is given the same rights
as those who have fought and been granted the right to end their life according to their
religious beliefs—or their indelible rights based on their physical conditions.

10.3.5 Step 5: evaluate the model’s performance

All models of care need to be periodically evaluated to determine their usefulness and
value and to ensure that they are consistent with good clinical practice (O’Meara, Maguire,
Jennings, & Simpson, 2015). A central motif of this ethical model is to involve all
stakeholders in the decision-making process to ensure transparency and accountability of the model’s effectiveness (Varekamp, 2004). This practice can be viewed as promoting collaboration and inclusion, which is consistent with the ethical principles of fairness and equality (Roberts & Dyer, 2007).

Most ethical models have in-built strategies to combat and prevent decision-making biases (Cottone & Claus, 2000; Manley et al., 2001). One such strategy is to conduct regular focus groups. A symbolic interactionalism approach can be applied to focus groups to identify underlying values, beliefs and worldviews of the participants (Crotty, 1998).

These groups can provide a large amount of information from different perspectives over a relatively short period (Liamputtong, 2013a; Marshall & Rossman, 2010). In addition, focus groups can be initiated at any time, are cost-effective and can be delivered in different formats (e.g., face-to-face, phone and internet) and settings (Kitzinger, 2003; Morgan, 1996; Stewart & Shamdasani, 2014).

Typically, they are facilitated by an experienced moderator whose role is to stimulate and direct conversations between group members and monitor group dynamics (Liamputtong, 2013a; Marshall & Rossman, 2010; Morgan, 1996; Stewart & Shamdasani, 2014). These discussions should be focused on specific issues relating to the topic (Hennink et al., 2010; Kitzinger, 2003).

Liamputtong (2013a) and Stewart and Shamdasani (2014) suggested that group sizes should vary from six to 12 participants, but in some instances, they can support a higher number of participants (but no more than 15). Hennink et al. (2010) advised a period of 60–90 minutes to ensure adequate coverage of the topics. The concept of saturation can also be applied to focus groups (Berglund, 2001).

It is common to use either a purposive or convenience sampling method to recruit participants, both of which are suitable for this model (Liamputtong, 2013a; Stewart &
Shamdasani, 2014). To contribute to the group discussion, all recruited participants should share a common interest (Berglund, 2001; Stewart & Shamdasani, 2014). A summary of the key points can be collated and distributed to members to determine their validity. This feedback could then be gradually incorporated into the model. This consultative process invites all stakeholders to engage in deeper and more thoughtful dialogue about clinical, legal and ethical considerations regarding the delivery and provision of healthcare. It also becomes an opportunity for clinicians to use one another as ‘sounding boards’ to reflect ideas and viewpoints when providing patient care (Stewart & Shamdasani, 2014).

Further, it provides a means of ‘checks and balances’ when assessing and examining the values and beliefs of the various parties. Some of these may lead to an abuse of power and control (e.g., pro-life and other agendas) and may influence the ethical decision-making process (e.g., coerced treatment) and undermine the model’s reliability (Coulter et al., 2008; Draper, 2000). In addition, stakeholders can identify the limitations or strengths of the model (Hill et al., 1998). Overall, this collaborative process will encourage an open, flexible style of communication that limits the chance of autocratic leadership, which can lead to an imbalance of power (Liamputtong, 2013a).

The rationale of the evaluative process is to allow the model to evolve and to calibrate it in accordance with the individual needs of women with SE-AN. In addition, the information can be used to determine whether the model can be adapted to various settings and cultural contexts (see Sections 8.5 and 7.8.4). Of course, the evaluative process is not limited to qualitative methods; quantitative measurements can also be applied. For example, questionnaires involving a Likert-type scale are useful for evaluating and measuring people’s perceptions and attitudes regarding the model’s efficiency and effectiveness (Berglund, 2001; Charles et al., 1997; Coulter et al., 2008; O’Leary, 2014). This can be helpful in assessing the performance of healthcare professionals in the implementation of PADs.
It would be a gradual process to tailor and implement the model to suit the needs of individual clinical settings (Alharbi et al., 2014) and may require additional external support (i.e., those with prior experience) not necessarily from eating disorder professionals, but from clinicians from other settings, such as palliative and geriatric fields, who may have adopted a similar model of care into their workplaces.

10.4 Conclusion

Based on the research findings, a five-step inductive model of care has been developed, framed under the auspices of PADs, to address ethical concerns (e.g., iatrogenic effects of hospital care) relating to the care of people with SE-AN. The key components of this model are to build a collaborative relationship between the patient and the doctor (see Section 10.3.1), engage in participatory decision-making (see Section 10.3.2), identify appropriate safeguards to protect against coercion (see Section 10.3.3), recognise a person’s quality-of-life decisions (see Section 10.3.4) and evaluate the model’s performance (see Section 10.3.5). This thesis concludes that the principles of beneficence and autonomy are not mutually exclusive; rather, they can be integrated into an ethical shared decision-making model to inform clinical practice.

