

Women's experiences of anal incontinence  
following a history of obstetric anal sphincter injury  
An interpretive phenomenological research study.

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# DECLARATION OF ORIGINALITY

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This thesis contains no material which has been accepted for the award of any other degree or diploma in any university and that, to the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis. I consent to my thesis being made available for photocopying and loan if accepted for the award of the degree.

Signed

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Date 15/6/2012

# ACKNOWLEDGEMENT

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As a woman, mother, wife and professional working with women with anal sphincter injury, I am acutely aware of the emotional vulnerability and devastating impact anal incontinence has on every aspect of their daily lives. The reported research thesis presented an emotionally charged and taxing experience for the researcher and participants. My interest within the research area provided the impetus and ongoing drive to complete my research thesis. The support received from my family, professional colleagues and friends allowed the completion of a journey which has provided a deeper understanding of what it is like to live with anal incontinence.

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# ABSTRACT

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Anal incontinence (AI) has a debilitating and devastating impact on a person's quality of life. However the impact is often unreported due to the social stigma that surrounds AI and the utilisation of ineffective symptom severity scores which accurately assess the impact on quality of life. There is a significant amount of research literature which addresses the prevalence and cause of AI. Less information addresses the increased risk of AI following vaginal delivery and damage to the anal sphincter. Furthermore, women's experiences of AI following obstetric anal sphincter injury (OASIS) and the impact on their quality of life are poorly reflected within research literature. The research study reported within this thesis adds to the existing body of knowledge surrounding AI, OASIS and impact on quality of life. Accordingly findings from the reported study will assist health professionals to derive a greater understanding of the issues that surround AI and further promote the development of sensitive appropriate healthcare.

The reported interpretive phenomenological study explored and interpreted ten women's experiences of AI following a history of OASIS, and illuminated the impact of AI on their quality of life. Heidegger's interpretive phenomenology and Van Manen's methodological framework guided the reported research study. Semi-structured open ended interviews were adopted as they encouraged a relaxed informal discussion between the researcher and participant eliciting rich in-depth accounts of women's experiences. Data collection, analysis and interpretation were undertaken utilising Van Manen's procedural framework. This framework aided the development of three essential themes; *grieving for loss*, *silence* and *striving for normality*.

The research findings highlighted the debilitating physical, social and emotional impact of AI on women's lives. Women described the need to adopt strategies to cope with the impact of AI. These strategies included lifestyle changes, silence, avoidance and denial.

Furthermore it was evident from within the findings that new knowledge had arisen. Women grieved the loss of their identity, and ability to form successful relationships and loss of control as an adult, a mother and a partner. Loss was further compounded by the insidious and unpredictable nature of AI which negatively impacted on women's psychological wellbeing.

Findings from the reported research study will challenge the reader's current assumptions of AI and its impact on women's quality of life. In addition, health professionals need to be well informed as to the risks and impact of vaginal delivery, OASIS and AI. Recommendations for health professionals practice include adopting a proactive approach in breaking the silence that surrounds AI, illuminating potential health issues and promoting sensitive appropriate health care and informed choice in birthing outcomes.

Paucity within research literature and current findings provide the impetus for further research within the area of AI and importantly, the psychological impact of AI on women's quality of life.

# CHAPTER ONE

## INTRODUCTION

---

### **Introduction**

Continence is defined by the social fabric in which we live, and to be incontinent of faeces is deemed socially unacceptable, isolating and carries a high level of stigmatisation (Norton 2004a). Providing opportunity for women and health professionals to openly discuss anal incontinence (AI), will assist in placing the issue of AI in context, reducing stigmatisation, and enhancing a person's self-esteem and quality of life (Garcia, Crocker & Wyman 2005). There is limited available evidence which explores women's experiences of AI following a history of obstetric anal sphincter injury (OASIS), and how this affliction impacts on their quality of life.

In an area where little information exists, the interpretive phenomenological research study reported in this thesis offered women an opportunity to voice their experiences of AI and accordingly, through a deeper understanding of AI, highlighted how AI had impacted on their quality of life.

Knowledge gained from the current research study will provide health professionals the opportunity to question their preconceived ideas and assumptions of AI and provide a reference point for the development of education and professional practice. Informed health professionals could further the development of sensitive, appropriate care to reduce the negative sequel on both the health of women and the health care system, thereby optimising women's quality of life.

This chapter provides a brief account of how anecdotal evidence from within current continence nurse practice provided an interest and direction for the research study. The research study will be placed in context to relevant research literature, and the research

question, purpose, aims, objectives, and significance of the research study will be presented. In keeping with the philosophical underpinnings of interpretive phenomenology, the chosen research framework, the researcher's assumptions have also been stated. This chapter concludes with a summary of each of the following chapters.

## **Context of the Study**

Anecdotal evidence within Continence Nursing Service (CNS) practice, working with women with pelvic floor dysfunction, identified an increase in the prevalence of AI (Steel, Robinson, Coates & Tucker 2011). A large component of CNS practice included birthing women aged between 16-40 years, who have had a history of OASIS. The researcher's interest in AI and the impact on a woman's quality of life stemmed from the stories these young women divulged to the CNS (Steel, Robinson, Coates & Tucker 2011). It was evident that the disclosure of AI was embarrassing and caused a sense of vulnerability for most of these women. Through women's stories the stigmatisation of AI and negative effects on the quality of their lives, and the importance for women to feel safe and have the freedom in which to openly discuss their individual stories was evident. The physical, emotional and social impact of AI had portrayed itself as a very real issue which affected many aspects of women's ability to control the basic tasks of daily life. Women's experiences revealed that the taboo associated with AI had prevented them from seeking help from health professionals who often appeared disinterested. The stories of these women and their personal journeys with AI provided the impetus for this research study to develop a deeper understanding of women's experiences of AI.

A review of research literature highlighted the prevalence and cause of AI, notably within the birthing population. Subsequent vaginal births and ageing have also been cited as contributing factors to the increased incidence of AI (Chiarelli, Murphy & Cockburn 2003). Importantly, the literature reflected the incidence of AI was projected to increase to 1,122,749 women by 2030 (Continence Foundation of Australia 2011). The negative impact of AI on a person's quality of life was noted within all reviewed research literature; however descriptions were limited to short statements, providing no

depth or understanding to the debilitating impact of AI on every facet of a person's life. Qualitative research provided a deeper, richer insight into women's experiences of AI following a history of OASIS, highlighting the debilitating psychosocial and emotional impact of AI on quality of life (Rasmussen & Ringsberg 2009; Williams et al., 2005). However, qualitative research within this area is limited, globally and in particular, within Australia. Furthermore, the review of qualitative literature did not reveal any research into the 'lived experience' of AI.

### **Statement of research problem**

Anecdotal evidence from within CNS practice highlighted the prevalence of AI within the birthing population (Steel, Robinson, Coates & Tucker 2011). A review of research literature demonstrated women who sustained OASIS following vaginal delivery are at risk of AI and furthermore, there is an increased risk of worsening AI through subsequent birthing and ageing (Chiarelli et al., 2005; Collings & Norton 2004). An in-depth account of the impact of AI on the physical, emotional, psychological, social and cultural aspects of women's lives have often gone unreported. The impact of AI on a person's quality of life is debilitating, yet a review of current research literature demonstrated a paucity of women's experiences of AI following OASIS (Garcia, Crocker & Wyman 2005; Rasmussen & Ringsberg 2009; Williams et al., 2005).

### **Purpose of the study**

The purpose of the reported interpretive phenomenological study was to explore and interpret women's experiences of AI following a history of OASIS, and to illuminate the impact of AI on their quality of life. Articulation of the research findings will contribute to a greater understanding by health professionals of the issues surrounding AI for women with a history of OASIS and further promote sensitive appropriate care for women with AI, and provide an impetus for future research and health education by health professionals.

## **Aim of the study**

To reveal women's experiences of AI following a history of OASIS and illuminate how those experiences affected their lives.

## **Specific Objectives**

1. To explore and develop an understanding of women's experience of anal incontinence following a history of obstetric anal sphincter injury.
2. To interpret women's experience of anal incontinence following a history of obstetric anal sphincter injury.
3. To identify the impact of anal incontinence on women's quality of life.

## **Statement of research question**

Anecdotal evidence of women's stories of AI from within current nursing practice provided guidance for the formulation of the research question; 'what are women's experiences of anal incontinence following a history of obstetric anal sphincter injury, and how does it impact on their quality of life?'

## **Significance of the study**

AI is prevalent within the Australian community and is projected to increase by 2030 (Continence Foundation of Australia 2011). Women are at greatest risk of AI following vaginal delivery as a result of anal sphincter damage, yet the debilitating impact of AI on a person's quality of life has been poorly represented within research literature (Collings & Norton 2004). As a result, there is a paucity of rich, in-depth information that depict women's experiences of AI.

The inability of health professionals to develop a deeper understanding as to the impact of AI on person's quality of life, further effects how appropriate health care is assessed planned and delivered.

This original research study will add to the current literature by providing a detailed account of women's experiences of AI with the intention of gaining a deeper understanding of the impact on women's quality of life. Continence status is socially constructed and impacts on how each person understands AI, and for health professionals this may impact on health care provision and delivery (Norton 2004a; Wilson 2007). Articulation of the research study findings will promote health professionals to question their own beliefs and values of AI and further provide health professionals with a deeper understanding as to the impact of AI on a woman's quality of life following OASIS. Through a deeper understanding of AI, health professionals can develop and provide sensitive appropriate health care for women with AI and bring about changes in education, practice and policy development around the issue of AI. Finally, the current research and will promote the impetus for future research in the area of AI and OASIS.

### **Researcher's Assumptions**

The current research study required the researcher to acknowledge prior awareness, assumptions, beliefs and bias. In stating these assumptions and beliefs the researcher brings to the foreground their past experiences to be acknowledged, reflected and challenged within the research process (Mackey 2005). The researcher's assumptions were documented within the research journal to enhance the validity of the research outcomes (Carpenter 2011). As a CNS working with women who have sustained OASIS, the researcher was aware of the incidence of AI for these women. The day to day interaction with these women highlighted the impact of AI on their quality of life. Listed below are the researcher acknowledged preconceived ideas:-

1. AI will have some impact on the quality of life of women following a history of OASIS.

### **Definition of key terms used within the thesis**

**Anal sphincter:** Sphincter muscle of the anus



**Anal incontinence (AI):** As being any loss of a liquid or solid stool and involuntary loss of flatus from the anal sphincter.

**Anus:** Is an opening which excretes faeces.

**Being-in-the-world:** Central to interpretive phenomenological beliefs. The inter-relationship of a person and in their world can not be separated; each is pivotal in understanding in challenging new understandings and develops new beliefs.

**Faeces:** Bodily wastes excreted from anus.

**Incontinence:** The inability to control excretions.

**Interpretive phenomenology:** A qualitative research methodology described by Martin Heidegger (1927-1962). Interpretive phenomenology is ontological in nature. It is interpretive; it does not bracket thoughts and feelings. Through the use of language; people are aware of their existence and question 'being in this world', formulating new experiences.

**Heidegger:** A pupil of Edmund Husserl (1859-1938), who questioned Husserl's concept of bracketing and was concerned with acknowledging prior awareness, 'being-in-the-world' and interpretation of an experience through the process of co-constitution of researcher and participant.

**Husserl:** A German philosopher who is known as one of the founders of phenomenology.

**Husserlian phenomenology:** is epistemological in nature. This type of phenomenology is descriptive and seeks to bracket pre-conceived thoughts; feelings form what is being observed.

**Hermeneutic circle:** Through the use of language a cyclic process occurs where pre-conceived beliefs are challenged by new beliefs. The articulations of pre-conceived thoughts are brought to the foreground through language and are challenged by the present experience reformulating new understandings and ideas.

**Lived experience:** Life cannot be conceptualised. Every experience and feeling of everyday living contributes to who we are and how we live.

**Obstetric anal sphincter injury (OASIS):** Damage to the anal sphincter following vaginal delivery.

**Phenomenology:** A qualitative research methodology which seeks to understand the ‘lived experience’.

**Postnatal:** The period following the birth of a baby.

**Postpartum:** The period after the birth of a baby.

**Quality of life:** a perception of how a person places themselves within the context of their life. This is impacted on by multiple facets including, physical, psychological, social, emotional wellbeing of a person.

**Sphincter:** Ring of muscle which opens and closes an opening such as the anus.

**St Mark’s incontinence score (Vaizey Score):** Symptom and severity assessment tool utilised in measuring the severity of anal incontinence and impact on quality of life.

**Van Manen:** A phenomenological researcher, who built on the works of Martin Heidegger. Van Manen’s six methodological themes provide a structural framework for hermeneutic phenomenology (Van Manen 1990).

## **Summary of thesis**

This thesis portrays an interpretive phenomenological account of women’s experience of AI following a history of OASIS and impact on their quality of life. The summaries of chapters are detailed below.

### **Chapter 1: Introduction**

The introduction has provided discussion on the background, rationale, purpose, and significance for this interpretive phenomenological research. The researcher’s interest

and pre-conceptions are noted. A summary of thesis chapters have been included within this chapter.

## **Chapter 2: Literature review**

The literature review provides a current review of evidenced based literature within a ten year timeframe, with relation to the impact of AI on women's quality of life following a history of OASIS. The literature review established inconsistencies within the definition and prevalence of AI, reporting of AI, and impact on a person's quality of life. Gaps within the literature have been noted and provide strong support for the reported interpretive phenomenological research study.

## **Chapter 3: Methodology**

This chapter describes the theoretical framework within which this research study is located. Interpretive phenomenology as a qualitative research methodology is discussed and the justification as the chosen methodology is given. The two major schools of thought of phenomenology by Martin Heidegger (interpretive) and Edmund Husserl (descriptive) phenomenology are discussed in relation to their philosophical and methodological stance. Van Manen's six methodological themes have been described as a procedural framework to guide the chosen interpretive phenomenological research. The relevance of interpretive phenomenology and nursing practice has been outlined, providing further support for the current research.

## **Chapter 4: Method**

This research design and methods employed to answer the research question are outlined within this chapter. The sample population including inclusion and exclusion criteria and recruitment strategies have been detailed. Ethical considerations, data collection and analysis methods have been discussed. Van Manen's procedural steps which assisted with data collection and analysis are outlined. Methodological trustworthiness and credibility are demonstrated within this chapter.

## **Chapter 5: Analysis**

The process of thematic analysis is presented and discussed within this chapter. The emergence of essential themes and subthemes are discussed in relation to the participant's shared experiences, and provides the basis for the interpretation presented in chapter 6.

## **Chapter 6: Interpretation**

This chapter provides interpretation of essential themes and sub-themes. The findings are discussed thematically and provide detailed interpretations of women's experience of AI and the resultant impact on their quality of life. The emergence of the three essential themes were; *grieving for loss, silence and striving for normality* and eight sub-themes; *near the edge, loss of young adulthood, loss of middle adulthood, keeping silent, professional silence, breaking the silence, compromise and retreating inside*.

## **Chapter 7: Discussion**

The final chapter summarises the reported interpretive phenomenological research study. This chapter highlights the common themes and their significance in answering the research question. The significance of the research and research findings are discussed in context to reviewed literature. Furthermore, limitations of the study are reported and recommendations for current health professional practice and further research have also been outlined.

## **Appendices'**

The attached appendices contain an endorsement letter from the Women's and Children's Division, a recruitment flyer, an information sheet, a consent form, an interview schedule and examples of data analysis statements, essential theme and subthemes.

## **Summary of chapter**

The introductory chapter has provided an overview as to the purpose, rationale and significance for the reported interpretive phenomenological research study. It has explained the researcher's interests and assumptions in regard to women's experiences of AI following a history of OASIS and resultant impact on their quality of life. The introduction has summarised the content of the remaining chapters comprising this thesis. Chapter two will provide a background of available literature relating to women's experiences of AI following a history of OASIS and provides strong support for the chosen interpretive phenomenological research study.

# CHAPTER TWO

## LITERATURE REVIEW

---

### **Introduction**

This chapter provides a summary of previous literature investigating women's experiences of anal incontinence (AI) following a history of obstetric anal sphincter injury (OASIS) and the associated impact on their quality of life. The review of literature identifies the gaps and inconsistencies within research and thus provides support for the reported interpretive phenomenological research study. The main focus of the reviewed literature highlights the prevalence of AI and use of expert driven quality of life questionnaires to assess the impact of AI on a person's quality of life. The research literature reflects limited awareness of the impact of AI from the perspective of those it impacts upon. Qualitative research, in particular grounded theory research, provides a greater insight into the social impact of AI on quality of life however; research within this area is limited globally and in particular within Australia. Furthermore, the review of literature reveals little evidence of phenomenological research within the reported research study area.

An extensive online literature search was undertaken within the medical and nursing databases including the Cumulative Index of Nursing and Allied Health Literature (CINHAL), Scopus, Pub med and Medline. Key search terms included anal incontinence, faecal incontinence, anal sphincter injuries, obstetric complications, trauma, obstetric, postnatal care, experiences, women's experience and quality of life. The literature search was further refined through fields which included English language only, literature published within the last ten years and full text articles.

## **Prevalence of Anal incontinence (AI)**

Anal incontinence (AI) is not a disease or illness; AI is the involuntary loss of a liquid or solid stool and flatus due to an underlying medical condition or illness (Milsom et al., 2009). Bowel continence relies on intact anal sphincter muscle, damage to the anal sphincter muscle (OASIS) following vaginal delivery is a predominant cause of AI in one to two thirds of women, subsequent vaginal deliveries and ageing, further increase the risk of AI (Chiarelli, Murphy & Cockburn 2003; Dudding, Vaizey & Kamm, 2008; Rasmussen & Ringsberg 2009).

The long-term impact of vaginal delivery and prevalence rates of AI in postnatal women were reflected in a study by Pollack et al. (2004) in which 15% of 242 first-time Swedish mothers sustained a primary OASIS following vaginal delivery. At nine months, 44% of women who had sustained OASIS reported a history of AI. After five years, this rate had increased to 53% (Pollack et al., 2004). Women who have had a prior history of OASIS, and were symptomatic of AI in the postpartum period were eight times more likely to be at risk of persistent AI at five years (Pollack et al 2004). Interestingly, it was indicated that 25% of study participants who had no reported sphincter tears, reported symptoms of AI at nine months (Pollack et al., 2004). After five years the rate of AI had increased to 32 %, representing occult damage to anal sphincters. It was evident that whilst AI is an increased risk for women with a prior history of OASIS, AI is a real risk for all women who birth vaginally.

Pollack et al (2004) provided strong evidence of an increased incidence of AI with ageing, rates of AI at five years postnatal reflected trends of AI within the aged population. AI rates were often reported at more than 50% of aged care residents, and have consequently been cited as the most common factor for admission to residential care (Milsom et al., 2009). It was evident within the reviewed research literature that AI is prevalent within the Australian community affecting one million people, half of which are women (Chiarelli et al., 2005). An investigation into the trend of AI within Australian residential and community populations reported an increase of AI to 1,835,340 people by 2030 of whom 1,122,749 of these people would be women and 253,113 in residential aged care (Continence Foundation of Australia 2011).

Whilst research literature revealed the prevalence of AI within the Australian community, there were noted variations in prevalence rates (Chiarelli, Murphy & Cockburn 2003; Ho et al., 2004). Variations were due to differences within the definition of AI, study size, study sample and disclosure of information by participants (Chiarelli, Murphy & Cockburn 2003; Ho et al., 2004). Lack of consensus within the definition of AI and faecal incontinence limit the comparison of research outcomes, resulting in limited awareness of the true impact of AI within the population (Chiarelli, Murphy & Cockburn 2003). Lack of awareness keeps AI hidden and further compounds the provision of adequate health care provision to meet women's needs, negatively impacting on quality of life.

The standardisation of terminology relating to AI by the International Consultation on Incontinence (ICI) provided a closer step in accurately reporting the prevalence of AI. The current definition of AI is defined as any loss of a liquid or solid stool and involuntary loss of flatus (Milsom et al., 2009). However, upon the review of past prevalence rates of AI it was evident a disparity in reporting existed. This was primarily due to the use of definitions which omitted flatus incontinence and accounted for the wide variation in prevalence rates with regard to current research (Milsom et al., 2009). This was apparent when reviewing previous research by Kamm (2002) where reported rates of faecal incontinence in the mid 1980's were 2-5%, these rates were not supported by Milsom et al. (2009) who utilised the ICI definition of AI and cited wide variations of AI from 1.5–50 %, with the highest prevalence in aged care. Two Australian studies reflected further differences within reported faecal incontinence with rates of incontinence between 6.9% and 20.7% (Chiarelli, Murphy & Cockburn 2003; Ho et al., 2004). Interestingly, Chiarelli, Murphy and Cockburn (2003) research included high risk birthing women and reflected higher rates of incontinence with the inclusion of precursor symptoms of women with 24.4% flatus incontinence. The higher rates of faecal incontinence within Chiarelli, Murphy and Cockburn (2003) research supported the general consensus that AI increased with age and high risk vaginal delivery. However, neither Chiarelli, Murphy and Cockburn (2003) nor Ho et al. (2005) research included women with a known history of OASIS.



Two Swedish prospective observational studies reflected higher rates of AI within the postnatal population who sustained OASIS (Fornell et al., 2005; Pollack et al., 2004). Fornell et al. (2005) noted a pronounced increase of flatus incontinence ten years post delivery however, their study was small and their results could not be generalised. Pollack et al. (2004) reflected an increased rate of AI at 53% within five years of delivery. Comparisons between the four studies of AI rates (Chiarelli, Murphy & Cockburn 2003; Fornell et al., 2005; Ho et al., 2004; Pollack et al., 2004) were limited due to the definition of AI and study sample. Reported outcomes however reinforced AI as a significant issue within society and its prevalence was notably higher in the postnatal population who sustained OASIS. Anecdotal evidence within a continence nurse practice in a large northern metropolitan hospital reflected increased trends of AI following OASIS and supported the need for research which would uncover an in-depth rich understanding of women's experiences of AI and the impact on quality of life (Steel, Robinson, Coates & Tucker 2011).