The core theme of a ‘lack of control’ was identified as the main problem that prevents women from recovering from SE-AN. Therefore, this model was designed, throughout all of its stages, to provide adult women with SE-AN with a voice that will enable them to gain a sense of control and power over their medical care. Table 10.1 features a number of recommendations to enable clinicians to effectively engage with people with SE-AN and thereby minimise the risk of coercion.
<table>
<thead>
<tr>
<th>Step 1: Key recommendations to develop a collaborative relationship</th>
<th>Step 2: Key recommendations to engage in respectful decision-making</th>
<th>Step 3: Key recommendations to identify safeguards to optimise patient care</th>
<th>Step 4: Key recommendations to improve the quality of life for people</th>
<th>Step 5: Key recommendations to evaluate the care model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop a relationship that is built on openness, honesty and trust</td>
<td>Adhere to the principle of respect for autonomy</td>
<td>Adhere to the principle of respect for autonomy</td>
<td>Respect a person’s life plan, decisions and goals</td>
<td>Incorporate feedback at all stages of the model</td>
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<tr>
<td>Maintain good listening skills, a non-judgmental attitude and an empathic stance</td>
<td>Integrate Goldner’s (1989) treatment refusal principles</td>
<td>Respect a person’s maturity of experience. Identify what works and what does not work regarding their medical care</td>
<td>Respect a person’s right to bodily integrity</td>
<td>Must be periodically reviewed to ensure its relevance and performance</td>
</tr>
<tr>
<td>Regular training about SE-AN will help to reduce negative attitudes and pessimism</td>
<td>Facilitate participatory decision-making in ward rounds so that patients are properly informed about the risks and benefits of treatments</td>
<td>Provide general education and training regarding the condition of anorexia</td>
<td>Have discussions with patients at the end of the hospital admission</td>
<td>Conduct regular focus groups with all stakeholders</td>
</tr>
<tr>
<td>Delivery of healthcare involves the inclusion of families and significant others</td>
<td>Promote the inclusion of families and significant others in decision-making</td>
<td>Build collaborative relationships between specialised eating disorder and general mental health nursing staff</td>
<td>Respect a competent person’s right to refuse treatment</td>
<td>Can be used as a screening tool to detect biases and prejudices in decision-making</td>
</tr>
<tr>
<td>More emphasis on psychological care for patients with SE-AN</td>
<td>Beneficence outweighs autonomy in the context of patient safety</td>
<td>Implement PADs as a means to enhance collaboration and encourage</td>
<td>Explore the use of alternative models of care (i.e., palliative care)</td>
<td>Can be adapted to fit other patient groups</td>
</tr>
<tr>
<td>Step 1: Key recommendations to develop a collaborative relationship</td>
<td>Step 2: Key recommendations to engage in respectful decision-making</td>
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<tr>
<td>Use a multidisciplinary team approach to enhance collaboration</td>
<td>Honour and respect PADs to enhance collaboration</td>
<td>Initiate appropriate referrals to SEDCs</td>
<td>Listen to the views of family members and significant others</td>
<td>Supports a collaborative rather than an autocratic style of communication</td>
</tr>
<tr>
<td></td>
<td>An existing PAD can be revoked when there is evidence of incompetency</td>
<td>Seek informed consent and explain treatment options</td>
<td>Develop collaborative and supportive relationships</td>
<td>Recommends the use of a purposive or convenience sampling method to recruit members</td>
</tr>
<tr>
<td></td>
<td>Engage in person-centred informed decision-making to increase a person’s sense of control and confidence</td>
<td>Where possible, encourage voluntary hospital admission</td>
<td>Consider a person’s meaning and perception of ‘suffering’ within a historical and current context of illness</td>
<td>Recommends 6-12 participants</td>
</tr>
<tr>
<td></td>
<td>Provide sufficient time for patients to evaluate PADs; meetings should be conducted on a regular basis (not just weekly ward rounds)</td>
<td></td>
<td>Honour and respect a person’s PAD or proxy representative</td>
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</table>
10.5 Final Conclusion

This doctoral thesis was based on the (revised) research question: Can PADs minimise the iatrogenic effects of psychiatric care for women with severe and enduring anorexia? In answering this question, it was recognised that PADs are a new ‘paradigm for management’ of people with SE-AN and offer a solution to the ethical debate of forced treatment.

The literature review confirmed that PADs can be an effective tool to improve the quality of care for people with SMIs and thereby reduce the need for coercion. The findings from this study support this assertion. All participants were in favour of PADs; however, a lack of knowledge about their purpose and applicability prevented their uptake. The literature review demonstrated that this absence of knowledge and information prevents women from engaging in decision-making regarding their care. It also denies them the opportunity to have a ‘voice’ and take responsibility for their own illness. This study confirmed these findings. All five women wanted to maintain a sense of ‘control’ and self-direct their healthcare based on their treatment preferences and their ‘maturity of experience’ of living with the illness, but were instead subjected to coercion. The study concluded that coercion remains an ethical concern for people with SE-AN. Many anecdotal accounts revealed that coercion robs people of their dignity and autonomy, contributes to the chronicity of the illness and, more importantly, prevents women from recovering. The women in this study unanimously felt a sense of a ‘lack of control’.

One of the basic tenets of PADs, and of this thesis itself, is to promote social justice. All five women in this study experienced oppression and marginalisation. The interpretation of the findings of this study showed that issues of power differentials, staff pessimism and health service inequalities were contributing factors to this social phenomenon. To address these systemic issues, an ethical model was inductively built. The purpose of the model is to empower marginalised women in their emancipation of psychiatric care and to provide
clinical direction to clinicians to develop more collaborative ways to assist women in their health and recovery.