### **Women's experiences of anal incontinence**

Continence is defined by the social fabric in which we live, and to be incontinent of faeces is socially unacceptable and carries stigmatisation (Norton 2004a). As a child we adopt the values and beliefs within our community as to the accepted norms of physical bowel control; by adult-hood we assume control of bodily functions and normal bowel control is buried within our subconscious and is a voluntary process (Norton 2004b). Underlying health conditions disrupt the status quo and those who are incontinent are challenged by social taboos and stigmatisation of AI which thus impacts on nondisclosure (Collings & Norton 2004).

Nondisclosure of AI contributes to a lack of understanding as to the true prevalence and impact of AI on a person's quality of life (Bliss, Norton & Vodusek 2010). This has been cited within evidence based research as a major issue in the underreporting of AI, which further contributes to the low priority given to AI in health care education, service provision and policy making (Bliss, Norton & Vodusek 2010; Dugdale & Hill 2005; Rasmussen & Ringsberg 2009).

Health care professional's attitudes have the potential to further influence the disclosure of AI (Norton 2004a). Rasmussen and Ringsberg (2009) research found woman often felt marginalised due to health professional's inability to listen and understand their concerns of living with AI. This may have been contributed too by health professionals underlying beliefs of AI and the low priority AI receives within society and the health care system (Norton 2004a). Rasmussen and Ringsberg (2009) recommended that health professionals need to be proactive promoting dialogue with those afflicted by AI. Open dialogue develops awareness as to the impact of AI on women's lives and promotes the development of appropriate health care (Rasmussen & Ringsberg 2009).

The social stigma attached to AI further prevents people from speaking out, yet effective communication was cited within research literature as essential for those afflicted with AI to voice their experiences in order to raise awareness as to the impact of AI on quality of life (Norton 2004a). The holistic nature of nursing as a caring professional practice places the nurse in a prime position to open dialogue in an area which is deemed taboo within society and allows women to voice their experience (Norton 2004a). The opportunity to share personal experiences of AI provides further information as to the effects of AI, and provides a base from which informed health care can be built (Koch, Selim & Kralik 2002).

Qualitative research, a common research methodology utilised by nurse researchers, employs the use of semi-structured open ended interviews to gain an understanding of the multiple complexities of an experience from the participant's viewpoint (Streubert 2011a). Grounded theory research, a qualitative research methodology, has been adopted by nurse researchers to identify the effects of AI on quality of life (Rasmussen & Ringsberg 2009; Wilson 2007). Wilson (2007) investigated how a person lived with AI within the community providing a detailed description and understanding of the stigma and shame associated with AI and negative impact on quality of life. Whilst Wilson's (2007) research raised awareness and understanding as to the negative effects on a person's life, Wilson's research was a mixed gender study and provided little information as to the impact of AI following OASIS.

Rasmussen and Ringsberg (2009) and Williams et al. (2005) addressed the psychosocial and emotional impact of OASIS injury. Research outcomes highlighted both the significance of OASIS on quality of life and the importance for skilled health professionals to develop an understanding of the problems associated with OASIS and AI through open dialogue (Rasmussen & Ringsberg 2009; Williams et al., 2005).

The reviewed research literature identified the social stigmatisation of AI and the negative effect on disclosure rates. Norton (2004a) suggested an informal friendly approach promotes effective communication and reduces embarrassment for those afflicted by AI. Interpretive phenomenology a qualitative research methodology adopts this approach and promotes an environment in which a rich in-depth understanding of the complex nature of the debilitating impact of AI on a woman's life and is reported upon within this thesis.

### **Women's voices and quality of life**

The World Health Organisation states a person's quality of life is an individual perception of what their life means and this is influenced by a person's culture, beliefs and expectations (WHO 1997:p.1). Quality of life is affected by the physical, psychological, social, independence, belief system and relationship to the environment (WHO 1997:p.1).

Anecdotal evidence within CNS practice highlighted the impact of AI on a women's quality of life (Steel, Robinson, Coates & Tucker 2011). Conversations provided an insight into the shame, humiliation and anger associated with the impact of AI on the psychological, social, sexual and physical aspects of women's lives. This view was supported by research literature which detailed the devastating effect of AI on a person's quality of life, however the nature and depth of AI has been poorly portrayed (Rasmussen & Ringsberg 2009).

Clinically derived measuring tools have been developed to assess and measure the impact of AI on quality of life. A variety of scoring systems such as the Cleveland, Wexner and St Marks incontinence score (Vaizey score) have been developed to

quantify and objectively assess the physical impact of AI on a person's life. The Vaizey score assesses the frequency and impact on daily living and is deemed the more reliable objective assessment in the severity and impact of AI (Roos, Sultan & Thakar 2008). However, the Vaizey score only assesses two quality of life areas, which include the frequency to wear a pad and deferment time, providing little in-depth information as to the impact of AI on a person's quality of life.

Fornell et al. (2005) described the use of a clinically derived questionnaire which assessed psychological, sexual and social aspects of AI on women's lives following vaginal delivery, the findings of the research are sparse and provide little depth or understanding to the impact of AI on women's lives. Clinically derived questionnaires by nature often underestimate the participants perspective, coupled with nondisclosure by women due to the stigmatisation of AI; this results in the true experience and impact of AI remaining largely unknown (The Lancet 1995).

Rockwood et al. (2000) stated that to date, no validated quality of life tool existed to assess faecal incontinence. Rockwood et al. (2000) designed a faecal incontinence quality of life scale which is noted for its reliability and validity, although their quality of life tool is clinically derived and not relevant to the postnatal population. This was reflected within the majority of reviewed literature which highlighted the use of expert and clinically derived questionnaires to report on quality of life outcomes and the consequent reduction of participant's perspectives and provided a poor reflection on the true experience of AI on a person's life (Cotterill et al., 2008; The Lancet 1995).

The mixed method research undertaken by Cotterill et al. (2008) highlighted the benefits of including patient perspectives in the development of questionnaires which evaluated incontinence symptoms and impact on quality of life. Cotterill et al. (2008) research formed the basis for the ICIQ-B questionnaire, a tool which provided a more accurate assessment for those people living with AI.

Three quantitative research papers utilised validated quality of life scales to capture the experiences of AI in postnatal women (Cockell et al., 2003, Samarasekera et al., 2008; Tin et al., 2010). Tin et al. (2010) and Samarasekera et al. (2008) utilised clinically

derived quality of life scale which focused primarily on the physical impact of AI, providing no depth to the social and emotional impact on quality of life. Cockell et al. (2003) sought to redesign a faecal incontinence quality of life tool utilising a mixed method approach in research. This provided a richer and deeper understanding of the interpersonal impact, health provider response and pre-occupation of AI affecting postnatal women's quality of life (Cockell et al., 2003). However, as with all quality of life scales, they only reflect a bearing on the status of quality of life; and do not provide women the opportunity to have their concerns voiced in any depth within the research.

Rasmussen and Ringsberg (2009) and Williams et al. (2005) qualitative research provided a greater insight into women's experiences following a history of OASIS highlighting the debilitating psychosocial and emotional impact on their quality of life. Additionally Rasmussen and Ringsberg (2009) provided a deeper understanding as to the marginalisation and negative impact of AI on a woman's quality of life where as Williams et al. (2005) provided only a limited discussion in regard to the direct impact of AI on a person's life. The nature of qualitative research findings are difficult to generalise to the wider population. Nevertheless, both Rasmussen and Ringsberg (2009) and Williams et al. (2005) provided a valuable insight into an issue which is currently poorly researched and understood.

The review of literature has demonstrated there was minimal research that identified any depth or understanding of women's experiences of AI following OASIS and impact on quality of life. Given the increasing prevalence of AI within the Australian community by 2030 and lack of disclosure due to the nature of AI, there is an urgent need for qualitative research that will provide personal accounts of the experiences women encounter as a result of AI and resultant impact on quality of life.

## **Summary of Chapter**

This chapter has presented the current literature relating to women's experiences of AI following a history of OASIS and impact on quality of life, and identified inconsistencies and gaps within research. The review of literature identified the social stigma related to disclosure of AI and the importance of open communication in

identifying and addressing afflicted women's' concerns. The paucity of information surrounding the impact of AI on quality of life had provided justification for a qualitative research methodology which seeks to uncover a rich descriptive account of women's' experiences of AI. Knowledge gained from the research study will provide recommendations for health care professional education and practice in developing appropriate health care for women with AI. Chapter three discusses a qualitative research methodology, interpretive phenomenology as the chosen methodology which underpinned the reported research study.

# CHAPTER THREE

## METHODOLOGY

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### **Introduction**

This chapter describes the nature and intent of phenomenology, the chosen methodology which underpins the current research study. The two major schools of thought of phenomenology by Edmund Husserl (descriptive phenomenology) and Martin Heidegger (interpretive phenomenology) are discussed in relation to their philosophical and methodological stance. Rationale is given for the adoption of Heidegger's interpretive phenomenological approach as a research method for the current research study. Explanation will be given for the adoption of Max Van Manen's procedural framework to guide methods.

### **Qualitative research**

Qualitative research has struggled throughout history to be recognised for the depth and breadth it offers in understanding the holistic nature of human experience (Boyd 2001). Unlike the quantitative paradigm which is objective and aims to predict and control the area of study, qualitative research is subjective and seeks to discover, interpret and develop understanding (Streubert 2011a). The benefits of qualitative research have been recognised since the late 1800's in the United States of America (Boyd 2001). Qualitative strategies were utilised at that time to develop an understanding of the social conditions brought about by industrialisation and the findings were seen as an impetus for change (Boyd 2001).

Qualitative research provides an approach which seeks to develop a deeper understanding of human beliefs, values and cultural experiences where little is known

(Streubert 2011a). This type of research focuses on the whole experience of a phenomenon, and seeks to understand and meaning of the multiple human realities that exist for a phenomenon of interest (Streubert 2011b).

Meaning from an experience is contextual and cannot be constructed in isolation from the bigger picture of participant's lives. Therefore the experience of anal incontinence (AI) cannot be separated, or objectified from how women see their experience of AI in the broader context of their lives. Adopting a qualitative research methodology for the reported research study provided an opportunity for the multiple realities of women experiences of OASIS and AI to be highlighted.

Qualitative research identifies the researcher and participants as active actors immersing themselves within the phenomenon and constructing meaning through the exploration of beliefs, experiences and attitudes (Streubert 2011b). Through the use of language, a dialogue between the researcher and participants, within the current research study liberated the whole nature of a phenomenon and uncovered the multiple layers and understanding of the experience of AI (Boyd 2001; Streubert 2011b).

Phenomenology, grounded theory and ethnography are all qualitative research traditions that contain common features as outlined above, within their research designs. However, these approaches differ due to what the research question seeks to reveal about the lived experience of a phenomenon (Polit & Beck 2009). The methods used to gain understanding of an experience are further dictated by the research question (Streubert 2011b). In an area which has been poorly researched and shrouded in stigmatisation the research study reported within this thesis sought answers to the question; *what were women's experiences of AI following obstetric anal sphincter injury (OASIS) and how does it impact on their quality of life?* The research question dictated the use of a phenomenological approach and method which would elicit quality information regarding this experience. Phenomenological research attempts to develop an in-depth rich understanding of a 'lived experience' of a phenomenon through the use of interviews (Cohen, Kahn & Steeves 2000). Semi-structured open ended interviews provide a less structured approach and facilitate a relaxed conversational interview



process. This process elicits understanding of an experience which otherwise would be difficult to identify, and further supported the adoption of phenomenology as an appropriate research methodology which underpinned the research study reported within this thesis (Whitehead 2007).

## **Phenomenology**

Phenomenology is derived from the Greek word *phaenesthai*, which is defined as something that is shown (McConnell-Henry, Chapman & Francis 2009). Phenomenon is also described as something revealed or shown and therefore phenomenology studies phenomenon (McConnell-Henry, Chapman & Francis 2009; Whitehead 2007). This style of research method does not generalise or formulate theories; its strengths lie within understanding phenomenon providing a rich in-depth understanding of a person's experience of being in their world (Streubert 2011b). The negative impact of AI on a person's life results in emotional turmoil and resultant nondisclosure for afflicted persons. Nondisclosure of AI not only isolates individuals but also detracts from any understanding of their lived experience (Norton 2004a). Therefore phenomenology is a useful research method to employ when it is difficult to quantify or control what is being researched such as emotions and feelings (Whitehead 2007). Furthermore, phenomenology brings to light the 'lived experience' of a phenomenon through the use of language (Cohen, Kahn & Steeves 2000). Through the use of language, phenomenology provided a pathway to illuminate the unique experiences of AI within the research study reported within this thesis.

Phenomenology is both a philosophy and methodology whose origins are founded in the early 20<sup>th</sup> century European philosophical movement (Carpenter 2011). The preparatory, German and French phases make up the phenomenological philosophical movement (Carpenter 2011). The second phases, the German phase, concerns the works of Husserl and Heidegger and are outlined within this chapter to provide an overview of their philosophical stance and further justified the use of Heidegger's interpretive phenomenology which underpinned the research study reported within this thesis.

## **Descriptive phenomenology**

Edmund Husserl is noted as the father of the modern phenomenological movement. Husserl was a mathematician and philosopher who sought an alternative to the empirical approach to research, and he developed a descriptive phenomenological approach which is epistemological in nature and seeks the nature of knowing (Carpenter 2011; Lavery 2003).

Central to Husserl's philosophy was intentionality, where subjects were in a world of objects and knowledge arose from the conscious awareness of those objects (Lavery 2003). The true essence or meanings of a phenomenon would only be revealed when preconceived ideas, beliefs and assumptions were suspended; this was referred to as bracketing. Husserl noted bracketing as the goal of phenomenological reduction (McConnell-Henry, Chapman & Francis 2009). Bracketing enhanced the description, objectivity and validity of what is uncovered without impact from preconceived ideas, beliefs and understanding (Koch 1994). Given the sensitive nature of AI and the social taboos, stigmatisation that surround AI, it was questionable if bracketing and phenomenological reduction would have fully described and interpreted an experience which could not be separated from the complex nature of living.

The beliefs of the researcher within the reported research study were grounded in a worldview which embraced all prior experiences, understandings and beliefs were central to the lived experience. To detach those experiences and understandings from the world in which we live, would not portray a true account of living in that world and further supported the adoption of Heidegger's phenomenology for the research study described within this thesis.

## **Interpretive phenomenology**

Martin Heidegger was a student of Husserl; however Heidegger questioned the separation of the individual and the experience (Whitehead2007). Heidegger's phenomenology is ontological in nature and focuses on the person as a self interpreting being, having the ability to experience and make sense of a phenomenon and place it in context in their world (Carpenter 2011). Central to Heidegger's phenomenology is that a

person is in their world, *being in the world*, and an experience can not be described or interpreted in isolation of that world (Carpenter 2011). Heidegger believed the unity between the person and their world, co-constitution, was ever changing and therefore interpretation of experiences were unique and evolving for each individual (Lavery 2003; Mackey 2004).

Interpretive phenomenology does not seek to utilise reduction or bracketing, instead Heidegger acknowledged the importance of making prior awareness known (Carpenter 2011). Heidegger believed reality is constructed from experience and to bracket thoughts and feelings would impact on the interpretations of a new experience (McConnell-Henry, Chapman & Francis 2009). These aspects are fundamentally different to Husserl's beliefs of bracketing and description (Mackey 2005).

Due to professional experiences, the researcher acknowledged the importance of background knowledge of AI in providing an interest and development of the research question. These experiences placed the researcher in context with the phenomenon of interest. As an active participant within the research process the researcher made explicit prior awareness and revisited these beliefs and assumptions throughout the research process to reflect and reveal meaning of women's experiences of AI (Mackey 2005).

Heidegger's hermeneutic circle acknowledges prior awareness as an integral step in the development of a deeper understanding of a phenomenon of interest (McConnell-Henry, Chapman & Francis 2009). The hermeneutic circle is described as a circle of understanding from being in the world (Mackey 2005). Through this process partial preconceived ideas or assumptions are brought to the fore-ground, reflected upon and challenged by new beliefs and understandings of an experience revealing a deeper meaning of an experience at hand (Munhall 2001a). Meaning is derived through dialogue between the researcher and participants. The backwards and forwards process of the hermeneutic circle facilitates the interpretation of the experience as the researcher becomes immersed within the research process, reflecting and uncovering the essence of an experience through repetitious reading and writing of data (Mackey 2005). Therefore

an understanding through interpretation of an experience cannot be viewed out of context or as a static experience, and Heidegger's philosophical concepts of *temporality* and *spatiality* are essential to being in the world (McConnell-Henry, Chapman & Francis 2009).

Heidegger's concept of *temporality* is described in how a person comes to see themselves; temporality is present in everyday experiences (Mackey 2005). This concept recognises the past, present and future experiences are linked and are continually re-shaped through our daily life (Mackey 2005). The current research study acknowledged women's experiences of AI as individual experiences situating each woman in time; however commonalities existed between their experiences of AI and provided a deeper understanding of AI (Mackey 2005). Researchers who ascribed to Heidegger's belief of temporality need to be mindful of data collection techniques such as the need to re-interviewing participants. To re-interview participants is not congruent to the concept of temporality as there is a potential for participants stories to change and not reflect the true experience (McConnell-Henry, Chapman & Francis 2011).

Heidegger philosophical concept of *spatiality* describes a person as self-interpreting in their world where meaning of experiences are continually derived (Mackey 2005). Spatiality grounds a person in context to their world and how the person is involved in their world is through what Heidegger called *concern* (Mackey 2005). Heidegger's concept of *spatiality* assisted the researcher of the reported research study to derive meaning from women's experiences of AI in the context of their lives. The researcher who ascribes to Heidegger's belief of *spatiality* needs to consider both the experience that is brought to the foreground and the experience which is obscured in the background of the woman's experience to gain a deeper understanding of the experience of AI (Mackey 2005).

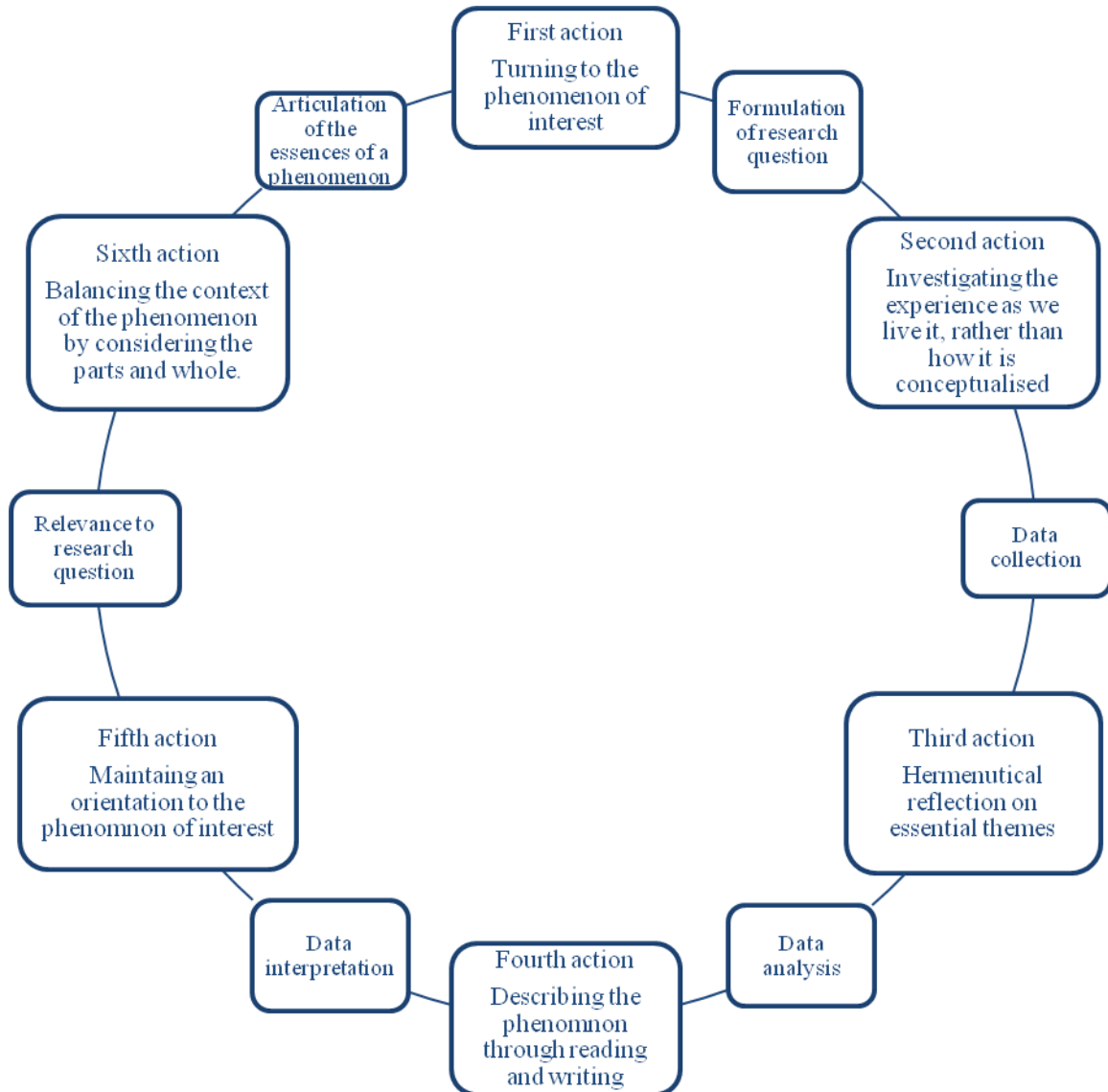
Interpretive phenomenology philosophy and methodology was congruent with the research question and researcher's worldview and therefore was an appropriate framework to underpin the research into women's experiences of AI and the impact on their quality of life.

## **Max Van Manen's procedural framework**

Van Manen is a phenomenologist whose works are concerned with the human sciences (Boyd 2001). Van Manen's states phenomenology is scientific in that it purports an inter-subjective, self critical and systematic approach which reveals a deeper meaning of everyday life (Boyd 2001). In order to gain a deeper understanding a human experience, Van Manen subscribes to the belief that the researcher's assumptions and pre-understandings are important to be made known at the beginning of the research process. Through an ongoing reflexive and reflective process within all levels of the research process the stated assumptions will be brought into question as new information is interpreted and reformulated into a new meaning, reflective of Heidegger's hermeneutic circle (Van Manen 1990).

Van Manen's phenomenology is consistent with the philosophical underpinnings of Heidegger's interpretive phenomenology, and offers a link between philosophy and method (Munhall 2001b). Van Manen's procedural framework for enquiry offers six methodological actions for the researcher undertaking interpretive phenomenology. The six methodological actions are not intended as a step by step guide as there is circular interplay between the actions (Van Manen 1990) (Diagram 1).

Diagram 1: Van Manen's procedural framework



Briefly, the first procedural action involves turning to the phenomenon of interest, which essentially means finding an experience of interest and the formulation of a research question. Investigating the experience as we live it rather than how it is conceptualised, is the second procedural action within Van Manen's framework and requires the researcher to become part of the research process and utilise research methods which will gain a deeper understanding and interpretation of the lived experience. The third action; hermeneutical reflection on essential themes requires the researcher to adopt a reflective approach to grasp the meanings that are central to the experience utilising three approaches in isolating thematic descriptions. Describing the phenomenon through writing and re-writing is the fourth action within Van Manen's framework, this process is reflexive and reflective in nature bringing the researcher closer to the written text, this process helps to draw the experience to the fore in its entirety too be understood. Maintaining an orientation to the phenomenon of interest is Van Manen's fifth action, this step acknowledges the importance of not losing site of the research question and experience. The last procedural action balances the context of the phenomenon by considering the parts and whole of the phenomenon of interest. Ideally this addresses the significance of each interview in relation to all interviews in answering the research question. Van Manen's framework as briefly outlined underpinned data collection, analysis and interpretation within the research study and is discussed in the following methods chapter.

### **Interpretive phenomenology and nursing practice**

Qualitative research by nature is inductive, reflexive and seeks the holistic view of an experience and this approach has been frequently adopted by nurse researchers to provide depth and clarity to everyday nursing practice in order to gain an understanding of a person's experience (Munhall 2001a, Whitehead 2007). Qualitative research offers health professionals the opportunity to develop an awareness to issues which otherwise are difficult to measure or control, such as women's experiences of AI (Whitehead 2007).

Phenomenology a qualitative research methodology, is a popular research methodology utilised by nurse researchers as it reflects the human experience in context with a person's everyday life and is the central belief of nursing philosophy and practice (Whitehead 2007). The strengths of phenomenology lie within the interpretation, interaction of researcher and those being researched, encompassing a holistic approach which reveals multiple realities of the 'lived experience' for a specific group in time (Van Manen 1990). Differences however do exist between phenomenological philosophy and methodologies (Carpenter 2011). Therefore nurse researchers need to be congruent with the philosophical and methodological underpinnings of the selected research, as a disparity will not guide effective research and ultimately answer the research question (Munhall 2001a).

Interpretive phenomenology is an accepted research methodology amongst nurse researchers in studying the human experiences related to nursing practice and research. This type of research provides interpretation of an experience in context of a person's life and provides a deeper and diverse understanding of the complex nature of an experience (Mackey 2004). Interpretative phenomenology was congruent with the researcher's central beliefs that all aspects of life are intertwined and can not be interpreted in isolation from everyday life.

Interpretive phenomenology differs to other phenomenological approaches, as the researcher makes explicit prior assumptions and beliefs, and is an active participant within the research process, utilising a reflexive and reflective approach to data collection, analysis and interpretation (Carpenter 2011). The methods utilised within interpretive phenomenology uncover and interpret meanings of an experience in context with everyday life, which would otherwise remain concealed (Carpenter 2011).

Women's experiences of AI following a history of OASIS have been poorly portrayed within qualitative research literature and furthermore, it is not a topic which is easily discussed within the community as it is shrouded in taboo and shame (Norton 2004a). Interpretive phenomenology was best suited to the research study reported within the



thesis as it was congruent with the nurse researcher's worldview and the stated research question.

### **Summary of Chapter**

In summary, this chapter has discussed phenomenology as a research philosophy and methodology to uncover meaning of an experience. Discussions of the two main philosophical frameworks of phenomenology have been discussed and justification has been given for the use of interpretive phenomenology within the research study. Van Manen's six procedural actions have been discussed in relation to interpretive phenomenology and are further outlined within the following methods chapter.

# CHAPTER FOUR

## METHODS

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### **Introduction**

Heidegger's interpretive phenomenological approach informed by Max Van Manen methodological framework underpinned the current research study. This approach sought to uncover and interpret the meaning of women's experiences of anal incontinence (AI) in the context of their everyday lives.

This chapter discusses how the study design was utilised to answer the research question. Included within this discussion is information regarding sample population, inclusion, exclusion criteria and recruitment strategies. Ethical considerations are described with relevance to the research process and ethical guidelines. Van Manen's procedural framework which is used as a guide in data collection, analysis and interpretation within the research study is outlined. Methodological trustworthiness and credibility have been outlined within this chapter.

### **Research sample**

Sample sizes within phenomenological studies are often small due to the extensive amounts of in-depth information generated from participants (Sandelowski 1995). The review of the literature identified only two qualitative research studies relating to obstetric anal sphincter injury (OASIS) and AI; each study containing nine to ten participants (Rasmussen & Ringsberg 2009; Williams et al 2005). The review of current research literature provided a guide for sample size for the current research study in that the research designs would require seven to ten participants to generate information to answer the research question. However sampling continued until no new data was

identified within the area of interest and data saturation of information was reached (Polit & Beck, 2004). Saturation was reached at ten participants.

### **Study setting**

The research study was undertaken in the continence nursing service (CNS) of a large Northern Metropolitan Hospital outpatient department. This service operates within a multidisciplinary framework within the obstetrics and gynaecology departments. This department is accessed by women for bladder, bowel and pelvic floor dysfunction. Women with a history of OASIS form a large component of the CNS clinic.

### **Sample population**

Purposeful sampling is a common sampling method utilised within phenomenological research. This type of sampling requires the recruitment of participants who can provide a rich, in-depth description of their experience, thereby meeting the research aims, objectives and answer the research question (Donalek 2004). Purposeful sampling was utilised within the current research study. Ten women who had experienced the phenomenon of interest agreed to participate.

### **Recruitment**

Women with a history of AI and OASIS are routinely followed-up in the outpatient department of a large teaching hospital in the Northern suburbs of Adelaide, South Australia, by the CNS team. As a member of the CNS team the researcher had no direct involvement in the recruitment of potential participants, this reduced the potential for bias within this research study. The initial recruitment stage of eligible participants was undertaken by a member of the CNS team. Participants who had a history of OASIS and AI and who were willing to provide in-depth accounts of living with AI were recruited (Streubert 2011b). During recruitment, information flyers were displayed within the CNS teams work environment (Appendix 1).

Fifty women were initially invited by the CNS to participate. Each potential participant was supplied with a recruitment information flyer and patient information sheet by the CNS team (Appendix 1 & 2). These documents gave a full explanation in non medical

terms of the research, how the research would be conducted, and the benefits and risks to participants. The information sheet reinforced that participation was voluntary, and that any time during the study the participants maintained the right to withdraw without penalty. The patient information sheet detailed measures taken to ensure confidentiality and anonymity. Participants were also made aware of complaint pathways (Appendix 2), and contact details of the researcher and University supervisor were included to answer queries from potential participants.

The recruitment phase was slowed due to potential participants declining to participate. Feedback from the CNS team identified this was due to the sensitive nature of AI and confidentiality. The researcher liaised with the CNS team members to reinforce to potential participants aspects of confidentiality and anonymity within the research study. Twelve women initially agreed to participate, however two women declined involvement due to the emotional discomfort of disclosing their experience.

Potential participants were followed after one week via phone. This allowed participants time to reflect on their willingness to participate (Coup & Schneider 2007). Interviews were then arranged with participants, who were willing to participate.

### **Selection criteria**

The selection criteria utilised within the current research study included women with a history of OASIS, AI and were willing to articulate their experiences of AI and its impact on their quality of life.

The CNS identified at each point of contact, the severity and impact of AI with the use of an accredited AI assessment tool, the St Mark's incontinence score, referred to as the Vaizey score (Vaizey, Carapeti, Cahill & Kamm 1999). A Vaizey score of zero indicates a person is fully continent; a Vaizey score greater than zero indicates some impact of AI on a person's life. Women who scored a Vaizey score greater than zero, were invited to participate within the research.

In addition women needed to be able to articulate in English their experience of AI. Women who did not speak English were excluded due to the lack of funding for

interpreters. Interpretation through a third party may also have restricted full disclosure of the true essences of AI for non-English speaking women.

Women with a known medical or surgical history which impacted on bowel function and resultant AI were excluded from the research study. Such medical and surgical conditions include neurological disease, pudendal neuropathy, inflammatory bowel, anal surgery, sphincterotomy and haemorrhoidectomy.

### **Ethical considerations**

Ethics approval for the current study was obtained from the University of Adelaide, Human Research Ethics Committee (HREC) and the Adelaide Health Service Human Research Ethics Committee (TQEH/LMH/MH). The study did not commence until HREC approval was granted from both ethics committees (Appendix 3) and written consent (Appendix 4) was obtained from the participants. Departmental support was also obtained from the Women's and Children's Division of the Lyell Mc Ewin Hospital (Appendix 5).

### **Consent**

Participants were required to provide informed consent prior to the commencement of the research (Appendix 4) following the provision of research study information (Appendix 1). Written consent was sought by a CNS team member at the initial point of contact (Appendix 4).

Participants were made aware prior to the consent process and commencement of their interview that all digital recordings of the interviews would be transcribed by a professional transcription service trained in medical legal transcribing. Participants were informed that the transcription service was bound by a confidentiality agreement (Appendix 6). Participants were aware that research information would be used for current research purpose only and pseudonyms for each participant would be utilised as outlined in the patient information sheet (Appendix 2). Ten women signed written consents and participated in the current research study.

## **Anonymity and Confidentiality**

Participants were made aware that all research information and their identity was kept confidential. The researcher only had sole access to research information which was stored on a password protected universal serial bus (USB). Anonymity was maintained by assigning a numerical code to each digital taped recording. Transcribed texts were assigned a corresponding numerical code and participants were assigned a pseudonym. Confidentiality was enhanced further with the omission of any references to names or locations which could potentially have identified the participants. Pseudonyms have been utilised throughout the reported thesis.

## **Storage of data**

All information gained throughout the research was password protected on a Universal Serial Bus (USB) and securely locked in a filing cabinet within the Robinson Institute, University of Adelaide. The researcher had sole access to the research information. Research information will be kept for 15 years and then destroyed, as described by SA Health Act Guidelines ((NHMRC 2007).

## **Specific considerations**

The researcher appreciated the stigmatisation of AI and consequently, the resultant emotional impact through disclosure, which may have resulted in either the participants or researcher seeking counselling. Mental Health Services within the Lyell McEwin Hospital were aware of the research study and willing to provide ongoing support through the established hospital referral pathways. The sensitive nature of AI and resultant disclosure of information proved to be emotionally challenging throughout the interview process for all of the ten participants. Although all participants were offered the opportunity to cease the interview, none took the option. At the completion of the interviews all of the participants were offered further support from the mental health services, located within the health service where the current research study was undertaken. All of the women declined.

## **Data collection**

Van Manen's (1990) methodological framework was adopted to underpin the current research study. It offered six procedural actions to assist with data collection, analysis and interpretation (Diagram1). The procedural actions are not linear; this approach adopts a cyclical nature which assists the researcher guidance to remain true in answering the research question (Van Manen 1990). The following discussion provides an explanation of how each research action underpinned the current research study.

## **Turning to the phenomenon of interest**

An essential process in interpretive phenomenology is turning to an experience that truly interests the researcher in order to derive meaning and understanding; this is identified in the first of Van Manen's (1990) procedural actions. A central component of the researchers' current nursing practice included women who had experienced OASIS and AI. This provided a strong interest for the current research study and led the researcher to question what it was like for women to experience AI and the consequent impact on quality of life, thus resulting in formulation of the research question.

The acquisition of knowledge is often seen as an issue for phenomenological research as there is a tendency to interpret an experience without truly understanding it's meaning (Van Manen 1990). Heidegger's methodology identifies that a pivotal point within data collection is the role of the researcher to acknowledge their pre-understandings and beliefs (Van Manen 1990). The researcher acknowledged preconceived ideas that AI would impact on the quality of life of women following a history of OASIS. This process brought to the fore-ground the researcher's beliefs of AI. As research progressed these beliefs were challenged and re-shaped to incorporate a newly developed understanding of a woman's experience with AI (Whitehead & Annells 2007).

### **Investigating the experience as we live it rather than how it is conceptualised.**

The second procedural action identified by Van Manen (1990) investigates the 'lived experience' as a person lives it, rather than how it is conceptualised. The collection of 'lived experience' within the current research study included language; dialogue and textual representation which awakened a depth and richness to the experience of AI; whilst acknowledging these experiences were only a reflection of the lived experience (Van Manen 1990). The researcher as an active participant within the current research study immersed herself into the lives of the ten women interviewed to gain an in-depth insight and understanding of their experiences. Semi structured open ended interviews enabled the collection of data in a relaxed environment, in which the researcher and participant were able to freely exchange conversation with emphasis on the researcher listening to the participant's story and not in guiding the interview (Cohen, Kahn & Steeves 2000).

All interviews occurred within an environment where participants felt comfortable to disclose their experiences of AI. The significant number of women who had voluntarily accessed the CNS department reflected an environment where women felt comfortable in revealing their experiences of AI. All participants opted to be interviewed in the CNS clinic within the outpatient area.

### **Interview process**

Data collection often depicts the quantification of information. Van Manen (1990) describes data not in the quantifiable view but as something that is gained or given and therefore data collection within this research study only began once written consent from participants had been obtained. The interview process required each participant to participate in an semi structured open ended interview lasting between sixty to ninety minutes. Interviews were conducted at a time that was convenient to the participant although due to family situations such as illness and childcare, many interviews were rescheduled. Subsequent interviews were not required as this was not congruent with the research methodology. Heidegger's philosophical viewpoint of temporality



acknowledges that past experiences will influence both present and future ideas. Therefore, to re-interview women with AI would have altered their initial response to their experience of AI (McConnell– Henry, Chapman & Francis 2011).

Each interview began with a general statement asking women to tell of their experience of living with AI and the impact it had on their life (Appendix 7). The majority of interviews took more than twenty minutes to physically settle in to the interview process. It was apparent that participants were happy to discuss their experiences as they had provided written consent to participate in the research. However, all participants showed an uneasiness with the interview process as reflected in providing little depth to their shared experience, closed body language and quietened vocal tones. The researcher was intuitive to the participants' discomfort and tried to display a relaxed open friendly manner and paraphrased responses in a gentle-spoken and empathetic voice. The lengths of the interview were gauged by the participant's willingness to continue to discuss their experience and relevance to answering the research question. Given the emotional weight of this topic it was visibly evident by fifty minutes that most women were struggling emotionally to continue with the interview. The researcher was mindful of the emotional safety of the interviewee whilst attempting to answer the research question.

Interviews were tape recorded and allowed the researcher to participate fully within the interview process by observing nonverbal cues and in seeking clarification from the participant which enabled further development of the relationship with the interviewer and thus a deeper understanding of the experiences of AI could be obtained (Van Manen 1990). Through ongoing dialogue and reflection, the experience of AI was brought to life for the researcher and the ten participants (Lavery 2003). All interviews required some prompting from open ended questions, paraphrasing and re-clarification from the participants to truly reflect their experience (Appendix 7). Data collection continued until no new information was identified. Saturation of information was reached at ten participants (Carpenter 2011).

A journal was kept throughout the research study and allowed for the documentation of the researcher's pre-conceived ideas, assumptions and reflections from interviews. Journaling further developed insights from each new participant and assisted in the development of themes thus adding further depth to the experiences of AI. An excerpt of the researcher's journals entries (Appendix 8) identifies the reflexive process of hermeneutical research.

## **Data Analysis**

### **Hermeneutical reflection on essential themes**

Hermeneutical reflection on essential themes, Van Manen's third procedural action, provided a pivotal point for analysis within the current research study; the process of analysis is further outlined within chapter five analyses.

Through dialogue, women's stories of AI and the impact on their quality of life were illuminated within the current research study. The reflexive and reflective nature of the hermeneutic circle brought to the fore-ground beliefs and experiences often obscured in our everyday lives (Carpenter 2011). These beliefs were challenged by the current, evolving understanding of women's experiences of AI and reconsidered in a new light. This process allowed the researcher to clarify interpretations of the experience with the participants. Participants were invited to review their transcriptions at a time and place convenient to them. Participants agreed to review transcriptions within the outpatients department two to three weeks following their initial interviews. The review of transcriptions assured accurate representation of participants 'lived experience' and allowed for clarification of the evolving themes

Following interviews, audio recordings were transcribed verbatim and assessed for accuracy. Journaling provided the researcher opportunity to reflect on the interview and add emotions and nonverbal body language not reflected within the transcribed texts, adding further depth to the evolving experience of AI. The researcher immersed herself within the collected data through reading transcribed texts, journal entries, listening to

interviews and by identifying keywords, statements and phrases for commonalities which provided grounding for concepts, sub-themes and essential themes (Appendix 9 & 10). Concepts which shared common features were combined on a excel spreadsheet and provided an emerging sense and understanding of women's experiences of AI.

Isolation of themes was undertaken by the researcher utilising Van Manen's three approaches; the sententious, highlighting and line by line approaches (Van Manen 1990). The sententious approach looked at the whole text seeking an overall understanding of the text. The highlighting approach revealed statements and phrases that were essential in understanding the experience of AI. The third approach, the line by line approach asked what a sentence revealed about the experience. This process was cyclical in nature. The isolation of thematic statements is discussed further within the following chapter.

### **Describing the phenomenon through writing and re-writing**

Data collection, analysis and interpretation were not non-linear processes within the current research study, but rather a cyclical process of reading and writing which allowed the researcher to redefine and re-clarify themes and thoughts into a narrative text. Describing the phenomenon through writing and re-writing is the fourth procedural action identified by Van Manen (1990). This cyclical process brought to life women's experience of AI.

### **Maintaining an orientation to the phenomenon of interest**

Remaining orientated to the phenomenon of interest, the fifth procedural action identified by Van Manen (1990) assisted the researcher to remain true to the research question and genuinely reflect women's experiences of AI. The interview process within the current research study proved to be emotionally taxing and women often diverged from their stories this provided a challenge for the researcher. A general interest within the research area provided an impetus to remain focused to the research question and journal reflections identified a trail of thoughts and feelings that enabled

the researcher to constantly question the accuracy of themes as a true representation of women's experience of AI (Van Manen 1990).

### **Balancing the research context by considering the parts and whole**

Interpretive phenomenology's cyclical process of data collection, analysis and interpretation considered the parts and whole of the phenomenon within the current research study. Transcribed texts, journal entries and audio recordings ensured the experience of AI was captured and described in context. Thematic analysis allowed for the breaking down of individual interview transcripts to their basic parts which provided an understanding of these individual sections and the relationship to the overall whole meaning of AI, as identified by Van Manen's sixth procedural action, balancing the research context by considering the parts and whole. Individual interviews were then considered in relation to each other and the whole experience of AI.

### **Methodological rigor in interpretive research into women's experiences of AI following a history of OASIS.**

The aim of qualitative research is to illuminate a phenomenon of interest in an accurate and truthful manner. Four aspects which judge the rigor within qualitative research are credibility, dependability, confirmability and transferability (Streubert 2011c).

The credibility of the research study of women's experiences of AI was enhanced through the recruitment process, data collection methods and analysis. Women who provided an in-depth experience of AI following a history of OASIS were recruited by the CNS service. The researcher provided no input to recruitment as this was deemed unethical and a potential bias for the research. The CNS service utilised a severity symptom score (Vaizey score) for AI, ensuring all women within the research were symptomatic of AI. The participants' profiles (chapter six) reflected a variation in age and incontinence symptoms assisting in a richer description of AI experiences within a diverse group of participants. Recruitment continued until saturation of data was

achieved further enhancing the credibility of the research (Graneheim & Lundham 2004).

Semi-structured open ended interviews were an effective form of data collection, allowing women to tell their stories of AI and the impact on their quality of life (Carpenter 2011). Validity of the data was enhanced during the interview process, in line with Heidegger's hermeneutic circle through the reflexivity of the researcher, re-clarification of concepts, the co-constitution of data and development of themes (McConnell-Henry, Chapman & Francis 2009). The credibility of this research was enhanced further by the use of direct quotes and description of participants lived experiences.

Tape recordings of interviews allowed the researcher to participate fully within the interview enhancing the accuracy and trustworthiness of data collection (Carpenter 2011). All interviews were digitally tape recorded and compared to verbatim transcribed texts within 48 hours, whilst the researcher's recollections were clearly defined, further enhancing the accuracy of information disclosed (Carpenter 2011).

Women were not re-interviewed due to Heidegger's view of temporality; to re-interview women with AI would have altered their initial response to their experience of AI and affect the credibility and trustworthiness of the research findings (McConnell-Henry, Chapman & Francis 2011). The researcher was aware that member checking was not congruent to Heidegger's methodology however research findings were discussed with the researcher's supervisor to determine if the researcher, as a novice researcher and student had utilized the correct pathways for data collection and analysis, further ensuring trustworthiness of the research.