There is a growing body of evidence to support a new paradigm approach to the care of people with SE-AN. The results of this study support this view. This requires a shift in values and ethics—from paternalism to supported decision-making—where people have ‘real’ choices in their care, even when this choice includes ending their life. It also requires a change in clinical practices, with more emphasis placed on the coordination of services and clinical referral pathways among allied health professionals and specialist eating disorder services. A change in staff attitudes and behaviours towards patients with SE-AN is warranted; this can be achieved through additional supervised clinical training. In turn, this may bring about change. For instance, instead of adopting a punitive, adversarial approach in which a woman feels disempowered and blamed for their illness, a more collaborative approach could be achieved through the use of PADs, in which the woman’s values and wishes are respected and they feel supported in their efforts towards recovery.

The AN literature supports the conclusion that adopting a person-centred approach with a focus on developing a collaborative alliance with patients with SE-AN produces better clinical outcomes. All participants valued the importance of having a therapeutic relationship in which they felt heard and understood, and in which their autonomy was respected. Until these changes are made, it will be difficult to challenge the systematic issues related to involuntary treatment.

Today, it is an ethical imperative to remove the ‘shackles of paternalism’ and work towards a consumer-focused model of care in which women have more control and ownership of their mental health and in which their ‘voices’ are being heard respectfully. This can instil hope and ultimately restore a person’s ‘ontological view of the self’ as a ‘capable’, ‘resilient’ and ‘autonomous’ being to overcome their illness.
10.6 Contributions to Knowledge

The main purpose of writing a doctoral thesis, and indeed a requirement, is to make a significant original contribution of knowledge to a specific field of study and thereby develop a solution to the research problem (Blaxter, Hughes, & Tight, 2001; Bloomberg & Volpe, 2015; Evans et al., 2011; Hennink et al., 2010; Holloway, 2005b; O’Leary, 2014; Oliver, 2013; Phillips & Pugh, 2010; Sengstock, 2008).

Charmaz (2006) believed that qualitative researchers generally contribute new knowledge by building on or extending the ideas of others—that is, putting ‘a fresh slant on existing knowledge’ (Goulding, 1998, p. 51)—or by introducing different research methods of learning and applying them to the research question. To date, there are few published studies on women with SE-AN; therefore, little is known about the phenomenon (Conti et al., 2016; Stockford et al., 2018). To the author’s best knowledge, this research is ground-breaking because it is the first time that the GT method has been used to build a model of care involving adult women with SE-AN.

Different definitions of ‘new knowledge’ have been summarised by Phillips and Pugh (2010, p. 62). However, these definitions refer to quantitative research and are reflective of the language used to describe this new knowledge. Words such as ‘testing’, ‘material’, ‘synthesis’ or the use of a single technique all have meaning when using quantitative methods, but they are not relevant to qualitative research.

In contrast, Kvale (1996) stated that one of the major tenets of social research is to ‘contribute knowledge to ameliorate the human condition and enhance human dignity’ (p. 109). This line of thinking is supported by the physicist Richard Feynman, who stated that ‘[w]e are at the very beginning of time for the human race. It is not unreasonable that we grapple with problems … Our responsibility is to do what we can, learn what we can, improve solutions, and pass them on’ (Feynman, 2007, p. 54). In light of these words, the proposed
Ethical model was designed to enhance women’s self-agency, preserve their dignity and alleviate their psychological suffering (coercion) through the use of advance care planning when receiving hospital care.

On a practical level, some researchers (particularly of feminist research) advocate that research findings should be useful in creating social justice for women (Charmaz, 2012; Wuest, 2011). Juliet Corbin, an influential writer on GT, stated that ‘I am practical in what I want to accomplish with my research … I want to develop knowledge that will guide practice … I want to bring about change’ (p. 27). These words formed the framework of this thesis.

This research pays homage only to women’s ‘voices’ (Jo, Mary, Jade, Sue and Amy) and therefore eliminates the androcentric male view (Gillies & Alldred, 2012; Henwood & Pidgeon, 1995; Marshall & Rossman, 2010; Matoff & Matoff, 2001). Indeed, listening to women’s voices helped to challenge and overcome patriarchal biases and paternalistic and conservative male views regarding the issue of hospitals’ treatment towards women with SE-AN (Gillies & Alldred, 2012; Jafree, Zakar, Fischer, & Zakar, 2015). This research also acknowledges and respects women’s lived experience of SE-AN (seen through the participants’ eyes) as validated knowledge to understand women’s health problems (Crooks, 2001; Henwood & Pidgeon, 1995; Pérez et al., 2015).

To the author’s knowledge, no prior study has developed an ethical decision-making model using PADs and involving adult women with SE-AN (Elzakkers et al., 2014; Manley et al., 2001; Wonderlich et al., 2012). Therefore, this study makes a unique contribution to the eating disorder field because it provides opinions from multiple perspectives—consumers and clinicians—regarding PADs and their potential value in resolving ethical conflicts relating to the care of women with SE-AN in psychiatric care. In addition, few studies have been conducted on PADs in Australia; therefore, this study contributes to the small body of
existing literature. Most studies have been conducted in the US and the UK (Atkinson, 2007; Boddy et al., 2013; McLennan et al., 2015; Rhee et al., 2012).

The new knowledge identified in this study was achieved by conducting a comprehensive literature review of the available data (qualitative and quantitative) relating to the research topic (Carpenter & Suto, 2008; Silverman, 2005).