The researcher stated her beliefs and assumptions at the commencement of the interpretive phenomenological research study, which enhanced the confirmability of the research findings (Carpenter 2011). A research journal was kept by the researcher to record the researcher's own pre- understandings, bias, observations and evolving beliefs from the interview process (Carpenter 2011). The reflexive nature of journaling and interview process further enhanced the confirmability of the research data and

contributed to an audit trail (Polit & Beck 2004). Polit and Beck (2004, p.712) state an audit trail is:

*...the systematic documentation of material that allows an independent auditor of a qualitative study to draw conclusions about the trustworthiness of data.*

The justification of the research question, methodology and methods as outlined in previous chapters, identified the beginnings of the researcher's audit trail. The audit trail was enhanced following each interview, as the researcher created individual folders for participants, containing transcriptions, journal entries and notations taken during the reading process. The nonverbal cues or relevant information from the interviews were documented in the researcher's journal following the interview process. This information was then transferred to the participant's transcribed text as notations, adding a further level of meaning to the experience of AI and allowed for reflection during subsequent stages of analysis.

Transcriptions in conjunction with audio recordings and journal entries were read and re-read to establish concepts and sub-themes. Transcriptions were then compared with each other to ascertain commonalities and essential themes identified (Appendices 10 & 11). These findings were confirmed by the researcher's supervisor to further establish trustworthiness of the data.

Qualitative research findings are not transferrable. However, Polit and Beck (2004) state the detailed descriptions of qualitative research findings act as an impetus for the interested reader to contemplate whether transferability is indeed possible. The audit trail and research findings of the research into women's experiences of AI would allow interested readers to question their own beliefs of AI and contemplate the applicability of the research findings to similar situations (Koch 1994).

## **Summary of chapter**

This chapter has provided a detailed account of methods utilized within the research into women's experiences of OASIS and AI. The chapter commenced by detailing the sample population, recruitment strategies, ethical considerations and data collection.

Also included were strategies for analysis and interpretation of the data. The following chapter provides a detailed account of Van Manen's thematic analysis and the identification of the essential themes which tell women's stories of AI and the impact on their quality of life.

# CHAPTER FIVE

## ANALYSIS

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### **Introduction**

Interpretive phenomenology was adopted as an appropriate research methodology to explore, identify and interpret women's experiences of anal incontinence (AI) following a history of obstetric anal sphincter injury (OASIS) and the impact of AI on their quality of life. Van Manen's procedural framework was adopted to guide method within the reported research study within this thesis to elicit a deeper understanding of the lived experience of AI.

This chapter describes Van Manen's procedural actions as a framework for analysis within the current research study. Van Manen's method for isolating themes and the development of sub-themes and essential themes are further outlined.

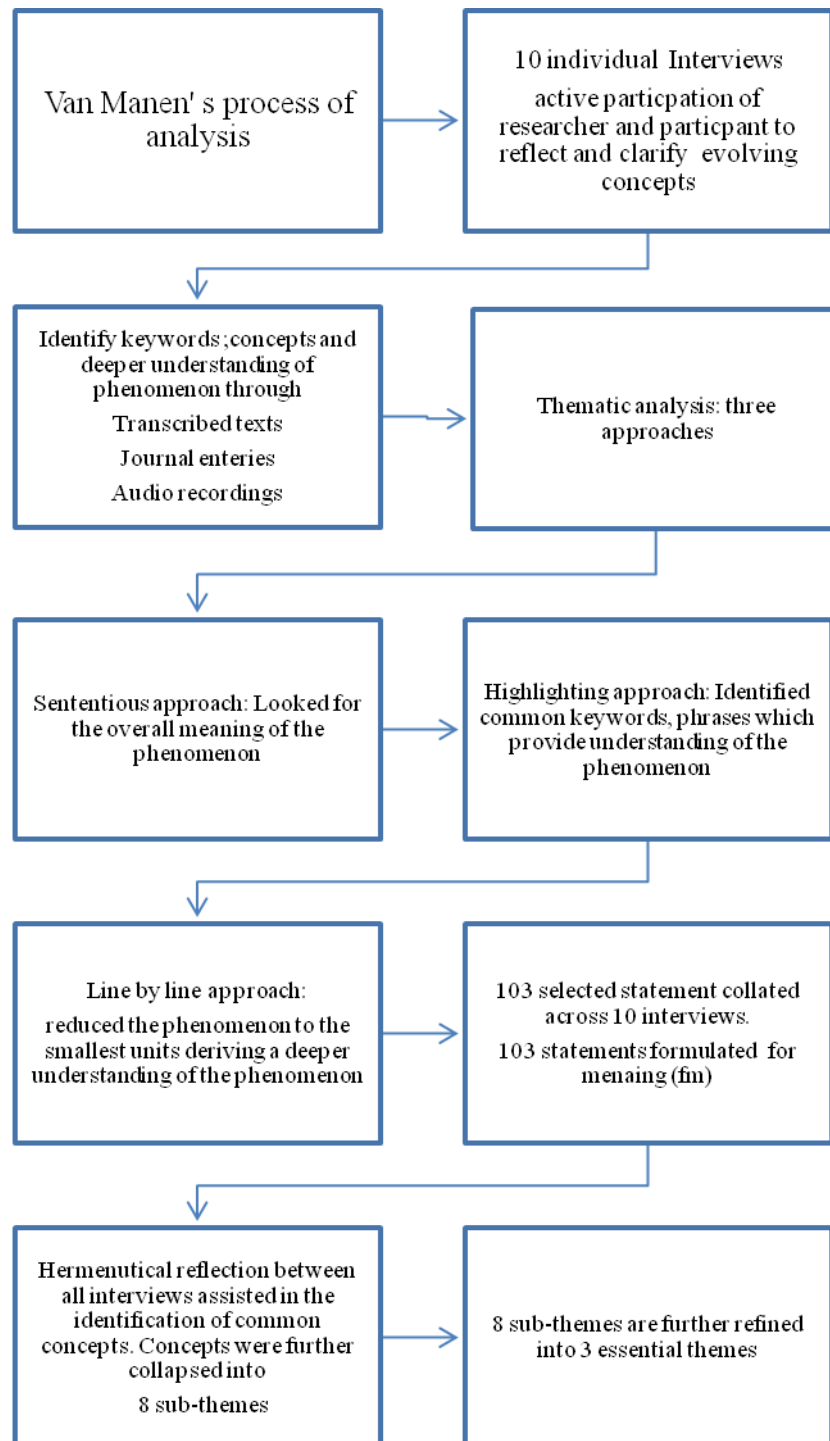
### **Analytical framework**

Rich in-depth descriptions of any 'lived experience' provide an opportunity for analysis and uncovering themes which describe the multiple layers of an experience (Van Manen 1990). Descriptions of 'lived experience' come in various forms such as written transcripts, poetry, oral stories, journals and audio recordings and vary in the depth and quality of information uncovered (Van Manen 1990). In order to derive a richer and deeper understanding of women's experiences of AI following OASIS, the researcher utilised Van Manen's six procedural actions as a framework which underpinned the research methods within the current research study (Diagram 1).



Data collection, analysis and interpretation occurred simultaneously and therefore analysis began when the initial interview commenced. The first two procedural actions of Van Manen's framework enabled the researcher to remain focused to the research and orientated to the research questions, aims and objectives. A genuine interest enhanced effective communication and developed dialogue between the researcher and participants thus facilitating the co-constitution of data. The interview process allowed the researcher to listen, observe the participants and thus participate in their life world through conversation in order to uncover the true essence of the experience of AI. The third and fourth procedural actions were concerned with data analysis and interpretation. Diagram 2 outlines a flow chart utilising Van Manen analysis.

**Diagram 2: Flow chart of Van Manen's process of analysis**



The hermenutical nature of the interview process assisted with the identification of keywords and concepts. Through reflection, paraphrasing and clarification, analysis and interpretation occurred. Table 1; describes the process of paraphrasing and clarification

utilised within the interview process to derive meaning of the negative impact of AI on future family planning. The entries underlined provided further clarification of the participant's experience. As the analysis process continued, commonalities within statements and concepts were identified and grouped together across all ten interviews.

**Table 1: Example of paraphrasing and clarification within the transcribed text**

I	<i>Probably did delay our future family planning and perhaps that's why we're having trouble now... because I am 39, and I was dead-set certain, <u>no way am I going through that again.</u></i>
Q	<b>Can you tell me about that?</b>
I	<i><u>I don't want that again [AI], I don't – if I have another baby and that happens again which I was told most likely it will, you know there's things we can do we can, you know, have really experienced midwives and all the rest of it – if it happens again I was like, AH AH – because <u>I will be wearing nappies.</u> I'm mortified about having to wear a nappy under my clothes and its like if I have another one of those [OASIS], that's the result, it will not be good.</u></i>
Q	<b>So wearing the nappies, you say you will be mortified? Tell us a bit more about that.</b>
I	<i>Oh my God. Oh – I [pause], I [pause] <u>there's nothing to say about that, and I don't want to wear a nappy, that's just... [Silence].</u></i>
Q	<b>Is that because of the incontinence or are there other reasons then?</b>
I	<i>Yeah because of that. <u>Its bad enough thinking you might have an accident at work let alone having one in a nappy.</u> What are you going to do then? I don't know, what would you do, you still have to get in the car and go home and I don't know. Oh, I don't know <u>it just terrifies me, the thought of that.</u> It's probably a really silly, unfounded fear but to me it's like, oh no, that won't be happening (Julie-Anne P 25, L 4-27).</i>

NB: I = Participants pseudonym; Q= Researcher; P=page; L =line number

The participants' and researcher's voice have been represented within the reported thesis. In the above extract *I* refers to the participant and *Q* refers to the researcher. A pseudonym has been allocated to each participant. Direct quotes by participants are indented, italicised in Times New Roman size 12 font. Quotes have been referenced with a pseudonym, page [P] and line number [L]. This process continues throughout the reported thesis.

Interviews were transcribed verbatim and compared to audio recordings for accuracy. Thematic statements were isolated utilising Van Manen's isolation of themes. Isolating thematic statements is outlined further within this chapter.

The multiple layers of the lived experiences of women's experiences of AI were uncovered within the ten interviews, transcribed verbatim text, journal entries and audio recordings. The researcher found it necessary to utilise all forms of data collection methods to reveal each layer of a women's experience. To read the verbatim transcribed text in isolation provided little understanding as to the depth of women's experiences of AI. The audio recordings of the interviews generated a deeper appreciation of feelings and emotions not captured within the transcribed verbatim text. The audio recordings provided the researcher with desperate and emotionally moving accounts of living with AI. The researcher's journal entries provided another layer of information from the researcher's reflections, assumptions and participants nonverbal cues which were not reflected within the transcribed text or audio.

The researcher continually read and re-read the transcripts to uncover the essential meaning from the data, this reflective and reflexive process continued throughout all ten interviews. Following the interview process participants were followed to further clarify the accuracy of the transcribed text and evolving concepts and themes.

The interview process was emotionally charged and provided a challenge for the researcher to remain focused in answering the research question. However a deep interest in the research area and the use of a reflective journal assisted the researcher in maintaining an orientation to the experience of AI and answering the research question. Maintaining an orientation to the phenomenon of interest is Van Manen's fifth

procedural action. The hermeneutic conversations with participants further clarified the experiences that truly reflected their experience of AI and the impact on a person's quality of life, Van Manen's sixth approach assisted in the analysis process of individual interviews, the parts, were then compared to all interviews, the whole, for common themes and essential themes.

### **Thematic analysis**

In interpretive phenomenology, thematic analysis is a process whereby themes are recovered from a 'lived experience' (Carpenter 2011). Hence, themes are seen as threads of an experience and they hint at the deeper level of understanding that an experience offers (Van Manen 1990).

Themes however are not objects, they are complex, inter-connectable and attempt to provide meaning and depth to an experience (Van Manen 1990). According to Van Manen (1990, p. 90) themes are defined as:

*"...phenomenological themes are not objects or generalizations...they are more like knots in the webs of our experiences, around which lived experiences are spun..."*

The ten interviews provided a depth of information into women's lived experience of AI. Thematic analysis was undertaken utilizing three approaches; the sententious, highlighting and line by line approaches, as described by Van Manen (1990) (Diagram 2).

### **Sententious approach**

The sententious approach aimed to find an overall understanding or significance of the text (Van Manen 1990). This required many re-readings of the text including the audio recordings and journal entries by the researcher to provide a deeper appreciation of what the women were expressing.

Van Manen (1990) suggests this approach is individualistic and multiple interpretations by different readers can occur. In order to stay true to the research question and women's experience of AI, the researcher continually questioned the findings; *what does this reflect of women's experiences of AI and what is the impact on their quality of life?* As a result the initial interpretations of the texts were refined as the researcher became immersed within the literature. A phrase which captured the overall meaning was derived from each participant's text. Overall meanings from the text were tabulated and compared to the concepts and sub-themes that arose from the highlighting and line by line approach within analysis. Comparison of the individually analyzed interviews to the overall understanding of all interviews provided the researcher with a deeper understanding of the experience of AI.

### **Highlighting approach**

The highlighting or selective reading approach was the second approach in isolating themes within the current research study. Individual transcribed texts were read and re-read to seek clarification of each woman's experience of AI. Entries were made on individual transcribed texts from audio recordings and journal entries. This approach highlighted phrases and statements which stood out and thus provided a greater awareness of the experience. The audio recordings provided the researcher with the emotion and emphasis placed on words not captured within the text. These recordings depicted the strength and value of ontological and epistemological silence and assisted with thematic analysis providing a further level of understanding to women's experiences of AI (Van Manen 1990).

Reflection on transcribed texts allowed for the identification of words, phrases or repetition of words that provided a further understanding to the experience of AI. Table 2; describes the repetitious use and emphasis of words in providing a deeper account of living with AI.

**Table 2: Description of repetitious words in illuminating experiences of AI**

Selected Statements	Formulated meaning	Concepts	Sub-theme
<i>...so I was <u>really, really very embarrassed with this thing because it's really taking me very hard life, indeed very hard life because I can't be in the public and I can't do what I was doing before...</u> (Penny P4, L 4-6).</i>	Women with AI grieve their loss of life and normality.fm 54*.	<u>Restricted life</u> , loss of normality, vulnerability	Loss middle adulthood
<i>I don't know <u>it is embarrassing [pause]... It is, it is embarrassing but I don't know whether it is more embarrassing or frustrating that you know, you know, as an <u>adult or a parent</u> there so many things that I can control, but this <u>I can't</u>.</u> (Matilda P13, L15-17).</i>	As an adult it is frustrating and embarrassing having no control over what is considered controllable. fm 47*.	Anger at <u>lack of control</u> embarrassment sadness	Loss of middle adulthood

\*NB: fm= represents formulated meaning coded with numbering. fm54 = 54<sup>th</sup> formulated meaning

The highlighting approach identified selected statements, these statements were cut and pasted into excel spreadsheets for each participant. Table 3 describes the development of selected statements and formulated meanings. Statements were then compared between interviews for commonalities and cut and pasted to a main excel spreadsheet for ease of comparison. One hundred and three statements which offered a vivid account of the experience of AI were selected and their meanings were formulated to capture the essences of the experience of AI. They were subsequently copied and tabulated and are described in Appendices 9 & 10.

**Table 3: Development of formulated meanings**

Selected Statements	Formulated meaning
<i>I'm only 32 and I've got to deal with this for the rest of my life ... I thought it was just elderly people that sort of dealt with that sort of thing (Hallie P4, L27-29).</i>	There is an expectation AI only happens to the elderly, yet young women are faced with the inevitable loss of their identity.fm 8.
<i>I mean I'm not old (37 years) but like, you know, if this is where I am its only downhill; it's not going to improve... (Anna P19, L22-23).</i>	There is an expectation that AI worsens with ageing, women are already compromised and sense the impending burden of AI.fm1

### Line by line approach

The line by line approach attempted to reveal further information about the phenomenon of interest (Van Manen1990). The following extracts reveal the development of keyword and concepts from selected statements identified from within the transcribed texts. Keywords are underlined:

*I'm only 32 and I've got to deal with this for the rest of my life....I thought it was just elderly people that sort of dealt with that sort of thing...*

(Hallie P4, L15-17).

Anna's statement described similar keywords:

*I mean I'm not old (37 years) but like, you know, if this is where I am its only downhill; it's not going to improve... (Anna P19, L22-23).*

Initial analysis highlighted and grouped key words within individual transcripts; concepts were further developed through reading and re-reading of the interviews. Selected statements, keywords and concepts were tabulated on an excel spreadsheet, as described in Table 4. Individual statements, keywords and concepts were then reviewed for commonalities between all ten interviews and led to the development of sub-themes. All entries were tabulated on a main excel spreadsheet.



Commonalities between keywords and concepts were gathered together and led to the development of the sub-theme, *near the edge* as described in table 4.

**Table 4: Development of formulated meaning, concepts and subtheme.**

<b>Selected Statements</b>	<b>Formulated meaning</b>	<b>Concepts</b>	<b>Sub-theme</b>
<i><u>I'm only 32</u> and I've got to deal with this <u>for the rest of my life</u> ...I thought it was <u>just elderly people</u> that sort of dealt with that sort of thing (Hallie P4L27-29).</i>	There is an expectation AI only happens to the elderly, yet young women are faced with the inevitable loss of their identity. fm 8.	Role conflict, Loss of identity, sadness and Disgust	Near the edge
<i>I mean <u>I'm not old (37 years)</u> but like, you know, if this is where I am its <u>only downhill</u>; <u>it's not going to improve...</u> (Anna P19 L22-23).</i>	There is an expectation that AI worsens with ageing, women are already compromised and sense the impending burden of AI.fml	Loss of identity, impending burden	Near the edge

**NB: Keywords/concepts underlined**

The following tables 5 and 6 illustrate the process utilised to group common keywords, concepts and sub-themes; *near the edge*, *loss of young adulthood*, *loss of middle adulthood* , which led to the development of the essential theme; *grieving for loss*.

**Table 5: Development on the sub-theme loss of young adulthood**

Selected Statements	Formulated meaning	Concepts	Sub-theme
<p><i>I guess mainly when you want to have sex you're sort of <u>continually worried</u> that there's a possibility you're going to need to go to the toilet in the middle of it and sometimes suggesting you need to go to the toilet in the middle of it <u>isn't exactly the best turn on</u> and then if you don't you're not enjoying it because you're sort of trying to tense yourself up in case something happens (Ella P7L1-5).</i></p>	<p>The unpredictability of AI impacts on sexual relations, women continually worry AI will negatively impact on their relationship. fm 40.</p>	<p>Fear of sexual activity, <u>lack of sexual freedom</u>, loss of intimacy, anxiety</p>	<p>Loss of young adulthood</p>
<p><i>...<u>you just hope that it (AI) Does not happen</u>, it just... I don't know, it's <u>really hard to explain</u> you just, you just hope that it (AI) doesn't happen and then if it does, <u>is he going to be alright with it</u> (Heather P17L17-19).</i></p>	<p>A woman is faced with the constant fear and vulnerability that AI will occur during sexual relations and there is an uncertainty of how her partner will respond. fm 41.</p>	<p><u>Lack of sexual freedom</u>, vulnerability</p>	<p>Loss of young adulthood</p>

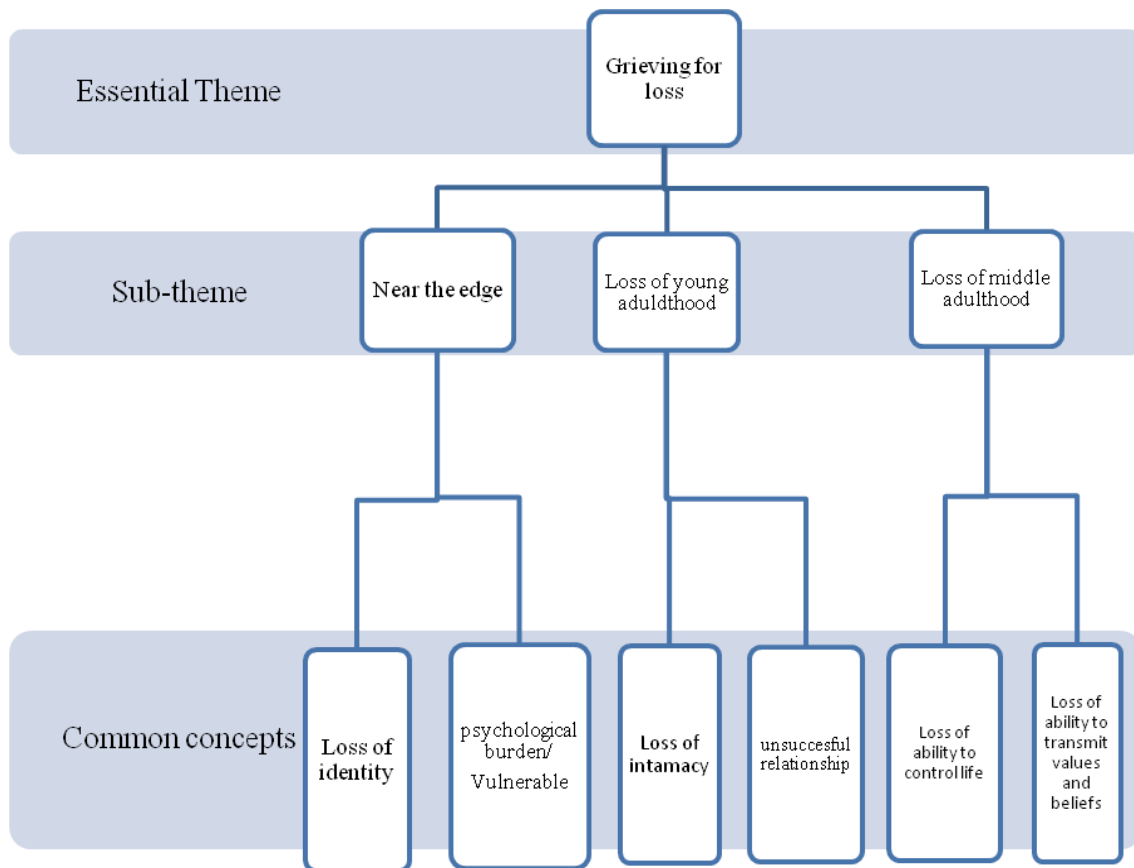
The concept of *lack of sexual freedom and intimacy* led to the sub-theme loss of young adulthood.