During the initial stages of the research, I identified a significant gap in the literature relating to adult women with SE-AN, the utility of PADs and the use of qualitative research methods. Therefore, this research makes significant contributions to the AN literature in the following areas:

a) It includes women’s ‘voices’ in clinical practice.

b) It demonstrates the value of qualitative research methods—specifically GT—and its application in investigating and understanding the phenomenon of SE-AN.

c) The research findings might change and contribute to existing policy and clinical practice.

d) The research findings contribute to the existing eating disorder literature by deepening our understanding of the phenomenon of SE-AN.

e) The inclusion of different professional perspectives adds new knowledge and insights into the research topic of PADs for people with SE-AN.

f) The collaborative model can be used as an adjunct to support the medical model of care.

g) The model can be applied to people with different mental health issues and can be delivered by different professionals.
h) The author’s ‘voice’ was part of the research process, having had a lived experience of SE-AN, and this inside knowledge contributes to the field of consumer research.

The most important contribution of this thesis, which is echoed through the voices of Jo, Jade, Sue and Amy, is that there is hope of recovering from this illness and of going on to lead a ‘normal’ life. It could equally be said that those like Mary, who wish to end their suffering, also hold on to hope. As Jade said, ‘I think there’s always that hope that we can get to live a normal, healthy, happy life’.
Appendix A: Austin Hospital Ethics Approval

Austin Hospital Human Research Ethics Committee

Ethical Approval For New Study

Dr Trish Melzer
RMIT University

30 June 2016

Dear Dr Melzer

AU RED HREC Reference Number: HREC/16/Austin/9

Austin Health Project Number: ND 16/9

Project Title: Ethical considerations in collaborative care in severe and enduring anorexia nervosa: an application of an ethical decision-making model

I am pleased to advise that the above project has received ethical approval from the Austin Health Human Research Ethics Committee (HREC). This HREC is organised and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Research Involving Humans (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

HREC Approval Date: 30/06/2016

Participating Sites:

Ethical approval for this project applies at the following sites:

<table>
<thead>
<tr>
<th>Site</th>
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<tbody>
<tr>
<td>Austin Health</td>
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<tr>
<td>Melbourne Health</td>
</tr>
<tr>
<td>The Melbourne Clinic</td>
</tr>
<tr>
<td>St Vincent’s Hospital</td>
</tr>
</tbody>
</table>

Approved Documents:

The following documents have been reviewed and approved:

Austin Health Ethics Approval of New Project Version 3, dated 01 Jun 2016
Site Specific Assessment:

SSA Authorisation is required at all sites participating in the study. SSA must be authorised at a site before the research project can commence.

The completed Site-Specific Assessment Form and a copy of this ethics approval must be submitted to the Research Governance Office in order to obtain authorisation to commence your project. It is recommended that you check details of governance application submission requirements with each participating site.

Conditions of Ethics Approval:

- You are required to submit to the HREC:
  - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice ‘Exposure of Humans to Ionizing Radiation for Research Purposes’ Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).

The HREC may conduct an audit of the project at any time.
Appendix B: Site-Specific Assessment Authorisation

**SITE SPECIFIC ASSESSMENT (SSA) AUTHORISATION**

**APPROVAL TO CONDUCT A NEW RESEARCH PROJECT AT AUSTIN HEALTH**

Dr Trish Melzer  
A/Prof Richard Newton  
Austin Health

27 January 2017

Dear Dr Trish Melzer and A/Prof Richard Newton,

**AU RED HREC Reference Number:** HREC/16/Austin/9

**Project Title:** Ethical considerations in collaborative care in severe and enduring anorexia nervosa: an application of an ethical decision-making model

**AU RED SSA Reference Number:** SSA/16/Austin/526

**Reviewing HREC:** Austin Health

**HREC Approval Date:** 30 June 2016

**SSA Authorisation Date:** 27 January 2017

I am pleased to advise that the above project satisfies Austin Health’s governance requirements and may now be conducted at Austin Health. Conduct of the project is subject to compliance with the conditions set out below and any additional conditions specified by the reviewing HREC.

**SSA Approved Documents:**

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austin Health HREC approval letter – including all listed approved documentation</td>
<td>30 June 2016</td>
<td></td>
</tr>
<tr>
<td>Austin Health HREC approval letter – including all listed approved documentation</td>
<td>20 October 2016</td>
<td></td>
</tr>
<tr>
<td>Austin Health Participant Information and Consent Form - Consumers</td>
<td>15 October 2016</td>
<td></td>
</tr>
<tr>
<td>Austin Health Participant Information and Consent Form - Carers</td>
<td>15 October 2016</td>
<td></td>
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<tr>
<td>Austin Health Participant Information and Consent Form - Clinicians</td>
<td>15 October 2016</td>
<td></td>
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</tbody>
</table>
Research Collaboration Agreement between Austin Health and Royal Melbourne Institute of Technology, dated 19 January 2017

Material Transfer Agreement between Austin Health and Royal Melbourne Institute of Technology, dated 19 January 2017

Research governance

Condition of Governance Approval:

1. Researchers must comply with the Investigator’s Responsibilities in Research Procedure and Good Clinical Practice (ICH GCP). The Principal Research is to ensure that all associate researchers are aware of terms of approval and to ensure the project is conducted as specified in the application and in accordance with the National Statement on Ethical Conduct in Human Research (updated March 2014).

2. The Principal Investigator must notify the 1) CPI, 2) Reviewing Human Research Ethics Committee (RHREC) and Sponsor (if applicable) of:
   - All related internal Serious Adverse Events (SAE) in accordance with the NHMRC Position Statement: Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009.
   - Any other serious adverse effects to or complaints from Austin Health participants and steps taken to deal with them
   - Your inability to continue as Principal Investigator
   - Any unexpected developments in the project with ethical implications
   - Notify the RHREC of the failure to commence the study within 12 months of the RHREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.