**Table 6: Development of sub-theme loss middle adulthood**

Selected Statements	Formulated meaning	Concepts	Sub-theme
<i>I suppose <u>cross and angry</u>... you know here's me trying to teach... my boys as they started to toilet train... and the baby and how to... be able to control their bowels and their bladder [pause]... and <u>thinking I can't</u> (Matilda P13 L20-23).</i>	Women are angry that they are unable to achieve basic bowel control like their children. fm 46.	<u>Loss of control</u> , Poor negative role modelling as a parent, sadness	Loss of middle adulthood
<i>Trying to pass wind [pause], well when I did try; I thought I was going to pass wind <u>I'd soil myself</u>. When I needed to go to the toilet to do Number Twos basically the minute I would step – open my legs and step off the bed, I'd soiled myself [pause] I was just <u>mortified</u>...(Anna P2L12-17).</i>	The lack of control of AI has a negative impact on a woman's physical and mental wellbeing. fm 50.	Physical loss devastation, shame, <u>loss of control</u>	Loss of middle adulthood

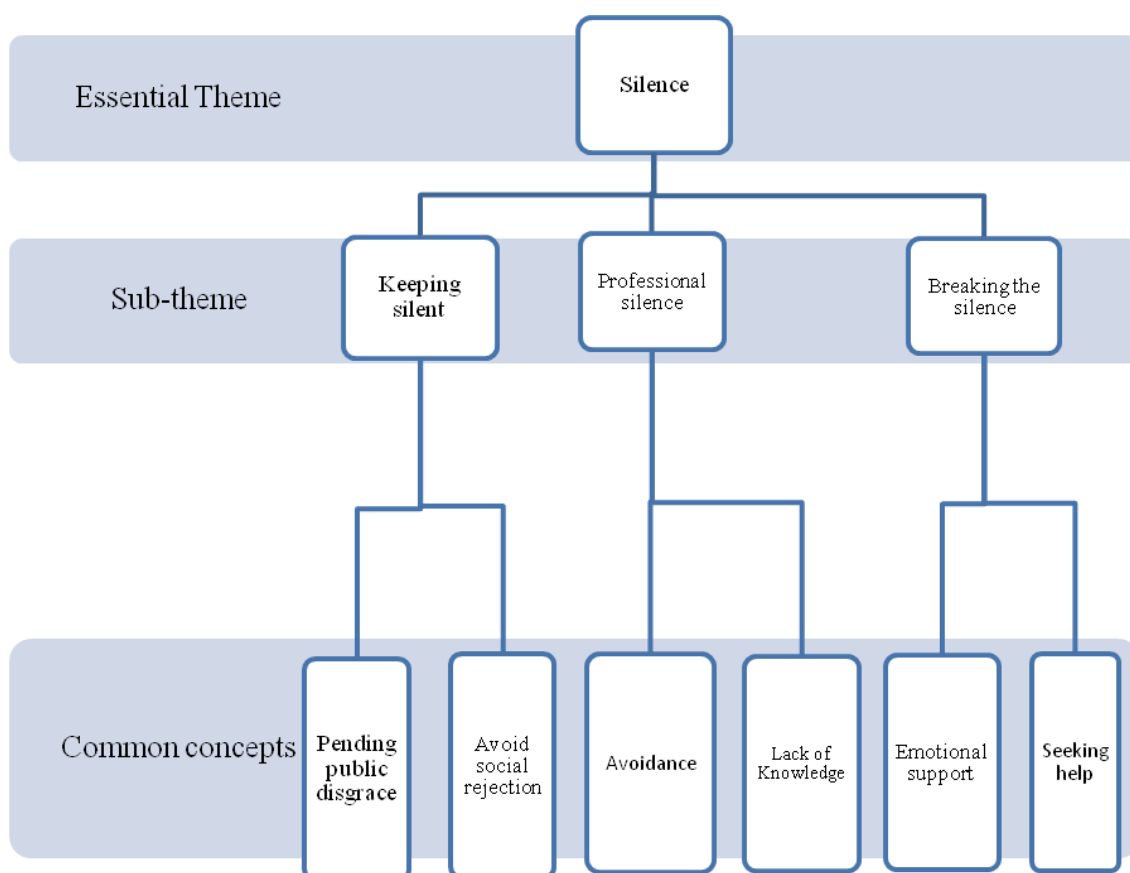
The concept *loss of control* led to the sub-theme loss of middle adulthood and development of the essential theme *grieving for loss*. Diagram 3 describes the development of the essential theme *grieving for loss*.

**Diagram 3: Development of the essential theme: *grieving for loss***



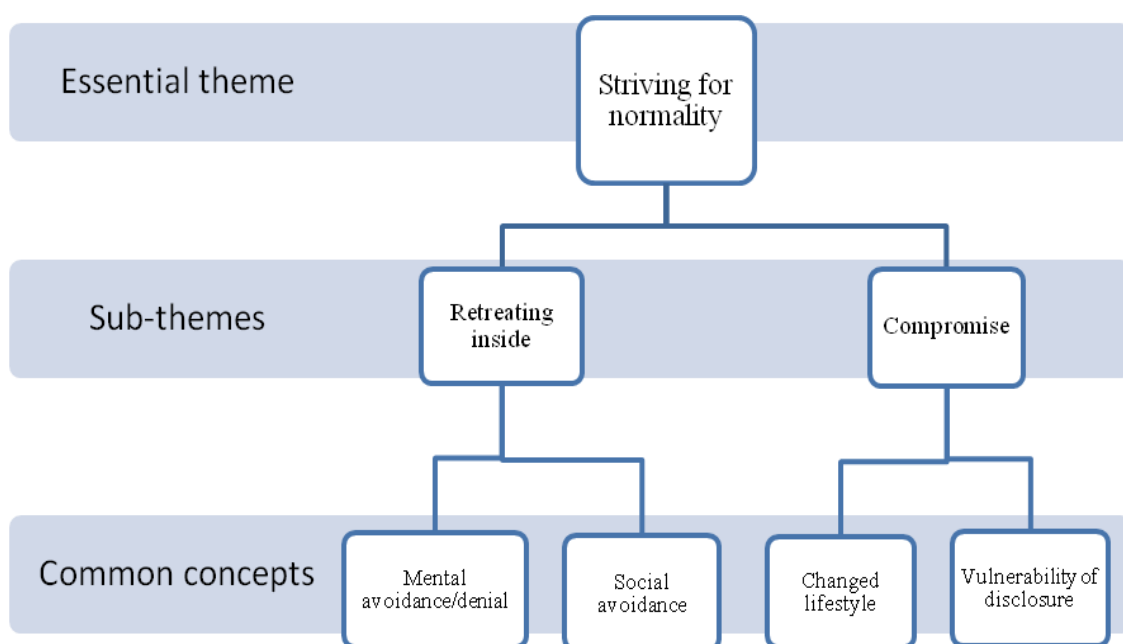
The current research study identified a further five sub-themes and two essential themes utilising the process of analysis as outlined. The sub-themes *keeping silent*, *professional silence* and *breaking silence* led to the development of the essential theme of *silence* (Diagram 4).

**Diagram 4: Development of the essential theme: *Silence***



The sub-themes of *retreating inside* and *compromise* led to the development of the essential theme, *striving for normality* (Diagram 5).

**Diagram 5: Development of the essential theme: *Striving for normality***



The process of analysis was ongoing as the researcher established the importance of each sub-theme and how that theme contributed to the overall experience of AI and development of the essential themes. Essential themes were deemed important in reflecting a true account of the experience of AI, without the essential themes the experience of AI would not have been reflected (Appendix 11) (Van Manen 1990).

## **Summary of chapter**

This chapter described Van Manen's procedural framework for analysis. The process of isolating thematic statements and development of themes was described. Analysis revealed three essential themes; *grieving for loss, silence and striving for normality* and eight sub-themes; *near the edge, loss of young adulthood, and loss of middle adulthood, keeping silent, professional silence, breaking the silence, compromise and retreating inside*. The interpretations from these themes are discussed within the following chapter six, interpretations.

# CHAPTER SIX

## FINDINGS AND INTERPRETATIONS

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### **Introduction**

This chapter provides a detailed account of essential themes and sub-themes derived from the current research study that illuminate and provide meaning of women's experience of anal incontinence (AI) and the impact on their quality of life. The findings and interpretations of the reported study are discussed thematically and the interconnections between themes are outlined, providing an overall understanding of women's experiences of AI. Pseudonyms have been utilised throughout the thesis to protect the participants' anonymity.

Analysis of the data arising from the ten interviews revealed three essential themes; *grieving for loss, silence and striving for normality* and eight sub-themes *near the edge, loss of young adulthood, loss of middle adulthood, keeping silent, professional silence, breaking the silence, retreating inside and compromise*. The essential themes and sub-themes are discussed within this chapter following a brief description of the participants.

### **Participants' profiles**

Interpretive phenomenological studies by nature seek a detailed understanding of the experience of AI and profiles of the participants seem of little importance within the research framework. However, the profiles of the ten participants within the reported



research study (Table 7) do provide some assistance in understanding women's experiences of AI as a result of obstetric anal sphincter injury (OASIS) and assists in placing their experience in context of their life.

The reported research study identified participant's aged between 26 -56 years (average age 35.4 years). There were a range of Vaizey symptom severity scores between 4 and 22; with an average score of 9.1. A Vaizey score reflects the severity of AI; a score of 0 denotes total bowel continence whereas a maximum score of 24 denotes total incontinence of bowel function. Women were symptomatic for an average of 5.5 years and 80% of women received their initial injury at their first delivery. Most women were still in a relationship with 80% of the women still in the relationship when the OASIS occurred.

**Table 7: Participants' profiles**

Interview	Pseudonym*1	Age	Vaizey *2	Marital status	Symptomatic (years)*3	Primary OASIS*4
1	Anna	37	14	Initial partner	3	1st Delivery
2	Flo	56	17	No partner	30	1st Delivery
3	Ella	27	6	New partner	2	1st Delivery
4	Matilda	40	11	Initial partner	6	2 <sup>nd</sup> Delivery
5	Hallie	33	3	Initial partner	2	1st Delivery
6	Penny	35	22	Initial partner	3	3 <sup>rd</sup> Delivery
7	Dianne	26	4	Initial partner	3	1st Delivery
8	Julie-Anne	39	4	Initial partner	2.5	1st delivery
9	Liz	27	4	Initial partner	0.6	1 <sup>st</sup> delivery
10	Heather	34	6	Initial partner	2.5	1 <sup>st</sup> delivery
	Average	35.4 years	9.1 (R0-24)		5.46 years	1 <sup>st</sup> delivery

**NB. \*1=Pseudonyms have been assigned to participants.\*2= Minimum Vaizey score =0= fully continence; maximum Vaizey score = 24 =total incontinence.\*3= Length of time symptomatic. \*4 =Initial OASIS injury**

## Emergence of themes

The hermeneutic nature of the interview process within the current research study facilitated the emergence of eight sub-themes. Sub-themes included *near the edge, loss of young adulthood, loss of middle adulthood, keeping silent, professional silence, breaking the silence, retreating inside and compromise*. Initial concepts and sub-themes were identified and clarified during data analysis. Significant statements which provided meaning of the experience of AI were selected from the transcribed texts and tabulated. The following extract describes a significant statement which reflected the concepts of social isolation and grief; sub-theme *near the edge* and the essential theme *grieving for loss*;

*I wouldn't allow people to come to the house so I basically used to get up in the morning and go feed some horses, there are no people around and only go out one morning a week and that was it, I never left the house. I still don't [30 years on] (Flo P3, L29-30; P4, L1-3).*

The researcher utilised all sources of data collection to assist with the interpretation process. The tape recordings of interviews provided the verbal cues not captured within the transcribed texts. The following extract emphasised the importance of the words; *I wouldn't allow people in and I never left the house... 30 years on*. Participant Flo was in tears during the interview process and the underlined words were expressed in a fearful and anxious tone;

*I wouldn't allow people to come to the house so I basically used to get up in the morning and go feed some horses, there are no people around and only go out one morning a week and that was it, I never left the house. I still don't [30 years on]. (Flo P3, L29-30; P4, L1-3).*

The researcher's journal entries allowed for reflection of the nonverbal body language and thoughts that arose from the interview process. This provided another layer to the complex nature of living with AI. Participant Flo's body language was closed, her hands clasped tightly together and she provided no eye contact to the researcher.

Each significant statement was reviewed utilising the above stated process. One hundred and three significant statements which reflected women's experience of AI were then formulated. Formulated statements were then grouped according to commonalities between concepts, leading to the development of eight sub-themes and three essential themes. Sub-themes included *near the edge*, *loss of young adulthood*, *loss of middle adulthood* which led to the emergence of the essential theme *grieving for loss*. *Keeping silent*, *professional silence* and *breaking silence* led to the emergence of the essential theme, *silence*. The remaining essential theme *striving for normality* was characterised by *retreating inside* and *compromise*.

Grief was a common characteristic within themes and has been woven through the following discussion to illuminate women's experiences of AI and the impact on their quality of life. Extracts from women's experiences describe and support each sub-theme and the interconnection of grief. The emotional responses to grief were reflected as anger, anxiety, sadness, shame and hopelessness.

### **Essential theme: *Grieving for loss***

The essential theme *grieving for loss* was characterised by the sub-theme *near the edge*, *loss of young adulthood* and *loss of middle adulthood*.

#### ***Near the edge***

The sub-theme *near the edge* is illustrated by the psychological response women endured with the loss of their identity as an adult and the precarious emotional burden of AI on their life.

Loss of identity as an adult and the impending burden of AI were identified by all participants. The following extract provided by participant Matilda described the loss of identity and embarrassment as an adult;

*...it had happened and there was nothing I could do about it... and not that anyone else knew about it, but because I did, I was embarrassed that this had happened. I was a grown woman, I am an adult... (Matilda P5, L20-23).*

Women often felt angry and disgusted in themselves as an adult they described the need to control simple tasks such as bowel control. Participants Liz described;

*...you're disgusted in yourself because you think it's such a simple thing to do. You take it for granted for sure. It's like anything, walking, breathing etc. Until you lose it you don't understand what it's like and I was, I was angry and upset with myself because I'm an adult (Liz P20, L16-19).*

The devastating impact of AI results in woman teetering near the edge, questioning their self-worth and value to society. Participant Flo stated;

*You know that you just felt so worthless, there were times when you thought why in the hell am I here. What good am I to anybody... absolutely nothing [pause] you can't function normally (Flo P11, L21-23).*

There was a fragile balance of being an adult, being incontinent and the resultant psychological impact which caused a sense of vulnerability. Julie-Anne described;

*...that's not what adults do. And yet there's a reason for it, wasn't my fault, I get all of that, I get all of that sensible stuff get it but who poos their pants on their way to work? I don't know it's embarrassing and humiliating if anyone had seen...(Julie-Anne P27, L15-17).*

Humiliation and shame were common feelings reflected by all participants who struggled with their loss of identity;

*I guess it's kind of a little bit demeaning knowing that you have to carry clothes around, you know, you do that for babies, you do that for toddlers but you never imagine that you're going to have to walk around with a baby bag that has your own clothes in it (Ella P14, L21-24).*

Participants often described AI as demeaning and there appeared a sense of loss for what they once had control of;

*...you just think of yourself as an adult and then when this happens you don't think of yourself as an adult, you think back to being a kid and how it felt to wet the bed or something as a little child (Liz P 20, L 22-24).*

There was a sense of vulnerability and heightened anxiety described by all participants regarding the loss of identity as an adult and the pending shame associated with loss of bowel control with ageing;

*I've controlled myself for the last 30 years... you know I can't lose that now I'm not even, I'm under 40, I'm not going to (long pause)... what I have to poo myself for the next 40 years (Julie-Anne P18, L10-14)*

Dianne described the disgust and hopelessness associated with loss of self-worth and the sobering thought of what her future holds;

*I used to think oh my God this is foul like I'm only 27 and this is happening, this is disgusting, if I'm like this now, it's only going to get worse when I get older (Dianne P14, L10-12).*

Ever-present in participant's minds was the hope for adequate control of bowel function for the future;

*...as I get older I hope that I can still have control of that (AI) because in the end, it's not supposed to happen to me (Heather P25, L30; P26, L1).*

However women sensed the impending burden of AI for the rest of their life and this resulted in anxiety and hopelessness;

*I mean I'm not old (37 years) but like, you know, if this is where I am its only downhill; it's not going to improve... (Anna P19, L22-23).*

This was further reflected by Matilda;

*...it's like going back to a child again [pause], so it's quite a big thing...for me it's not something that is going to get better... (Matilda P2, L19).*

There was an expectation that AI only happened to the elderly and young women were undeserving of the affliction of AI;

*I'm only 32 and I've got to deal with this for the rest of my life now, I thought it was just elderly people that sort of dealt with that sort of thing (Hallie P4, L27-29).*

Participants not only contended with their loss of identity and the devastating emotional impact of AI on their lives but were also faced with ostracism which was undeserved;

*... it (AI) kind of makes you feel like an outcast sometimes you know, like yeah that something's wrong with you but it's not really my fault (Heather P32, L 25-26).*

As women are forced to retreat from the public space to cope with the negative impact of AI they become isolated for the rest of their lives further impacting on personal identity and self worth;

*When you have lived so many years on your own... and you have cut off all social activities you are still on your own. It's got to the stage, it's the people you know the people you speak to on occasions don't want to be your friends anymore because you have isolated yourself for so long its, they're not really interested anymore ... so you are still on your own all the time (Flo P 26, L24-28).*

### ***Loss of young adulthood***

Young adulthood refers to women aged between 18 -35 years of age. Erik Erikson a psychoanalyst, proposed stages of psychosocial development which described the development of a person's identity across the lifespan (Harder 2012). Erikson's stage of young adulthood characterised the initial stage of becoming an adult and the development of mutually satisfying relationships, failure to build successful relationships ultimately resulting in isolation from significant others (Harder 2012). The sub-theme *loss of young adulthood* was characterised by the loss of intimacy and the inability to develop successful social relationships.

Anger was a common emotion described by participants who felt burdened by the negative impact on relationships as a result of AI. Heather described;

*I've got to worry about this crap all the friggin' time and I shouldn't have to be worrying about that... I could be playing with my daughter and then I stand up and pass wind ...and then she's going to go Mum you're stinky (Heather P26, L19-22)*

There was a real sense of loss of freedom as AI dictated women's lives; young women were forced to socially isolate themselves to cope;

*...it's been five and a half years and I still avoid saying yes to things if I'm sure that it's not going to be near a toilet even though since (Ella P2, L11-13).*

Participant Ella goes onto state;

*...the worst part was not really being able to go anywhere... I didn't have a car, so public transport was completely out of the question (Ella P1, L17-18).*

Women sought to socially isolate themselves to avoid the pending disgust and shame associated with AI. Participant Liz described;

*Thankfully I was at home, so at least being home I didn't have to worry about other people finding out about it, the embarrassment... (Liz P 1, L27-28).*

Whilst young women found safety in the home environment, the pending shame and emotional burden of AI was a constant thought for women. Participant Liz described;

*God if that had happened anywhere but my house, it would have been horrible (Liz P 5, L1).*

The unpredictable nature of AI impacted further on intimacy and loss of sexual freedom. Women described the constant fear and anxiety of AI occurring during sexual relations and there was uncertainty and fear of how significant others would respond. Heather explains;

*...you just hope that it (AI) doesn't happen, it just... I don't know, it's really hard to explain you just, you just hope that it (AI) does not happen and then if it does, is he going to be alright with it (Heather P17, L17-19).*

Participants described the continual psychological, physical and emotional burden of AI on their sexual relationships;

*I guess mainly when you want to have sex you're sort of continually worried that there's a possibility you're going to need to go to the toilet in the middle of it and sometimes suggesting you need to go to the toilet in the middle of it isn't exactly the best turn on and then if you don't you're not enjoying it because you're sort of trying to tense yourself up in case something happens (Ella P7, L1-5).*

### ***Loss of middle adulthood***

Middle adulthood referred to women aged between 35-65 years of age. Erikson described middle adulthood as *production and care* (Harder 2012). Women need to *be in charge* of their lives, where they can care for their families and transmit the values and beliefs of their culture (Harder 2012). This stage of development required women to maintain significant relationships within the work place and society (Harder 2012).

The sub-theme *loss of middle adulthood* was characterised by the loss of control as an adult with every facet of everyday life and the inability to transmit the values and beliefs of a mother and adult.

Women described their struggle and torment as an adult and mother to maintain social norms, values and beliefs in teaching others to control bowel habits, when they had no control over basic bowel function. Participant Matilda described;

*I suppose cross and angry... you know here's me trying to teach... my boys as they started to toilet train... and the baby and how to... be able to control their bowels and their bladder [pause]... and thinking I can't (Matilda P13 , L20-23).*



Role modelling as an adult was often challenged by the impact AI and resulted in humiliation;

*...in our culture like you do not pass wind in public...because if you did this (silence)... you are the big person... (Penny P7, L3-5).*

The humiliation and shame felt by all women was further described by Matilda;

*I so needed to go and I knew what was about to happen and I said boys, mummy doesn't want to poo her pants. I had to say this really quiet to them because I had to get to the toilet, I was so desperate ...I had to do it discreetly (Matilda P 8, L26-30).*

The impact of AI on a woman's life caused a sense of loss and despair;

*...so I was really, really very embarrassed with this thing because it's really taking me very hard life, indeed very hard life because I can't be in the public and I can't do what I was doing before...(Penny P4, L 4-6).*

The unpredictable nature of AI placed women in a precarious situation;

*... I had a bowel accident walking from my car to work, that was really horrible, I just got back in my car and went home and spent some time at home (Julie-Anne P 4, L 5-7).*

Women described the negative impact of AI on their psychological, emotional and sexual relationships. Anna described the burden of living with AI;

*...mentally I wasn't in the right space (head-wise anyway), I had the shits because you know couldn't control your urine and your shit – I mean if you can't control that, what can you control? [silence] So yeah, and sex was: What? Huh? I'm not even interested, you know, we're talking about that region just stay away from there (Anna P6, L10-14).*

Participants were often frustrated by their loss of freedom; this was voiced by participant Anna;

*I had a nappy bag and then I had to carry a bag with all of my crap, so I tried. That lasted probably 30 days and then that was it, I didn't venture out until, you know, I had either gone to the toilet (Anna P17, L5-8).*

Participants sensed there was no hope to regain control of their life instead AI dictated every facet of daily life. Participant Flo described;

*But you tried; you had to live your whole life around what your bowel was doing instead of the other way around (Flo P13, L 27-29).*

### **Essential theme: *silence***

The essential theme of silence was characterised *by keeping silent, professional silence and breaking the silence.*

#### ***Keeping Silent***

The sub-theme *keeping silent* was illustrated by participants as the need to hide from the pending public disgrace, associated shame and social rejection as a result of AI.