3. You are required to inform the Research Governance Office of;
   - The actual start date of the project at Austin Health
   - Any other matters which may impact the conduct of the project at Austin Health
   - Austin Health Investigators withdrawing from or joining the project.

4. Any amendments submitted to and approved by the RHREC, including changes to the protocol, approved documents and/or the addition of documents to be used at Austin Health, must be submitted for governance approval prior to implementation. After RHREC approval, the PI must submit a copy of all documents relating to the approved amendment, along with the RHREC approval certificate, to the Research Governance Office for approval.

5. Any changes to the indemnity, insurance arrangements or Clinical Trial Research Agreement for this project. This includes changes to the project budget or other changes which may have financial or other resource implications for Austin Health.

6. RHREC approval must remain current for the entire duration of the project. Investigators undertaking projects without current RHREC approval risk their indemnity, funding and publication rights.

7. If your project involves radiation:
   - It is your responsibility to ensure the research is added to the site Management Licence issued by Department of Human Services – Radiation Safety Section prior to study commencement should it be required (check your Medical Physicist Report). The site RGO must be notified when the research has been added to the licence.
   - You are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice ‘Exposure of Humans to Ionizing Radiation for Research Purposes’ Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
Clinical Trial projects:

8. For clinical trials where Austin Health is the Sponsor, you are required to contact the Research Governance Office to organise submission of the CTN to the TGA. This must be completed before commencement of your project.

9. Prior to commencement of the project a copy of the governance authorisation letter and CTN acknowledgement must be provided to the Clinical Trials Pharmacy.

10. It is the Principal Investigator’s responsibility to ensure they receive a copy of the submitted clinical trial notification acknowledgement letter for their site.

You are also required to submit to the Office for Research:

11. In addition to the reporting requirements of the RHREC, you are required to submit an Annual Progress Report for the duration of the project. Continuation of SSA approval is contingent on submission of an annual report. The annual report must be submitted and acknowledged by the RHREC first and then forwarded to the Austin Health Office for Research, along with the RHREC acknowledgement.

12. A comprehensive Final Report upon completion of the project. The final report must be submitted and acknowledged by the RHREC first and then forwarded to the Austin Health Office for Research, along with the RHREC acknowledgement.

The Office for Research may conduct an audit of the project at any time.

Yours sincerely
Appendix C: RMIT University Ethics Approval

Notice of RMIT Registration
Of an Approved External Human Research Ethics Application

Date: 17 August 2016
Approval number (principal HREC): HREC/16/Austin/9
Approving HREC: Austin Health
RMIT Reference number (RM): 26303
Project title: Ethical considerations in collaborative care in severe and enduring anorexia nervosa: an application of an ethical decision making model
Risk classification: More than low risk
Chief investigator and institution: Dr Trish Metzer, RMIT
RMIT Personnel: Dr Sophia Xenos, Dr Merv Jackson, Mr Richard Knight.
Registration: From: 17 August 2016 To: 20 July 2019

Terms of Registration:
1. Responsibilities of RMIT personnel
   It is the responsibility of the chief investigator to ensure that all other investigators and staff on a project are aware of the terms of approval and to ensure that the project is conducted as approved by external HREC and according to the terms of registration at RMIT. Registration is only valid whilst RMIT personnel hold a position at RMIT University.
2. Amendments
   Amendments to an approved application are sought according to the processes used by the external HREC. After approval for an amendment is received relevant documentation (copy of amendment and approval notice, etc) must be provided to the RMIT HREC.
3. Adverse events
   You should notify the RMIT HREC immediately of any adverse events that are reported to the external HREC.
4. Annual reports
   Copies of annual reports submitted to the external HREC must be provided to RMIT HREC.
5. Complaints
   Any complaints that are received regarding this project must be reported to the external HREC and also reported to the RMIT HREC.
6. Special conditions of approval
   Nil.

In any future correspondence please quote the RMIT reference number and project title above.

Prof Stephen Bird
Chairperson
RMIT HREC

cc: Dr Peter Burke (HREC secretary),
Appendix D: Plain Language Statement

Plain Language Statement
School: Health and Biomedical Sciences

Project: Ethical considerations in collaborative care in severe and enduring anorexia nervosa: an application of an ethical decision-making model

Dr Sophia Xenos (Supervisor)
Tel: +61 3 9925 1081 Email: sophia.xenos@rmit.edu.au
Associate supervisors: Dr Trish Melzer, Dr Merv Jackson, and Ass/Prof Richard Newton
Mr Richard Knight (Student researcher – PhD Candidate)
Email: [redacted]

What is the purpose of the study: We are seeking your participation in a project which will enable the research team to understand more about psychiatric advance directives (PADs), and their role in reducing people’s experience (or perception) of coercion (forced treatment) in psychiatric hospitals.

What are PADs? Advance care planning allows a competent person with a serious mental illness, to make future health care plans, based on their values, beliefs and treatment preferences, in the event that they lose the ability (capacity) to make decisions.

Why this project: Research shows that providing a person with an opportunity to be involved in the decision-making process, through the use of psychiatric advance directives, can increase an individual’s sense of being in control of their medical care. This could then reduce the need for coercive interventions such as involuntary hospitalisation. Further research is needed to better understand whether this benefit translates (or has any value) for those suffering from chronic anorexia.

What is involved: Participation involves attending an informal (1hour) face-to-face interview, with the possibility of a follow-up interview. Interviews will be audio recorded, and transcribed verbatim. We understand that participation in this project might cause some discomfort while responding to questions, particularly talking about your experiences of involuntary treatment. Counselling services will be available if needed.