Participants did not willingly disclose concerns of AI as there was an expectation that AI was a normal occurrence after vaginal delivery;

*I did wait for the nurse to say something..... at the start because as I said, I thought it was normal so I didn't really think much more of it (Hallie P6, L4-5)*

Participant described AI as a normal event following vaginal delivery; however this perception did not alter their vulnerability at sharing the impact of AI on their lives.

Women often waited for others to start relevant conversation;

*...embarrassed and uneasy and as I said it's not something that I guess you just generally bring up with people because they may not want to hear it, so it was just if they'd brought something similar up (Hallie P 9, L8-12)*

The disgust and anxiety surrounding AI impacted on disclosure, participant Matilda described;

*...you know, it is still obviously not something that you know, that you want to sit there and you want to have... it's not the topic of conversation (Matilda P15L13-15).*

Participant Matilda goes on to state the constant emotional burden and pending shame of AI prevented women from telling others what living with AI was really like;

*...it can be quite overwhelming and intimidating and embarrassing you know, you have to watch what you say and how you say things... (Matilda P15, L11-17).*

Non disclosure was seen by participants as a way to cope with the devastating physical and psychological impact of AI on their lives;

*I am lucky that no one else knew because I don't know that I'd be able to get over those emotions of someone knowing that that's what happened (Julie-Anne P18, L2-4)*

Women expressed tremendous anxiety and vulnerability living with AI, keeping silent allowed women to protect themselves from further shame and protect others from having to deal with this knowledge. Participant Dianne explained;

*I would just keep it to myself and wouldn't say anything to him...it's embarrassing I just don't want him to know (Dianne P10, L12-19).*

This was echoed by participant Liz, who wanted to be in charge of her life and protect her partner from knowing of any further devastation from the impact that resulted in AI;

*I don't think he really understood...I don't think I told him ...I told him what happened but I don't think I told him so much...because he was so worried with what happened (the birth) (Liz P 3, L22-25).*

Participant Julie-Anne summarised the lack of self worth and disgust women face and reasoning for keeping silent;

*You don't feel good about yourself when it happens which is probably why you just keep it to yourself* (Julie-Anne P16, L26-27)

Participants described the compounding impact of social rejection on nondisclosure which further impacted a woman's need to retreat from interaction within society;

*I just had to shut everybody out because the ones that knew that I had a problem didn't want to know me anymore ... they made it quite clear I wasn't worth knowing* (Flo P7, L23-25).

### ***Professional silence***

The sub-theme *professional silence* was defined as fear of client dissatisfaction, professional avoidance and lack of professional knowledge.

Participants felt that professionals feared client dissatisfaction and this prevented professionals from communicating the negative effects of AI following OASIS. Participant Penny described;

*... even the (professionals) are scared to tell you... they might think I will not be happy with them, I don't know* (Penny P14, L12-13).

Professional silence was seen as avoidance and caused women to feel angry at professionals;

*I feel like there's probably something that someone knows that I should be knowing, do you know what I mean... I feel like there's probably someone who has more information that I'm not getting* (Ella P11, L5-7).

and participant Heather reaffirmed this statement;

*It makes me feel like they're hiding something, like that they've kept that locked away and hoping that you know, I won't look into it any further (Heather P29, L15-16)*

Women described professional silence as professional misconduct. Participant Flo described;

*What that doctor did to me was cruel, because he never told me what he had done any damage ... let me go home not knowing..that was absolutely cruel what he did. I should have been given a referral to get help...rather than be let home and think later on, what's wrong with me (Flo P5, L29-30).*

Women were angry and frustrated by the inability of health professionals to effectively link them to appropriate services. This was often seen as professionals lacking knowledge relating to AI and OASIS or professional misconduct;

*...Like completely dumfounded as to why no-one knows about this clinic (continence)...right you (obstetrician) don't want to deal with it, send them here (continence clinic) (Anna P12, L4-9).*

### ***Breaking the silence***

The sub-theme *breaking the silence* was characterised by women voicing their concerns of AI as a means to coping with the devastating impact of AI on their lives.

The unpredictable nature of AI caused women to feel vulnerable and anxious. Women sought the support of significant others to cope with the burden of AI. Participant Ella stated;

*I wanted to make sure they knew my position so that if I did need to go to the toilet they could get me there as quickly as possible, or direct me there as quickly as possible (Ella P2, L30 -32).*

Disclosing the negative impact of AI to significant others resulted in a sense of emotional relief;

*I think it was the time that he started to understand and he actually said to me, he said ... I actually didn't realize you know, and I'm like this is what I have to live with every day (Matilda P11, L7-9).*

The ability to share the experience of AI with relevant health professionals helped participants to clarify that they were not alone and defective. Participant Dianne explained;

*...it's made it easier because obviously I don't have to ball it up all inside... like coming and seeing the continence nurse has been good because she's been able to explain it to me... so now at least I know there is something wrong, this is just not me being feral like (Dianne P18L 30; P19L1-2).*

Women often feel isolated due to the debilitating impact of AI on every aspect of their lives, having the ability to share with others was seen as therapeutic;

*...you know it'd be nice if you could talk to somebody who's gone through it especially not that long ago as well because then you don't feel like it's just you, so it's silly I know but women do that to themselves that's just how we are(Liz P21, L16-19).*

Participants chose to speak out to seek medical assistance and improve their quality of life;

*I think it's once you are telling it out it can help you...because if you did not tell it out nobody knows...I came here they found that I was incontinent... if I had denied it nobody would help me (Penny P13, L25-27).*

Although participants were often angry and frustrated that professionals did not listen to their concerns;

*You need to listen...; you need to listen like if someone had listened to me....there's only one person that actually did...the Midwife (Anna P21, L5-6).*

Women described the need for professionals to ask the right questions to facilitate effective communication surrounding AI and meeting women's needs. Participant Ella explained;

*She's asking you the right kinds of questions...* (Ella P20, L6)

### **Essential theme: *Striving for normality***

*Striving for normality* was defined as the need to be seen as normal and was characterised by *retreating inside* and the *compromise* of lifestyle to cope with the devastating impact of AI.

#### ***Retreating inside***

All participants utilised a combination of strategies to cope with the debilitating impact of AI on their lives, retreating inside referred to denial of AI and social avoidance.

Participants described their longing to fit in, to be seen as normal functioning adults. Denial was a strategy used by women to regain some normality within their lives. Participant Flo described;

*When you went out you tried to look normal like most people ... I used to ignore the fact that I had a problem ...* (Flo P5, L 18-20).

The insurmountable emotional burden of AI caused women to push any thoughts of AI out of their minds. Participant Heather explained;

*... I try and just forget about it (AI), just try and forget that it ever happened [still emotional] (Heather P 5 L14-15).*

Women described how denial often did not go to plan and resulted in devastating consequences;

*...so me thinking I can hold it now a little bit... has backfired on me... so I don't try and hold now...(Anna P8, L30; P9, L1)*

Participant Liz echoed similar thoughts;

*So unfortunately we do, if we do put things back, something simple like a haircut or something huge like making it to the toilet... (Liz P 23, L 5-6)*

Participants described the burden of AI was a lifelong struggle, in order to cope there was a need to push the impact of AI to their subconscious mind;

*It's been five and a half years and I'm still learning how to just push it to the back of my mind (Ella P3, L19-20)*

There was a constant need to push the thought of AI out of participants minds due to the precarious psychological state women endured due to the impact of AI. Participant Anna described;

*I was worried that I would, you know, make myself more, you know depressed and so forth so I would constantly try and not think about it (Anna P12, L5-7).*

Women described the fear and vulnerability of what the future held for them and avoided any contemplation of the future;

*I now subconsciously just don't even try and get myself involved ... because I'm not sure how its (Continence status) is going to go... (Ella P21, L11-12).*

The silent shame associated with AI resulted in women avoiding social situations. Participant Hallie explained;

*I'd try and avoid it [move away from people] [very quiet voice] or nothing would really be said, nothing would be said, so I'd just try and I guess cover it [AI] up (Hallie P8, L6-7).*

Participants described the need to retreat physically and mentally from society in order to cope;

*... you just sort of switch off and crawl into yourself (Flo P 12, L7).*



## ***Compromise***

Women described frustration and anger as AI dictated every aspect of their lives. Participants described their reluctance to put their needs before their family to cope with the psychological and physical impact of AI. Participant Matilda described;

*It is, it is just a matter of learning how to cope... knowing you have to change your life to (pause) you have to prioritize yourself when it comes to that [AI], and you just have to work around it, because otherwise it [AI] does get on top of you emotionally and... as well as a physical thing, it's an emotional thing (Matilda P 14, L 24 -28).*

There was increased stress associated with a need to prioritize activities of daily living to cope with the impact of AI;

*...just the balancing act, making priorities, the stress that it adds on top of everything else, I think that's pretty much it in a nutshell for me... because it hasn't happened a lot to me ... I got to the point where I got more confident and thinking I can do this (Liz P24, L 20-23)*

Women described the need to re-structure their day around their bowels as AI not only dictated their lives but the unpredictable nature of AI increased anxiety and fear. Participant Dianne explained;

*I won't go out anywhere until I've gone, like used my bowels, just in case something happens (Dianne P 6, L 20-23).*

The pending physical and emotion burden of AI resulted in women structuring their daily activities around their bowel habits;

*I'd go to do the shopping ... you know early in the morning when there are not many people around, but many a time you had to rush back to the car cause you had had an accident ( Flo P 4, L14-16).*

Women put strategies in place to cope with the unpredictable and demeaning nature of AI;

*I've got to carry a pair of underwear in my bag when I go to work just in case (Heather P4, L 29 -30).*

Participants described how AI resulted in loss of freedom. In order to cope participants described the constant need to think about how to dress, where to sit and how to avoid embarrassing situations.

*...I have to wear the dark trousers to help me. Like if I go in public, I know that I used to sit where there's lot of loud noise so that if anything did happen, nobody could hear (Penny P7, L 28-30).*

Women were constantly concerned how their diet would affect bowel control;

*I guess it's changed my diet but I don't... live on food that may upset my stomach...so that's a good thing (Julie-Anne P 5, L14-15)*

In order to establish and maintain intimate relationships women utilised humour to divulge to significant others the impact of AI on their lives, placing women in a precarious position;

*...it really could have meant the end of either friendships or partnerships ... but I think that's probably one of the things that it's one of my better sort of parts of my personality is that I'm open and I think humorous... (Ella P4L 10-14)*

Women described the vulnerability associated in seeking help and avoiding the worsening psychological impact of AI;

*When I was dropping low, I'd basically get up and go to family... so I wouldn't get in that black hole (Anna P 7, L 17-20)*

## **Overview of Women's experiences of AI**

Findings from the reported research study highlighted the disruption to normal bowel function and the resultant negative impact on the physical, cultural and social aspects of participant's lives. However there was an overwhelming negative impact on the psychological wellbeing of all participants within the current research study. It was clear that participants grieved the loss of normal bowel function, what was considered controllable as an adult. Women's emotional responses to grief were reflected as anger, sadness, anxiety, fear and disgust.

Women grieved the loss of their identity, the loss of intimacy, the loss of social encounters, loss of the ability to control activities of daily living and the inability to transmit values and beliefs of acceptable bowel control. The unpredictable nature and resultant impact of AI was constantly on women's minds. The pending humiliation, shame and disgust further increased anxiety and further impacted upon women's psychological wellbeing.

To escape the emotional burden of AI, women often kept silent to avoid public disgrace and social rejection. There appeared to be a duality to the sub-theme *keeping silent*. Women often described AI as a normal outcome to vaginal delivery however; women described ongoing vulnerability and anxiety in coping with the effects of AI.

Women often waited for health professionals to ask the right questions. This signalled to participants the permission to openly disclose the devastating impact of AI on their lives and seek appropriate care. However, women were often frustrated and angry that professionals remained silent and this further impacted on women's isolation and psychological wellbeing. Professional silence was often described as a lack of professional knowledge, misconduct or avoidance in delivering appropriate care. In seeking appropriate care women broke their silence. The anxiety and vulnerability associated with disclosure was insurmountable however this was outweighed by the desperate need to cope with daily living.

Women described the constant disgust, shame and humiliation of AI on their lives. AI made these women feel abnormal and defective, yet women voiced they just wanted to

be normal. Multiple strategies were utilised by women determined to be considered as normal. Denial and avoidance were common strategies used by women in separating the psychological impact of AI from everyday life. Compromise of lifestyle was another strategy. AI dictated every aspect of women's lives, in order to find some sense of normality women were forced to restructure their entire life and further challenge their role as a mother and adult.

### **Summary of the chapter**

The process of hermeneutical reflection enhanced the interpretative process within the current research study. The co-constitution of data between the participants and the researcher ensured the evolving concepts and sub-themes truly reflected women's experiences of AI. Extracts from verbatim transcribed texts highlighted and supported the interpretations adding further depth and understanding of the impact of AI on participant's daily lives.

It was evident from the current research study that women sensed a great deal of loss in their everyday due to the impact of AI. The emotional response to loss included anger, sadness, anxiety and disgust. Women described the burden of AI as insurmountable and inescapable. The psychological impact of AI was a constant feature for all participants and challenged women to walk a precarious line in maintaining their mental wellbeing.

The following chapter seven provides discussion of the interpretations described within this chapter and the significance of the major findings in terms of practice, education and future research opportunities.

# **CHAPTER SEVEN**

## **DISCUSSION OF MAJOR FINDINGS, RECOMMENDATIONS AND CONCLUSION**

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### **Introduction**

This final chapter discusses the significance of the reported interpretive phenomenological research study exploring women's experience of anal incontinence (AI) following a history of obstetric anal sphincter injury (OASIS) and its impact on their quality of life. The intention of the study was to explore and interpret women's experiences of AI and the resultant impact on their daily lives. Heidegger's interpretive phenomenology and Van Manen's methodological framework guided the reported research study and uncovered a rich description of women's experiences of AI. This chapter discusses the major findings that arose from the current research study and their significance in answering the research question. The significance of the research findings are further discussed in context to reviewed literature. Furthermore, limitations of the study are discussed and recommendations for current health professional practice and further research are outlined.

### **Major findings**

The participants within the reported research study illuminated the debilitating and insidious nature of AI on the physical, emotional, social and cultural aspects of their everyday lives. The review of evidenced based literature revealed a predominance of quality of life tools and symptom severity scores which are utilised in the assessment of AI and the impact on quality of life. The Vaizey score is widely adopted by clinicians as a reliable and reproducible tool which correlates with health professional's clinical assessment of AI (Bols et al 2007). Whilst these assessment tools provide a guide for

clinicians they often negate to reflect the important issues as identified by sufferers of AI resulting in a disparity between the Vaizey scores and women's experiences of AI (Cotterill et al. 2008). This was apparent within the reported research study. The Vaizey symptom severity scores within the reported research study ranged between 4 and 22. Young women with a Vaizey score of 4; indicating daily loss of flatus, described enormous anxiety, shame and humiliation of living with flatus incontinence and recounted the negative impact on their identity and socialization. Older participants with significantly higher Vaizey scores; indicating loss of flatus solid and liquid bowel actions, described the devastating impact on their lives however they displayed resilience in coping with the impact.

Heidegger's concept of temporality connected all of the participants in their world; providing multiple views of the impact AI had on women's lives. Temporality anchored participants in their world, where past experiences, coping strategies, contributed to the present experience of AI enabling new possibilities for the future (Van Manen 1990). Bowel control and the social norms surrounding acceptable bowel function are learned at a young age (Miller 1997). Young adults are primarily concerned with developing social relationships, unlike older women, younger women have not yet developed strategies to cope with life changing events, such as the impact of AI on their life and this may offer insight into the disparity between Vaizey scores and women's experiences of AI (Harder 2012). Furthermore, this supports the view that health professionals who utilise symptom severity scores need to adopt a comprehensive approach in the assessment of AI and impact on quality of life.

## ***Grieving for loss***

### ***Near the edge***

The psychological response women endured with the loss of their identity as an adult and the precarious emotional burden of AI on their life was a predominant concern between all participants within the reported research study. Loss presented itself in

many forms; loss of identity, loss of self-worth, loss of sexuality, the ability to build successful social relationships and loss of the ability to be in control as an adult and transmit the values and beliefs of a mother and adult. Participants described the psychological burden and emotional reaction to loss with anger, anxiety, shame, sadness and hopelessness. Minimal research exists which described the psychological response to loss following OASIS and AI. However Salmon (1999) acknowledged the fear and anxiety that women endured following perineal trauma in re-shaping their identity as a woman and a sexual partner. In addition, Rasmussen and Ringsberg (2009) described the constant anxiety and shame women are faced with as they are unable to fulfil roles as a women and sexual partner.

Women within the reported research study described the anxiety and vulnerability of living with AI as; *likened to teetering near the mental edge*. Women described a fine emotional line between coping and giving up hope of any normal life. Women often described the need to retreat into themselves, or push the thought of AI out of their head to cope with the devastating impact on their lives. The negative psychological impact of AI reinforced the loss women endured due to the impact of AI. This was compounded by taboo, denial and silence. Rasmussen and Ringsberg (2009) reinforced these findings, describing the negative effects of stigmatisation resulted in worthlessness. Furthermore, MacDonald and Anderson (1984) found women were more likely to suffer from stigmatisation due to changed body image and would utilise self imposed isolation in order to cope.

Women described the need to be normal and reclaim their old identity. This concurs with Rasmussen and Ringsberg (2009) who identified women wanted to live their life not just exist. AI challenged a woman's role as an adult, mother and sexual partner; participants often questioned their self-worth, identity and role in society. Participant Flo described the devastating psychological impact on her life;

*It [AI] didn't stop you ... feeling worthless... or making you feel bad about yourself, I should just go somewhere and hide... or sometimes maybe I should be dead. Why am I here... you are no use to anyone (Flo P 24, L 14-17).*

Mander (1994) described grief as an individual response to loss. There are five stages of grieving; denial, anger/confusion, bargaining, depression and acceptance (Kubler-Ross 2009). The stages of grieving are not linear and the focus of each participants experience dictated their response to loss. Denial, anger, bargaining and depression were commonly described by the research study participants. There is limited evidence to support these findings within OASIS and AI literature. Although Rasmussen and Ringsberg (2009) acknowledged denial and bargaining were common strategies employed by participants to protect their self-worth and attain some sense of normality and control over their life

### ***Loss of young adulthood***

Young women within the reported research study described the loss of intimacy and the inability to form successful relationships. Several women described anger as their lifestyle had been curtailed. Kubler-Ross (2009) suggested anger is a normal response to loss. Women described the reduction in their lifestyle; structuring their day around their bowel habits, the timing of outings or choosing to isolation themselves within the home environment to avoid the unpredictable nature and pending shame associated with AI. These finding concur with MacDonald and Anderson (1984) research which addressed the stigma and shame associated with rectal cancer and AI. MacDonald and Anderson (1984) proposed people who are stigmatised will isolate themselves from social activities. Home was often referred to as a safe haven where women avoided stigmatisation. *Spatiality* is referred to by Van Manen (1990) as a place that has special meaning, for the research study participants, home resembled a place where women felt protected. Wilson (2007) added home is a place where those afflicted by AI have privacy and regain some self-confidence.

MacDonald and Anderson (1984) stated social support assists the stigmatised person to fulfil expected roles. Women within the reported study described the physical and psychological support from their partners. However women often limited the level of



disclosure regarding AI as a need to protect others from the shame of AI and pending loss of sexual attraction from their partner. Rasmussen and Ringsberg (2009) supported these findings suggesting women need to protect their identity and role as a sexual partner, woman and wife.

Several women expressed the constant fear and anxiety associated with sexual intercourse. Women described the inability to relax and enjoy their sexual encounters due to the pending shame and disgust associated with AI. There appears to be no literature which related to AI and OASIS which support these findings. However, Williams et al. (2005) research described the anxiety related to increased pain following perineal trauma and the negative impact on sexual intercourse. Fornell et al. (2005) long term follow up of women with OASIS, provided an alternative position on sexual functioning following OASIS. Fornell et al. (2005) concluded that there was no impairment of sexual function following OASIS. However, their research provided no description of the psychological impact of OASIS on sexual relations.

Two women expressed concern at commencing a new relationship as this required disclosure of AI to prospective partners. The negative repercussions on new relationships, identity and self-worth caused heightened anxiety. One woman chose to remain single for thirty years due to the physical and psychological impact of AI on her life and relationships. These findings concur with Collings and Norton (2004) who described women's reluctance in disclosing AI to significant others due to the pending shame associated with AI.

### ***Middle adulthood***

Women within the reported research study utilised forms of bargaining to cope with AI. Women described the compromises they made as a mother placing their needs before their family to avoid the unpredictable and devastating consequences of AI. The emotional cost of this sacrifice resulted in further guilt and anxiety which impacted on negative self-worth and identity as a mother. Women also described sadness at the loss of ability to transmit values and beliefs as a mother and wife. Whilst Rasmussen and

Ringsberg (2009) and Wilson (2007) discussed the impact of AI on sexual identity, there appeared to be no research which discussed loss in relation to these findings.