Who it will involve: This study will involve patients, carers and clinicians such as doctors, nurses and other health professionals.

What will happen to this information: The information collected (data) will help the research team to develop a shared decision-making model (i.e., a step-by-step process for effective decision-making) aimed at promoting collaboration between consumers, carers and clinicians. Findings from this study will make an important contribution by improving ‘patient care’.

Do I have to take part: Participation is voluntary and confidential. You will not be identified in any of the documents, including interview transcripts that are produced for this project. You have the right to withdraw at any time without prejudice, and without affecting your current or future care.

To find out more: If you have any questions about the study, you can contact the researchers. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, at RMIT. Tel: [redacted] or Email human.ethics@rmit.edu.au
Appendix E: Recruitment Letter

RECRUITMENT LETTER

Dear Prospective Participant,

Title of Project:
Ethical considerations in collaborative care in severe and enduring anorexia: an application of an ethical decision-making model.

Purpose:
I am a student (PhD candidate) from the Department of Psychology at the RMIT University. I would like to invite you to participate in a research project, which examines your personal lived experience of chronic anorexia and involuntary hospitalisation.

You have been asked to participate in this research because you are: a female between the ages of 18 - 65, who have been formally diagnosed as having or having had chronic anorexia nervosa with a duration of at least 7 years, and may have experienced involuntary hospitalisation.

The project aims to develop a shared decision-making model in order to minimise a person’s experience (or perception) of coercion (e.g. forced treatment) by promoting a collaborative approach through the use of psychiatric advance directives.

Your contribution:
This project will involve attending an informal (1 hour) face-to-face interview, with the possibility of a shorter follow-up interview. Interviews will be audio recorded, and transcribed verbatim. All attempts will be made to protect your confidentiality and anonymity.

Remember, this is completely voluntary. Should you wish to have further information about the study before making a decision as to whether or not you wish to be contacted, please email the researcher Richard Knight on: email [redacted]

I appreciate your time and consideration.

Yours Sincerely (PhD Candidate)
Appendix F: Informed Consent Form—Individual Participants

Consent Form - Adult providing own consent

Title: Ethical considerations in collaborative care in severe and enduring anorexia nervosa: application of an ethical decision making model

Protocol Number: HREC/10/Austin9
Project Sponsor: RMIT University
Coordinating Principal Investigator:
Principal Investigator: Dr Trish Melzer
Associate Investigator(s): Dr Sophia Xenos, A/Prof Richard Newton, Dr Merv Jackson & Mr Richard Knight
Location: Austin Health

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.
I understand the purposes, procedures and risks of the research described in the project.
I have had an opportunity to ask questions and I am satisfied with the answers I have received.
I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.
I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) ______________________________________
Signature ___________________________ Date __________

Name of Witness* to Participant’s
Signature (please print) ___________________________ Date __________
Signature ___________________________ Date __________

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older.

Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher† (please print) ___________________________
Signature ___________________________ Date __________

† A senior member of the research team must provide the explanation of, and information concerning, the research project. Note: All parties signing the consent section must date their own signature.
Appendix G: Interview Guide (Clinicians)

Interviewing Guide (Clinicians)

**Participant demographic and characteristics information:**

a. Age:
b. Occupation:
c. Gender: M/F
d. Ethnicity: Please specify...

e. How many years of experience have you had working as a mental health practitioner? (excluding training) Please circle: 1, 2, 3, 4, or other - please specify......

f. What level of education have you achieved?
   - □ BA/BS / □ MSW / □ MA / □ MS / □ MPH / □ Other Masters / □ RN
   - □ OT / □ M.D / □ PhD / or other - please specify......

**Introduction**

My name is Richard Knight and I am a PhD candidate from RMIT University. I am part of a research team (Dr Trish Melzer, Dr Sophia Xenos, Dr Merv Jackson and Ass/Prof Richard Newton) who will be conducting research at the Austin hospital. We will be exploring the lived experiences of adult women with chronic anorexia nervosa who may have been subjected to involuntary treatment. Specifically, this study will explore your views and beliefs concerning the key topics of involuntary treatment and psychiatric advance directives.

The research team has suggested a number of online learning resources, which may help in developing your understanding of psychiatric advance directives (PADs). These can be found at the end of this document.

The following research questions are designed to help the interviewer (Richard) to guide and direct the interview conversation, and to encourage you to speak about the research topics. This does not necessarily mean that you’ll be asked all of the questions, or in a specific order, but rather that you will be prompted for more information based on your answers.
It is important to remember that there are no right or wrong answers. We are only interested in your views about these topics. We will not write your name in any of the write-ups of the research, and we will make sure that direct quotes cannot identify you.

A copy of the interview guide will be given to each participant.

**Our first topic today is about your experience of taking care of someone who's having or having had chronic anorexia nervosa**

1. Can you tell me briefly about your experience of caring for a person with anorexia?

2. What types of situations cause you most concern when providing care to a person with chronic anorexia?
   - Prompts - Could you give me an example?

3. What sort of meaning does the word “anorexia” have for you?
   - Prompts - Can you elaborate on your answer?

4. How would you describe your role as an eating disorder clinician?
   - Prompts - What does it involve? What factors influenced your decision to become an eating disorder clinician?

**Now, I would like to move onto a different topic: Involuntary hospitalisation**

1. Can you please tell me about your thoughts about involuntary hospitalisation?
   - Prompts - Can you tell me more about your answer?