Women described the debilitating effects of AI on their life and were fearful of what the future held. The psychological burden of future family planning caused women considerable anxiety and fear, this was compounded by health professionals who had little understanding or information as to the long-term physical and psychological impact of AI on a woman's life. Women described their personal guilt and assumed professional guilt of choosing a caesarean section to preserve their current bowel control and avoid worsening AI. There appeared to be little evidence to support these research findings. However Williams et al. (2005) agreed future family planning and further injury to OASIS with subsequent childbirth was a major concern for women resulting in anxiety and apprehension.

## ***Silence***

### ***Keeping silent***

There was a general belief amongst participants that AI was a consequence of vaginal delivery. However women were reluctant to disclose the impact of AI to significant others, this was largely due to women's need to protect others from the negative impact of AI, loss of self-worth and impending shame. There appeared to be limited research which described these findings in any depth in relation to OASIS. One research study identified the silent shame women endured living with the insidious nature of AI and the negative impact on self worth (Rasmussen & Ringsberg 2009). In addition research which primarily addressed AI described those afflicted with AI remained silent to avoid the pending disgust, shame and embarrassment (Kalantar, Howell & Talley 2002; Samarasekera et al., 2008; Wilson 2007).

### ***Professional silence***

Anger and blame were common emotions voiced by participants. The hermeneutic nature of the reported research allowed for clarification of anger. Women often blamed

themselves for the lack of control and loss of bowel function as an adult. However, there were high levels of anger and blame directed at health professionals for perceived lack of interest and knowledge regarding AI and provision of appropriate health care. Kalantar, Howell and Talley (2002) concur with these findings. Garcia, Crocker & Wyman (2005) provided further support stating poor professional attitudes negatively impact on self-worth and marginalise a person from society.

Women described the inability to adequately voice their concerns and this hindered understanding as to the impact of AI on their life, further contributing a low priority to AI within health care system and thus meeting their health needs (Bliss, Norton & Vodusek 2010). Women expressed the need for the health care professionals to initiate discussion of OASIS injury and resultant AI and provide guidance and appropriate health care. Collings and Norton (2004) supported this view describing the need for health professionals to initiate conversations with those afflicted by AI, to reduce alienation and provide strategies to enhance their quality of life. Anecdotal evidence within the Continence Nursing Service (CNS) identified the importance of re-clarifying client anger when discussing OASIS and AI (Steel, Robinson & Coates 2012). The opportunity to question women and share their personal experiences of AI provided the CNS further understanding of the physical and mental impact of AI on young women's lives (Koch, Selim & Kralik 2002). The therapeutic benefits for research participants to debrief were also noted by the CNS (Steel, Robinson & Coates 2012).

### ***Breaking the silence***

Participants described the need to seek support from significant others when they could no longer physically or mentally cope on their own. Enhanced social supports were recognised by women as essential in coping with the effects of AI. Collings and Norton (2004) supported these findings. Rasmussen and Ringsberg (2009) suggested providing an opportunity to listen and understand women's experiences of AI enhanced self-worth reduced the negative psychological impact of AI and assisted women in seeking effective health care. Indeed, the researcher found women who participated within the research study found the process therapeutic.

The decision to seek help was often fraught with anxiety and shame. Furthermore, participants who broke their silence in seeking help from health professionals were often frustrated by inattention, lack of acknowledgment and understanding from professionals. These findings were consistent with those of Rasmussen and Ringsberg (2009) which identified the impact of ongoing negative responses fuelled the vicious circle of desperation and marginalisation.

It was evident within the reported research study that participants benefited in recounting their experience of AI. Anecdotal evidence from the CNS team identified that participants had gained extra support and reassurance voicing their experiences and the impact of AI on their lives (Steel, Robinson & Coates 2012). Furthermore, supporting the need for health professionals to ask the right questions and listen to women stories of AI, allows them to develop an understanding of AI. Collings and Norton (2004, p.12) agreed with these findings and further described the possibility of healing as a '*renewed sense of self*' which occurs through empathetic listening.

## **Striving for Normality**

### ***Compromise***

Women described frustration and anger due to the limited control they exhibited over their life. They described how they had changed their entire lifestyle to cope with AI. The simplest of everyday activities were planned around the unpredictable nature of bowel habits. Dietary habits were altered, clothing that masked bowel accidents and odour were adopted and social outings were dictated by bowel habits. These findings were consistent with Collings and Norton (2004); Rasmussen and Ringsberg (2009) research. In addition, Wilson (2007) described the extraordinary routines women put in place to keep their AI hidden and avoid public shame.

Women described the added anxiety and stress to their lifestyle as insurmountable. In some circumstances women chose to isolate themselves from society. Wilson (2007) concurs with these findings, stating women often excluded themselves from the public

domain due to the unpredictable nature of AI, odour and pending shame of AI. Wilson (2007) further described how home was a safe place where women avoided public humiliation. However, ongoing isolation negatively impacted on women's psychological wellbeing, self-worth and identity. Rasmussen and Ringsberg (2009) described the isolation and marginalisation of women as they attempted to cope with the effects of AI.

### *Denial*

Denial and bargaining were common strategies employed by participants to protect their self-worth and attain some sense of normality and control over their life. Women would avoid wearing pads, attempted to delude themselves that AI never happened resulting in devastating outcomes. The smell of AI was often transferred to babies in women's care. These diversionary tactics were supported by Rasmussen and Ringsberg (2009) research. Women described how the resultant humiliation and shame associated with AI negatively impacted upon their identity and self-worth compounding their sense of isolation and worsening mental health. Previous research suggested, denial was a common strategy employed to protect self-worth and relationships (Rasmussen & Ringsberg 2009). Collings and Norton (2004) further supported these findings stating denial is a common strategy employed to cope with the negative effects of AI on daily life.

The interpretive phenomenological research findings reflected the debilitating impact of AI on the physical, social, emotional and cultural wellbeing of a person, and these findings are consistent with the researcher's beliefs and assumptions. However, the research study has illuminated the significance of loss and the overwhelming psychological impact of AI on the lives of women who have experienced OASIS and AI. The coping strategies utilised by participants were individual, nevertheless they do describe how women attempted to re-gain normality in their life.

## **Study limitations**

Qualitative research by nature has inherent limitations such as the inability to generalise research findings to the wider population (Carpenter 2011). The intention of the reported interpretive phenomenological research study was to explore and interpret women's experiences of AI and therefore the research study reported within this thesis provided a deeper understanding of the phenomenon of interest.

Recruitment of participants was undertaken by the CNS team member's to reduce research bias. However, the professional role of the researcher, as a Continence Nurse may have inadvertently influenced what participants disclosed and may be viewed as a limitation within the research findings.

Participants within the reported research study were recruited utilising purposeful sampling. Purposeful sampling may be viewed by the reader as a limitation due to sampling bias; however the nature of interpretive phenomenology as a research methodology required the recruitment of participants who could reveal information rich experiences of AI (Carpenter 2011). Ten women were recruited within the reported research study to illuminate the experience of AI on their quality of life. Sample size was small and may be seen as a limitation within research (Sandelowski 1995). However, the sample size within the reported research study was consistent with phenomenological principles as it included participants who could reveal in-depth experiences of AI. Ten participants were deemed enough to meet the research aims and objectives to answer research question. Further research is required to support research findings.

The lack of cultural diversity within the reported research study may be viewed as a further limitation. The research study included one Mediterranean woman, eight Australian women and one African woman; further research studies may describe the experience of AI in a different light due to cultural and social diversity.

The sensitive nature of AI and associated stigmatisation may well have impacted on a full account of the impact of AI on women's lives further contributing to limitations within the reported research study.

## **Recommendations**

The findings from the research study reported within this thesis will challenge the reader to reconsider their assumptions of AI, which may be potential roadblocks in developing an understanding as to the complex nature of AI and the impact on women's lives following OASIS.

The reported research study has illuminated several areas of concern for women with AI. It is not surprising that AI dictated every aspect of women's lives. Women struggled with the physical, social, emotional and cultural aspects of daily life. The resultant loss of life and the psychological impact was insurmountable. The stigma that surrounded AI prevented women from speaking out and seeking adequate health care. The findings from the reported research will be disseminated to nursing and midwifery professionals to further educate and inform the development of appropriate health care for women with AI following a history of OASIS. Acknowledging the issues which surround AI promote discussion from which health policy and procedures can be developed.

The reported research noted the inconsistencies of utilising symptom severity scores in the assessment and impact of AI on quality of life. The findings recommend health professionals who utilise these symptom severity scores need to further question women as to the impact of AI on their life. This will provide a comprehensive assessment of the impact of AI on their quality of life

It was evident that the physical and psychological impact of AI was compounded by lack of professional awareness and ineffective communication. Therefore the findings recommend that health professionals need to be well informed as to the risk and impact of vaginal delivery, subsequent OASIS and AI on a woman's psychological and physical wellbeing. Additionally they should adopt a proactive approach and break the silence for women who are marginalised by AI, providing opportunities to initiate conversation. Health professionals need to ask questions which illicit rich information about the impact of AI. There is a need to empathetically listen and hear women's concerns thereby reducing the isolation women experience and provide sensitive appropriate health care. Furthermore, these findings recommend health professionals

need to inform women as to the impact of AI following OASIS and future birthing options to reduce the physical and psychological impact on women's lives.

The therapeutic benefits of debriefing for women within the research study were apparent. The benefits of support groups would assist those afflicted by AI to self-manage their health and enhance their psychological well-being.

The review of evidenced based literature revealed little research in the area of women's experiences of AI following a history of OASIS and the impact on their quality of life. Further research is necessary to fill the gap that exists in understanding the complex nature of AI on a person's life. Furthermore, anecdotal evidence supports further research into the psychological benefits of debriefing following OASIS and AI.

## **Conclusion**

This chapter highlighted the major findings that arose from the current research study and their significance in answering the research question. This interpretive phenomenological research study explored and illuminated the lived experiences of ten women who had a history of OASIS and AI and the resultant impact on their quality of life. The essential themes; *grieving for loss*, *silence* and *striving for normality* provided an in-depth understanding of women's experiences of AI.

The research findings highlighted the debilitating physical, social and emotional impact of AI on women's lives. Women described the need to adopt strategies to cope with the impact of AI. These strategies included lifestyle changes, silence, avoidance and denial. These findings were consistent with evidenced based research literature. However, the reported interpretive phenomenological research study provided a deeper appreciation as to the impact of AI on every facet of a women's life.

Furthermore, it was evident from within the findings that new knowledge had arisen. Women grieved the loss of their life, this loss was compounded by the insidious and unpredictable nature of AI on a women's psychological wellbeing. The findings of the reported research study illuminate how AI placed women in a precarious psychological



position as adults, women and mothers. The stigmatization of AI and silence reinforced the negative psychological impact.

Women described the need to be heard, reaffirming their self-worth and to attempt at regaining some control of their life .There is limited research available to support these findings and thus provides a strong case for further research into the psychological implications of AI on a women's wellbeing.

The findings from the reported interpretive phenomenological research into women's experiences of AI following OASIS will provide the reader and health professionals as to a deeper understanding of loss and the psychological impact on a women's quality of life. This understanding will inform education and practice. Recommendations for future research have been outlined.

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# APPENDICIES

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Appendix 1: Recruitment flyer

Appendix 2: Patient information sheet

Appendix3: Consent form

Appendix 4: Ethics approval

Appendix 5: Departmental support from Women's and Children's Division

Appendix 6: Confidentiality agreement

Appendix 7: Interview schedule

Appendix 8: Excerpts from researcher's journal

Appendix 9: Selected statements, formulated meanings, concepts and sub-themes

Appendix 10: Formulated statements, concepts, sub-themes and essential themes

Appendix 11: Formulation of essential themes



NOTE:

Appendices 1-7 are included on pages 102-113 of the print copy of the thesis held in the University of Adelaide Library.

## **Appendix 8: Excerpt from researcher's journal**

### Excerpt from researcher's journal "Women's experiences of AI following a history of OASIS and impact on quality of life"

#### **Interview 1<sup>st</sup> Field notes**

Anna is a confident woman, actively engaging and leading the interview. She is vocal and passionate about telling her story; she states 'I *want to be heard*'. She highlighted much anger at the lack of professional care and the devastating effects of AI controlling her life. A lot of the discussion revolved around being heard not just listened to. Verbal anger and fists clenched with reference to the devastating impact on all aspects of her life, but also lack of professional guidance.

The researcher is confronted by anger towards health providers; this doesn't sit well with the researcher. The researcher needs to acknowledge this discomfort that challenges the caring professional role, to be able to understand what Anna is trying to disclose. There was a need to facilitate understanding around this point and get her to describe this anger.

Anna is angry with the devastating impact of AI on her life and not being heard when she seeks help. Teary emotions as she recounts the psychological impact on her life. The loss of control of her life her voice quietens/body turned /looking down. What does this tell [the researcher] about her experience?

Is Anna grieving loss of her role as a mother, woman, and adult? Loss of control of what is normal is her biggest issue.

She is vulnerable near the edge of coping and just wanted to be heard. She doesn't see all health professionals uncaring. Anna used vibrant verbal language and body language to recount her experiences. Raised angry voice as she talks about her obstetrician/ hands waving/fists clench? Heightened anger/ revisited several times- voice louder each time? Is this anger at lack of professional support or being heard?

Perplexed look when discussing why she wasn't referred. Same look for health professionals that referred but offered no information as to why it happens and to cope. Does this represent the loss feeling? Open body language/ vibrant positive discussion on information sharing and support pathways looking away/ shaking head for impact of "pooing yourself". Can this be suggestive of the increased psychological and physical impact on her life, vulnerability/disgust. Need to clarify with participant[following interview].

#### **Interview 2 Field notes**

Flo is a quietly spoken woman who was passionate about telling her story, but this was an emotive interview, with many tears throughout/ body language like jelly, does this

mean no control. Amongst her tears were times reflected by an angry voice, clenched fists/ fixed stare. Why is she angry?

How is this important to the experience of AI? Clarify with participant.

Flo is angry because of the damage to her anus and now she is incontinent all the time, she has no control over any aspect of her life. She feels robbed of her life, she is alone and she is angry at the doctor for poor communication and leaving her like this. This topic was revisited several times, identifying the impact on her wellbeing was huge she felt she was *defective* and there was self blame. Loss of control resulted in a life of self isolation. Uncontrollable tears, body turned in like... crawled into a ball, hands moving over and over each other. What does this reflect of the experience? There are few words but body language depicts grief of loss of control as an adult, abandonment, as Flo states *how can I go on; I am defective*.

From field notes 1 &2 Commonalities included loss of control, poor communication and the psychological impact of AI. The body language noted within journaling added to the audio taped and transcribed verbatim text provided a multifaceted view of the experience of AI. Reflected heightened levels of grief not reflected in text alone

Researcher entry: Interview 1&2 were emotionally challenging. The researcher needed to acknowledge situations that may have impacted on research outcomes such as anger against professionals. In acknowledging this conflict, the researcher brought to the foreground understanding of caring health professional, this was challenged by the new information arising and reformulated into a deeper understanding to identify what these women were truly stating.

Researcher entry: Noted body language: even though eager to share stories first 15 – 20 minutes guarded body language. The researcher was mindful in subsequent interviews and changed her body language and approach to asking questions. Women were encouraged to start the interview re-telling of the birth of their baby and then describe stories of the impact of AI.

**Appendix 9: Development of selected statements, formulated meanings, concepts and subthemes**

**Sub-theme: Near the edge, loss of young adulthood and loss of middle adulthood**

**Formulated meanings (fm) are numerically listed**

**Keywords are underlined.**

Statements	Formulated Meaning	Concepts	Sub-themes
I mean I'm not old [37 years] but like, you know, if this is where I am its <u>only downhill</u> ; <u>it's not going to improve...</u> (Anna P19, L22-23).	There is an expectation that AI worsens with ageing, women are already compromised and sense the impending burden of AI.fm1	Loss of identity, Impending burden	Near the edge
I still get <u>very emotional</u> about it, it (AI) took over and as I said it was so <u>demoralizing</u> ... made <u>you feel so bad about yourself...you truly believe you are not worth anything</u> ...there is no way you can feel you have any self-worth because you feel so abnormal...(Flo P17,L5-8)	AI causes a woman to feel abnormal and question herself worth.fm2	Loss of identity, Worthless Emotional devastation	
I guess it's kind of a little <u>bit demeaning</u> knowing that you have to carry clothes around, you know, <u>you do that for babies</u> , you do that for toddlers but you never imagine that you're going to have to walk around with a baby bag that has your own clothes in it (Ella P14, L21-24).	AI causes confusion between a woman's role as an adult and a childlike state, resulting in humiliation and shame.fm4	Shame, role confusion, loss of self, demeaning, disgust	

<p>...it had happened and <u>there was nothing I could do</u> about it... and <u>not that anyone else knew</u> about it, but because I did, I was embarrassed that this had happened. I <u>was a grown woman, I am an adult..</u> (Matilda P5, L20-23).</p>	<p>AI causes a woman to experience heightened anxiety, lack of self respect and grief as she is continually conflicted by the inability to control normal bodily function.fm 5.</p>	<p>Loss of identity, pending shame, sadness</p>	<p>Near the edge</p>
<p>...it's like going back to a <u>child</u> again[pause],so it's quite a big thing....for <u>me it's not something that is going to get better..</u> (Matilda P2, L19-20).</p>	<p>AI reduces a woman to a childlike state which impacts on her role as a parent/adult; there is little hope of improvement. fm 6.</p>	<p>Childlike, grief, resigned fate, sadness, vulnerability</p>	
<p>...it is <u>embarrassing</u> because I suppose you feel like, you know, <u>that's what your babies and toddlers do</u> (Matilda P2, L 10-11).</p>	<p>Adults should maintain continence; to be incontinent is humiliating. fm 7.</p>	<p>Emotional impact, Childlike, shame</p>	
<p><u>I'm only 32</u> and I've got to deal with this for <u>the rest of my life</u> now, I thought it <u>was just elderly people</u> that sort of dealt with that sort of thing (Hallie P4,L 27-29).</p>	<p>There is an expectation AI only happens to the elderly, yet young women are faced with the pending loss of their identity. fm 8.</p>	<p>Loss of identity, loss of freedom, Disgust.</p>	

I guess it's a bit <u>embarrassing for my age already</u> (HallieP1, L4).	There is an expectation that AI shouldn't happen to young people, they don't deserve it and there is embarrassment and shame surrounding AI .fm 9.	Youth versus ageing, undeserving shame	Near the edge
... <u>it's really, really hard</u> , I don't know how I am now at my age and how I will be later as I age...(Penny P4, L16-17).	Women with AI question the impact of AI on their life and are faced with uncertainty of their future.fm10.	Fear of ageing, Vulnerability of aging	
I have to live with that damage for <u>the rest of my life</u> and being <u>only 27</u> soon, it's hard... that's probably my <u>biggest, biggest thing</u> that I'm upset about (Dianne P9, L14-15).	Women are faced with the sobering thought that AI is with them for life.fm11.	Loss of life, Sadness, loss identity	
I used to think oh my God <u>this is foul</u> like <u>I'm only 27</u> and this is happening, this is <u>disgusting</u> , if I'm like this now, it's <u>only going to get worse</u> when I get older (Dianne P14, L10-12).	Women find it difficult to cope with AI at a young age; they feel disgusted that AI happens to young people as it is viewed as an elderly complaint.fm12	Fear of ageing, personal disgust, pending shame.	
... <u>it shouldn't</u> happen to someone <u>so young</u> (Dianne P16, L9).	Young women find it difficult to accept AI, AI is a complaint of the elderly.fm13	Age conflict, Not deserved, loss of life	

<p>I've controlled myself for the last 30 years... you know <u>I can't lose that now</u> I'm not even, <u>I'm under 40</u>, I'm not going to (long pause) what <u>I have to poo myself for the next 40 years</u> (Julie-Anne P18, L10-14).</p>	<p>Women are angry and struggle with the being incontinent at a young age and they fear AI this will worsen with ageing. fm14.</p>	<p>Fear of ageing, life sentence, sadness. loss of life</p>	<p>Near the edge</p>
<p>...<u>that's not what adults do</u>. And yet there's a reason for it, <u>wasn't my fault</u>, I get all of that, I get all of that sensible stuff get it but <u>who poos their pants on their way to work?</u> I don't know it's <u>embarrassing and humiliating</u> if anyone had seen (Julie-Anne P27, L15-17).</p>	<p>Women can rationalise the cause and impact of AI but as an adult, AI is not acceptable resulting in feelings of disgust and humiliation fm 15</p>	<p>Conflict with role, Disgust, sadness.</p>	
<p>...<u>you're disgusted in yourself</u> because you think it's such a simple thing to do. <u>You take it for granted</u> for sure. It's like anything, walking, breathing etc. Until you lose it <u>you don't understand what it's like</u> and I was, I was angry and upset with myself because <u>I'm an adult</u> (Liz P20, L16-19).</p>	<p>As an adult there is an expectation that you should control bodily functions to lose control results in a range of emotions including disgust, anger, sadness and disappointment. fm 16</p>	<p>Conflict with role, Mental burden, sadness.</p>	