2. In your opinion, what are some of the negative and positive factors of involuntary treatment?
   - Prompts - Are there any other reasons why you think that? What happens?

3. Can you describe to me how you recognise when a patient requires hospitalisation?
   - Prompts - Could you say a little more about that? What do you look for? Is it something they have said or done? Are there any signs?
4. How do you feel working in an eating disorder clinic?
   - Prompts - What do you mean by that?

5. Can you think of instances in this clinic when your values and beliefs about your own conduct or about that of another have been questioned?
   - Prompts - What happened? Who was involved? How did you deal with situation? What was the end result?

6. What is important for you when providing medical care to patients with anorexia?

7. In general, what are the main challenges that staff are faced with when providing services to patients with anorexia?
   - Prompts - What does that look like for you?

8. What, if anything, would you change about the provision of care for people suffering anorexia?

**This is our final topic today: Psychiatric Advance Directives**

1. What do you know about psychiatric advance directives (PADs)?

2. What kind of information do you give to your patients and their families during a hospital admission?

3. How did/do you engage with your patients about their treatment?
   - Prompts - What are they? What is your meaning of shared decision-making?

4. What might prevent you and your patients from having discussions about PADs?
   - Prompts - What are they?

5. What are your beliefs about people with psychiatric illnesses having PADs?
   - Prompts - I’m interested in what you think about this.

6. What do you think other nurses and doctors think about PADs?
7. How do you see your role as an eating disorder clinician in the context of psychiatric advance directives?

8. How might the treating team (interdisciplinary team) be useful in helping consumers to create PADs?
   - Prompts - Can you give me an example?

9. Do you see psychiatric advance directives fitting into and be used in mental health system?
   - Prompts - What are your thoughts about this?

Closing question:
1. Out of all the things we’ve talk about today – or maybe some topic we’ve missed - what should I pay most attention to? What should I think about when I read your interview?

2. Did you feel like it was helpful to talk about your experiences? How so?

You have been very patient, thank you for time and participation today.

Online learning resources about psychiatric advance directives


Appendix H: Interview Guide (Consumers)

Interviewing Guide (Consumers)

Participant demographic and characteristics information:

a. Age:

b. Occupation:

c. What is your relationship status? e.g., single, married, de facto

d. What level of education have you achieved? e.g., bachelor degree, post graduate degree, or other - please specify........

e. What type of income are you receiving e.g., part or fulltime employment, Centrelink payments or other - please specify......

f. How long have you had anorexia nervosa? Years........

g. Have you been diagnosed with any other mental disorders e.g., depression, anxiety, personality disorder or other - please specify......

h. How many times have you been hospitalised for your condition? Please circle: 1, 2, 3, 4, or other - please specify.......

i. Do you have a carer? e.g., family member, friend or other - please specify......

Introduction

My name is Richard Knight and I am a PhD candidate from RMIT University. I am part of a research team (Dr Trish Melzer, Dr Sophia Xenos, Dr Merv Jackson and Ass/Prof Richard Newton) who will be conducting research at the Austin hospital. We will be exploring the lived experiences of adult women with chronic anorexia nervosa who may have been subjected to involuntary treatment. Specifically, this study will explore your views and beliefs concerning the key topics of involuntary treatment and psychiatric advance directives.

The research team has suggested a number of online learning resources, which may help in developing your understanding of psychiatric advance directives (PADs). These can be found at the end of this document.

The following research questions are designed to help the interviewer (Richard) to guide and direct the interview conversation, and to encourage you to speak about the research topics.
This does not necessarily mean that you’ll be asked all of the questions, or in a specific order, but rather that you will be prompted for more information based on your answers.

It is important to remember that there are no right or wrong answers. We are only interested in your views about these topics. We will not write your name in any of the write-ups of the research, and we will make sure that direct quotes cannot identify you.

A copy of the interview guide will be given to each participant.

Our first topic today is about your ‘lived experience’ of chronic anorexia nervosa

1. How did you feel when you first learnt that you were diagnosed with anorexia?
2. Can you tell me briefly what has happened since you were first diagnosed with anorexia?
3. When you think about your illness, what are your feelings about it?
   - Prompts - Do you have any concerns about your illness? Could you please give me an example?
4. What does the term “illness” mean to you?
   - Prompts - How do you define it?
5. How does your family view your anorexia?
   - Prompts - How does that make you feel?
6. If you had to describe what anorexia means to you, what would you say?
   - Prompts - What words come to mind? What images? Do you have a nickname for it?
7. How do you think your experience of living with anorexia might be different from people with other illnesses?
   - Prompts - What are the differences? How might it be the same? What makes these illnesses go together?
8. Tell me about your thoughts on what you think is going to happen to your health in the future?
   · Prompts - What do you think about that? What would happen to you?

Now, I would like to move onto a different topic: Involuntary hospitalisation

1. What does involuntary hospitalisation mean to you?
   · Prompts - Can you tell me more about your answer?

2. What was your experience of involuntary treatment like?
   · Prompts - Did you feel differently about yourself while being hospitalised?

3. If you think that you have experienced forced treatments could you describe what these experiences were?
   · Prompts - Can you tell me more about your answer?

4. What would (did) you expect to happen when you were hospitalised?

5. How do you spend your time in the hospital?
   · Prompts - What do you do? Walk me through a typical day…?

6. Tell me what is important for you when receiving hospital care?
   · Prompts - What comes to your mind?

7. How do you know when you need to be hospitalised?
   · Prompts - What does that look like for you? What happens? Are there any signs?

8. What would happen if you were not hospitalised?
   · Prompts - Tell me what other options there are? What option you might want to take? How would you manage your eating disorder?
This is our final topic today: Psychiatric Advance Directives

1. What is your general sense of psychiatric advance directives are?

2. What kinds of information did you receive during your hospital admission?

3. Can you tell me a time when you thought about making plans about health care decisions for the future?
   - Prompts - What were they? Have you discussed your plans with your love ones?

4. What factors might prevent you and your treating team from having discussions about PADs?
   - Prompts - Can you tell what are they?

5. Can you think of any situations in which PADs might (or not) be used?
   - Prompts - Please tell me about the situation?

6. If you were admitted into the hospital in critical state and were not able to speak for yourself, have you thought of what kinds of treatment you would want, or not want?
   - Prompts - Interested in what you think about this? What are they?

7. If you were too sick to make decisions about your future health, who would be best able to represent your views and values?
   - Prompts - Why have you chosen this person?

Closing question:

1. Out of all the things we’ve talk about today – or maybe some topic we’ve missed – what should I pay most attention to? What should I think about when I read your interview? (Patton, 2015 p. 470)

2. What was it like (how was it) for you to participate in this interview today?

You have been very patient, thank you for time and participation today.
Online learning resources about psychiatric advance directives


Appendix I: Anorexia Diagnostic Criteria

A. Restrict of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.

B. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at significantly low weight.

C. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

The medical literature indicates that there are two subtypes of anorexia:

Restricting Type: during the last 3 months, the person has not regularly engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

Binge Eating/Purging Type: during the last 3 months, the individual has engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas) (APA, 2013, p. 338).
Table J.1

### Summary of Findings, Interpretations and Conclusions

<table>
<thead>
<tr>
<th>Findings</th>
<th>Interpretations</th>
<th>Conclusions</th>
</tr>
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<tbody>
<tr>
<td>All participants had developed accumulated personal knowledge</td>
<td>These women want to use their knowledge and experience to engage in informed decision-making about their health care needs.</td>
<td>These women want more autonomy and control in managing their illness.</td>
</tr>
<tr>
<td>(maturity of experience) about their illness.</td>
<td>They want autonomy and choice (power) in the decision-making process. They want to be respected and valued. They want to be listened to and understood.</td>
<td>Respecting patients treatment preferences increased collaboration and respect between health professionals and patients and reduced coercion.</td>
</tr>
<tr>
<td>An important finding was that all participants felt their rights were</td>
<td>Pessimism and negative beliefs about anorexia from health professionals were contributing factors.</td>
<td>Exposure to coercion resulted in a poor therapeutic relationship and prevented women from engaging in treatment services.</td>
</tr>
<tr>
<td>often violated, especially in decision-making.</td>
<td>These women wanted a holistic approach to their care relating to their physical and psychological wellbeing. Expressed a desire to have close, trusting therapeutic relationship with their helping professionals. Generally, participants did not support the use of forced treatment for competent patient.</td>
<td>Participants were responsive to person-care, integrated, multidisciplinary team-based approaches. Produced better health outcomes: increased treatment adherence, helped with their recovery, increased patient satisfaction, enhanced the therapeutic relationship, and changed people’s perception of coercion.</td>
</tr>
<tr>
<td>For those entering general hospital wards, resulted in an increase</td>
<td>This lack of knowledge was a contributing factor towards participant’s experience of coercion. This also maintained the power differentials between patients and doctors.</td>
<td>People with SE-AN require access to resources and trained staff, and information pertaining to PADs to make informed treatment decisions.</td>
</tr>
<tr>
<td>exposure to coercion and poor quality of care.</td>
<td>To protect them from all forms of coercion. To mitigate the impact of power differentials. To reduce their sense of disempowerment and mistrust of the mental health system.</td>
<td>They want to regain control over their medical care and maintain a personal sense of dignity in their care.</td>
</tr>
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<td>All participants reported that they value a collaborative person-</td>
<td></td>
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<td>centred approach.</td>
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<tr>
<td>A significant finding was that none of the participants, including</td>
<td></td>
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<td>focus groups, had prior knowledge about PADs.</td>
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<tr>
<td>All participants were in favour of using PADs to assist them with their</td>
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<td>recovery</td>
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**ETHICAL CONSIDERATIONS IN COLLABORATIVE CARE IN SE-AN**

Appendix J: Summary of Findings
## Findings

All participants reported having difficulty in accessing eating disorder services and trained staff.

The only discrepant finding of this study was that all the participants supported the use of involuntary treatment in circumstances where there was evidence of incompetency.

A major finding was that stigma and shame were identified as social barriers by all participants.

## Interpretations

Limited access to specialised services and staff resulted in an increased risk of coercion, prejudice, and discrimination, as well as not meeting the needs of people with SE-AN. It prevented a person from recovery.

Beneficence outweighs autonomy.

Motivated by the fear of dying.

Evidence of incompetence is a justification to violate a person’s rights to ensure their safety.

Shame / embarrassment exacerbated their illness and resulted in isolation. Acts of shame were perpetuated by clinicians, which contributed to people’s perception of coercion.

## Conclusions

General hospital services are not equipped to provide care to people with SE-AN. Improvements in general health care are necessary to ensure a reasonable standard of care.

They expressed a strong desire to have a better quality of life and to recover.

Stigma and shame were identified as predictors of poor quality of life for people with SE-AN. Prevented women from seeking out professional supports, from accepting their illness, and from engaging in treatment services.
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