<p>...you just think of yourself as an <u>adult</u> and then when this happens you <u>don't think of yourself as an adult</u>, you think back to <u>being a kid</u> and how it felt to wet the bed or something as a little child (Liz P 20, L 22-24).</p>	<p>AI reduces women to a childlike status, it's demeaning and humiliating. fm 17.</p>	<p>Loss of identity, shame, disgust</p>	<p>Near the edge</p>
<p>... not being able to do something that you used to do on any scale I think, makes you feel a bit <u>helpless</u>, makes you feel like, I don't know how best to describe it, but just feeling like (pause) <u>losing control</u> and that you're not an adult (Liz P20, L29-30; P21, L1-2).</p>	<p>AI causes a woman to feel vulnerable and lack control as an adult in everyday activities. fm 18.</p>	<p>Helplessness, loss of self, loss of control</p>	
<p>...as I get older <u>I hope</u> that I can still have control of that [AI]because in the end, <u>it's not supposed to happen to me</u> (HeatherP25, L30; P26, L1).</p>	<p>Young woman are resentful of the random occurrence and impact of AI on their life, there is a fear with ageing AI will worsen; women just want to control AI. fm 19.</p>	<p>Fear of ageing, anger, Not deserved, sadness, mental impact</p>	
<p>I managed to <u>grip myself together</u> while I leaned up and that is as far as I could hold it together [Long-pause] and then I <u>fell apart</u> [crying] I felt <u>humiliated</u> and completely <u>demoralized</u>, I felt <u>worthless</u>, and after I have cleaned up the floor and anything else that it had got on and taken my clothes off and had them rinsed and soaked to wash later. I would normally just get into bed and <u>cry myself to sleep</u> (Flo P3, L12-16).</p>	<p>There is immense physical, emotional and mental impact of AI on a woman's life.fm20.</p>	<p>Physical, emotional and mental devastation; isolation</p>	
<p>...when I get up there [to the toilet] <u>I hope no one else is there</u> and they hear everything....it's just more <u>embarrassing</u>. It's <u>just really, really embarrassing</u> (Heather P7, L17-18).</p>	<p>Coping with AI in public cause's anxiety and embarrassment for women with AI. fm 21.</p>	<p>Vulnerability, Loss of personal worth, mental impact</p>	



...if I know I've got to go, I've <u>REALLY</u> got to go (Heather P 21, L21-22).	Women do not have the luxury of controlling their bowel function, the unpredictable nature of AI results in urgency. fm 22.	AI dictates my life, No control, Anxiety	Near the edge
... it (AI) kind of makes you feel like <u>an outcast</u> sometimes you know, like yeah that something's wrong with you but it's not really my fault (Heather P32, L 25-26).	AI makes a woman feel ostracised and there is sadness associated with the fact she is undeserving of this affliction. fm 23.	Loss of social mobility and acceptance, isolated	
There's <u>that fear</u> that you won't find a toilet anywhere (Liz P6, L18).	The unpredictable nature of AI causes a woman to constantly fear having a bowel accident due to lack of appropriate services and brings into question the need for social interactions. fm 24.	Fear, Restricted lifestyle, ongoing anxiety	
So <u>I couldn't go in public</u> basically, if I went it was with my husband and I had to know where the toilets were and just pray to God that I didn't have the urge. So yes, I, I, I'm sure I went through a <u>depression at that stage [silence]</u> (Anna P2, L33; P3, L1-4).	The enormity of AI impacts physically and emotionally on woman, significant others and planning are essential for support. fm 25.	Restricted life, Anxiety, Mental strain	
<u>I wouldn't allow people to come to the house</u> so I basically used to get up in the morning and go feed some horses, there are no people around and only go out one morning a week and that was it, <u>I never left the house. I still don't [30 years on]</u> . (FloP3, L29-30; P4, L1-3).	AI impacts on a woman's ability to feel confident with social outings. Women prefer to isolate themselves and will only venture out if they feel they have supports in place. fm 26.	Imposed social isolation, restricted lifestyle, grief	
...so <u>I need to make sure</u> like when my <u>children</u> are little that I am near a toilet for them, I have to make sure <u>I am near a toilet for myself</u> (Matilda P1, L15-18).	The unpredictable nature of AI and lack of control impacts on a woman's freedom. fm 27.	Loss of freedom, restricted lifestyle, anxiety	

<p>...<u>everybody heard</u>, I feel like I won't too <u>enter into a grave</u> without anybody seeing me( Penny P6, L23-24).</p>	<p>Women feel the need to escape and hide due to the impact of AI on their lives. fm 28.</p>	<p>Need to hide, embarrassment, sadness</p>	<p>Near the edge</p>
<p>...it's <u>horrible</u> more so because <u>I'm so young</u> I think... it makes me [pause] I'm desperate for another one [baby] but then I think do I want one just in case I do <u>more damage</u> and <u>things get worse</u> (Dianne P9,L5-7).</p>	<p>AI has a negative emotional impact on how young women perceive their right to procreate and worsening impact of AI with further childbearing.fm 29.</p>	<p>Loss of right to procreate, Fear of childbearing, anxiety</p>	
<p>I don't want to go through that pain again but I don't want to go through this recovery again, and if that happened to me again I would have <u>a lot more incontinence</u> I'm sure and I'd have a lot more you know, wetting myself and bowel movements before I get to the toilet and <u>I do not want that again</u>. <u>I do not want that again</u> (Liz P19, L17-21).</p>	<p>The fear of worsening AI with future birthing causes a great deal of anxiety for woman. fm 30.</p>	<p>Loss of right to procreate, Fear of worsening AI, anxiety</p>	
<p>I hope that I get here on time and that I don't go into labour because... that's what doctors are saying to me that you know, if you have a normal birth that you'll quite possibly, well more than likely <u>end up with a colostomy bag</u> (Liz P24,L28-30; P25, L1).</p>	<p>The reality of further bowel damage with vaginal deliveries causes fear and vulnerability for women.fm 31.</p>	<p>Loss of bowel function, Fear, anxiety, devastation, mental impact</p>	
<p>...we <u>didn't have any intercourse</u> whatsoever for until the baby was <u>5 months</u>, a bit over 5 months old and that was me...that was [AI] I think in the <u>back of my mind</u> that's probably why (Julie-anneP19, L18-20)</p>	<p>Fear of AI is always in a woman's mind and restricts a woman's ability to engage in and enjoy sexual relations. fm 32.</p>	<p>Fear of sexual relations, Loss of sexual freedom, in my head</p>	
<p>I used to have a male friend; <u>he left me because of it [AI]</u>. (Flo P6, L14).</p>	<p>AI has a negative impact on a woman's personal relationship. fm33.</p>	<p>Relationship breakdown, sadness, ongoing grief</p>	

<p>...you would have <u>accidents during sex</u> and you would think oh God, <u>what does he think of me now</u> , it may not be a large accident but it was always some (Flo P 15, L26-28).</p>	<p>AI is a constant worry for woman during intercourse, impacting on a woman's self concept and relationship. fm 34.</p>	<p>loss of intimacy, shame, mental impact</p>	<p>Near the edge</p>
<p><u>I don't feel confident</u> that I would be able to hold it until I got to the toilet, so it's a <u>constant stress, constant pressure</u>, constant 'oh' do I need to go?, you can't concentrate on anything else... (Julie-Anne P5, L 5-8).</p>	<p>The fear of AI is always on a woman's mind, it is consuming and stressful dictating her life. fm 35.</p>	<p>Always in my head, Consuming, No confidence</p>	
<p>...you don't realise that some people suffer 7, 8, 12 months after it happens... and it can be <u>hard talking to people</u> because I don't think any of the mums had as much trouble as I did, and it makes you a <u>bit depressed</u> (Liz P13, L6-8).</p>	<p>The reality and impact of AI is unknown within the community as there is limited discussion on this topic, leaving affected women feeling isolated and depressed. fm 36.</p>	<p>Mental impact, Loss of networks, alone</p>	
<p>...there was <u>no mental relief</u> because I still felt like it could happen (Ella P3, L16)</p>	<p>Women feel vulnerable about the unpredictable nature of AI. fm 37.</p>	<p>Anxiety Vulnerability, mental strain</p>	
<p>When you have <u>lived so many years on your own</u>... and you have cut off all social activities you are still on your own. It's got to the stage, it's the people you know the people you speak to on occasions don't want to be your friends anymore because you have <u>isolated yourself</u> for so long its, they're not really interested anymore ... so you are still <u>on your own</u> all the time (Flo P 26, L24-28).</p>	<p>AI impacts on relationships, to cope women isolate themselves for so long they have no social networks. fm 38.</p>	<p>Alone, Sadness Emotionally bare, Vulnerable, Isolated on the edge</p>	

<p>I've got to worry about this crap <u>all the friggin' time</u> and I shouldn't have to be worrying about that... I could be playing with my daughter and then I stand up and pass wind ...and then she's going to go <u>Mum you're stinky</u> ( Heather P26, L19-22)</p>	<p>Women feel angry that they have to suffer from the effects of AI, it impacts negatively on their lifestyle and self concept. fm 39.</p>	<p>Anger, Intimacy versus isolation, Loss self worth</p>	<p>Loss young adulthood</p>
<p>I guess mainly when you want to have sex you're sort of <u>continually worried</u> that there's a possibility you're going to need to go to the toilet in the middle of it and sometimes suggesting you need to go to the toilet in the middle of <u>it isn't exactly the best turn on</u> and then if you don't you're not enjoying it because you're sort of trying <u>to tense yourself</u> up in case something happens (Ella P7,L1-5).</p>	<p>The unpredictability of AI impacts on sexual relations, women continually worry AI will negatively impact on their relationship. fm 40.</p>	<p>Fear of sexual Activity, lack of sexual freedom, loss of intimacy, anxiety</p>	
<p>...you just hope that it [AI] <u>doesn't happen</u>, it just... I don't know, it's <u>really hard to explain</u> you just, you just hope that it [AI] doesn't happen and then if it does, <u>is he going to be alright with it</u> (Heather P17, L17-19).</p>	<p>A woman is faced with the constant fear and vulnerability that AI will occur during sexual relations and there is an uncertainty of how her partner will respond. fm 41.</p>	<p>Lack of sexual freedom, Vulnerability</p>	
<p>Thankfully <u>I was at home</u>, so at least being home I didn't have to worry about other people <u>finding out</u> about it, the <u>embarrassment</u>...(Liz P 1, L27-28).</p>	<p>Home is a safe place where others are unaware of AI and associated embarrassment fm. 42.</p>	<p>Safety of home, Forced isolation</p>	
<p>God if that had happened anywhere but my house, it would have been <u>horrible</u> (Liz P 5, L1).</p>	<p>Women with AI find the home environment a sanctuary, to lose control of bowel function anywhere else is humiliating. fm 43.</p>	<p>Safety of home, Loss of independence</p>	

<p>...<u>the worst part was not really being able to go anywhere...</u> I didn't have a car, so public transport was <u>completely out of the question</u> (Ella P1, L17-18).</p>	<p>Young woman with AI are isolated from participating in everyday activities fm 44.</p>	<p>Social isolation, restricted mobility, sadness</p>	<p>Loss of young adulthood</p>
<p>...it's been <u>five and a half years</u> and I still <u>avoid</u> saying yes to things if I'm sure that it's not going to be near a toilet even though since (Ella P2, L11-13).</p>	<p>Young women with AI are forced to isolate themselves due to the vulnerability in social settings, this lasts for many years. fm 45.</p>	<p>Social avoidance, loss of social life, restricted mobility, anxiety</p>	
<p>I suppose <u>cross and angry...</u> you know here's me trying to teach... my boys as they started to toilet train... and the baby and how to... be able to control their bowels and their bladder [pause]... and <u>thinking I can't</u> (Matilda P13, L20-23).</p>	<p>Women are angry that they are unable to achieve basic bowel control like their children. fm 46.</p>	<p>Loss of control, Poor negative role modelling as a parent, <u>sadness</u></p>	<p>Loss of middle adulthood</p>
<p>I don't know <u>it is embarrassing</u> [pause]... <u>It is, it is embarrassing</u> but I don't know whether it is more <u>embarrassing or frustrating</u> that you know, you know, as an <u>adult or a parent</u> there so many things that I can control, but this <u>I can't</u>. (Matilda P13, L15-17).</p>	<p>As an adult it is frustrating and embarrassing having no control over what is considered controllable. fm 47</p>	<p>Anger at lack of control as an adult, <u>embarrassment</u> <u>sadness</u>,</p>	
<p>... It's an <u>emotional thing</u> because, you know like I said, it takes you back to being a <u>baby or a toddler</u> (Matilda P7, L8-9).</p>	<p>A woman with AI has increased anxiety and emotional turmoil due to the loss of control as an adult reducing a woman to a childlike state. fm 48.</p>	<p>Loss of parent role, childlike, Negative emotion</p>	

<p>...in our culture like you <u>do not pass wind in public</u>...because if you did this .... you are the <u>big person</u>...(Penny P7, L3-5).</p>	<p>As an adult there is an expectation you can control your bowel actions, to lose control causes conflict with the parenting role and expectations. fm 49.</p>	<p>Poor role modelling, Childlike, public shame</p>	<p>Loss of middle Adulthood</p>
<p>Trying to pass wind [pause], well when I did try; I thought I was going to pass wind <u>I'd soil myself</u>. When I needed to go to the toilet to do Number Twos basically the minute I would step – open my legs and step off the bed, I'd soiled myself [pause] I was just <u>mortified</u>...(Anna P2,L12-17).</p>	<p>The lack of control of AI has a negative impact on a woman's physical and mental wellbeing. fm 50</p>	<p>Physical loss devastation, shame, loss of control</p>	
<p>I so needed to go and I knew what was about to happen and I said boys, mummy doesn't <u>want to poo her pants</u>. I had to say this really quiet to them because I had to get to the toilet, I was so <u>desperate ...I had to do it discreetly</u> (Matilda P 8, L26-30).</p>	<p>Women are not only faced with the negative physical and emotional impact of AI, but are challenged by their role as a parent with AI, disclosing their urgent needs to their children. fm 51.</p>	<p>Physical urgency, desperation, no control, demoralised</p>	
<p>I am trying to hold on but I knew it wasn't any good and we pulled up and I just yelled out to my partner, <u>open the door, open the door</u> and I just ran inside, and it <u>was terrible</u>, it was <u>terrible</u> and I remember that was quite full on (Matilda P 13, L5-8).</p>	<p>There is a point of desperation where women are faced with the urgent need to find a toilet and are faced with the vulnerability of disclosing AI to others. fm 52.</p>	<p>Physical loss, devastation, lack of control</p>	
<p>I was at school, the teacher put a movie on, we are watching and I felt like something is coming, like even water or what, but that only took for me <u>30 second</u> and I was wet all the way, I got up, I went to the toilet, I found that all <u>my body was with poo</u> (Penny P3, L22-25).</p>	<p>The unpredictable nature of AI makes a woman feel vulnerable, impacted lack of control and resultant anxiety and negative physical sensations. fm 53.</p>	<p>Negative physical sensation, urgency, sadness</p>	

<p>...so I was <u>really, really very embarrassed</u> with this thing because it's really taking me <u>very hard life</u>, indeed very hard life because <u>I can't be in the public</u> and I can't do what I was doing before...(Penny P4, L 4-6).</p>	<p>Women with AI grieve their loss of life and normality. fm 54.</p>	<p>Restricted life, loss of normality, vulnerability</p>	<p>Loss of middle Adulthood</p>
<p>... I had a bowel accident walking from my car to work, that <u>was really horrible</u>, I just got back in my car and went home and <u>spent some time at home</u> (Julie-Anne P 4, L 5-7).</p>	<p>AI has a devastating impact on a woman's life, women will retreat from social interactions to feel safe. fm 55</p>	<p>Safety of the home, restricted lifestyle, sadness</p>	
<p>...<u>mentally I wasn't in the right space</u> head-wise anyway, I had the shits because you know couldn't control your urine and your shit – I mean if you <u>can't control that</u>, what can you control? [silence] So yeah, and sex was: What? Huh? I'm not even interested, you know, we're talking about that region just stay away from there (Anna P6, L10-14).</p>	<p>The consuming nature of AI has negative implication for a woman's sex life. fm 56.</p>	<p>Deterrent to sexual activity, loss of intimacy</p>	
<p>I needed to go and I didn't quite make it inside... so I was <u>mortified</u> (Julie-Anne P4L5-7)</p>	<p>Lack of control with AI results in personal emotional devastation. fm 57</p>	<p>Lack of control, Loss of personal self worth, shame</p>	<p>Near the edge</p>
<p>I had a nappy bag and then I had to carry a bag with all of <u>my crap</u>, so I tried. That lasted probably 30 days and then that was it, <u>I didn't venture out until</u>, you know, I had either gone to the toilet (Anna P17, L5-8).</p>	<p>AI dictates a woman's life, woman choose social isolation over the unpredictable nature of AI and the burden of carrying personal items. fm 58.</p>	<p>Restricted lifestyle, Lack of control, demoralised</p>	<p>Loss of middle adulthood</p>

<p>But you tried, you had to live your whole life around what <u>your bowel was doing</u> instead of the other way around (Flo P13,L 27-29).</p>	<p>AI controls every aspect of woman's lives. fm 59.</p>	<p>Lack of control</p>	
<p>...<u>You think you can hang on ,but you can't</u> (Matilda P3, L15)</p>	<p>Women are frustrated by the lack of control they have over AI. fm 60.</p>	<p>No choice to control, denial, sadness, vulnerability</p>	
<p>I don't know whether it is more <u>embarrassing or frustrating</u> that ...as an adult or a parent there are so many things I can, I can control, but this I can't (Matilda P13, L15-17).</p>	<p>Women are frustrated that they have no control of AI. fm 61.</p>	<p>Frustration, Lack of control</p>	
<p>...you are supposed to be <u>enjoying the moment [sexual Intercourse]</u>, and I am just laying there thinking please <u>don't have an accident</u>, please <u>don't have an accident</u> (Matilda P10, L 18-19).</p>	<p>AI negative impacts on a woman's sexual relationship, woman are constantly in fear that AI will occur they are unable to relax and enjoy sexual relations. fm 62.</p>	<p>Fear of sexual enjoyment, anxiety, loss of sexual pleasure</p>	<p>Near the edge</p>



**Development of selected statements, formulated meanings, concepts and subthemes**

**Sub-theme: Keeping silent, professional silence and breaking the silence**

**Formulated meanings (fm) are numerically listed**

Selected statements	Formulated meanings	Concepts	Sub-themes
<p><u>I am lucky that no one else knew</u> because I don't know that I'd be able to get over those emotions of someone knowing that that's what happened (Julie-Anne P18, L2-4)</p>	<p>Nondisclosure helps women to cope with the impact of AI. fm 63</p>	<p>Concealed Vulnerable, Anxiety, Pending shame</p>	<p>Keeping silent</p>
<p><u>Embarrassed and uneasy</u> and as I said it's not something that I guess you just generally bring up with people because <u>they may not want to hear it</u>, so it was just if they'd brought something similar up (Hallie P 9, L8-12)</p>	<p>Women don't divulge information about AI; they wait for others to prompt conversation due to their embarrassment of AI and fear of rejection. fm 64</p>	<p>Hidden Embarrassment Vulnerable, Fear of disclosure</p>	
<p><u>I did wait for the nurse</u> to say something..... at the start because as I said, <u>I thought it was normal</u> so I didn't really think much more of it (Hallie P6, L4-5)</p>	<p>Women wait for health professionals to discuss AI as they see AI as a normal process following delivery and cope with the consequences.fm 65.</p>	<p>Normality, Waiting to be asked</p>	
<p><u>You don't feel good about yourself</u> when it happens which is probably why you just <u>keep it to yourself</u> (Julie-Anne P16, L26-27)</p>	<p>AI cause women to have feelings of disgust about themselves and reinforces not to share with others. fm66</p>	<p>Bad feelings, Hiding, pending shame</p>	

<p>I just had to <u>shut everybody out</u> because the ones that knew that I had a problem <u>didn't want to know me anymore</u> ... they made it quite clear <u>I wasn't worth knowing</u> (Flo P71, L23-25).</p>	<p>Social rejection of AI makes woman feel worthless lack of social support results in isolation.fm67</p>	<p>Avoidance, Mental devastation, socially devoid, grief</p>	<p>Keeping silent</p>
<p>I would <u>just keep it to myself</u> and wouldn't say anything to him...<u>it's embarrassing I just don't want him to know</u> (Dianne P10, 112-19)</p>	<p>Women choose not to share their struggle of AI with significant others, they find it embarrassing.fm68</p>	<p>Hidden from others, Embarrassment, Sadness</p>	
<p><u>I don't think he really understood...I don't think I told him</u> ...I told him what happened but <u>I don't think I told him</u> so much...because he was so worried with what happened [birth] (Liz P 3, L22-25).</p>	<p>Women only disclose what they feel they need to in order to protect and care for others resulting in under informed support networks. fm69</p>	<p>Isolation, Protecting others, fear</p>	
<p>...you know, it is still obviously <u>not something</u> that you know, that you want to sit there and you want to have... <u>it's not the topic of conversation</u> (Matilda P15, L13-15).</p>	<p>Women will not openly disclose AI as it is not acceptable to openly discuss in society. fm70</p>	<p>Not acceptable, Hidden, disgust</p>	
<p>...it can be quite <u>overwhelming and intimidating</u> and <u>embarrassing</u> you know, you have to <u>watch what you say</u> and how you say things,( Matilda P15, L11-17)</p>	<p>AI has devastating emotional impact on a woman's life, women are careful of whom they disclose information too. fm 71</p>	<p>Emotional devastation, Avoidance, Vulnerability</p>	
<p>... even the [professionals] are <u>scared to tell you</u>... they might think I will not be happy with them, I don't know (Penny P14, L12-13).</p>	<p>Women believe nondisclosure by health professionals is due to fear of client anger and dissatisfaction.fm72</p>	<p>Professional avoidance, client anger, Vulnerability, Uncertainty</p>	<p>Professional silence</p>

<p>I feel like there's probably <u>something that someone knows</u> that I should be knowing, do you know what I mean... I feel like there's probably <u>someone who has more information that I'm not getting</u> (Ella P11, L5-7).</p>	<p>Women believe professional silence is due to avoidance resulting in anger and frustration. fm 73</p>	<p>Isolated Anger, Frustration</p>	<p>Professional silence</p>
<p>...<u>Like completely dumfounded</u> as to why no-one knows about this clinic [contenance]...right you [<u>obstetrician</u>] <u>don't want to deal with it</u>, send them here [contenance clinic] (Anna P 12, L4-9).</p>	<p>Women want to be referred to appropriate services are dumfounded and angry that professionals don't know or support other networks.fm74</p>	<p>Frustration, Anger, Professional avoidance</p>	
<p>What that doctor did to me <u>was cruel</u>, because <u>he never told me what he had done any damage</u> ... let me <u>go home not knowing</u>...that was absolutely cruel what he did. I should have been given a referral to get help...rather than be let home and think later on, <u>what's wrong with me</u> (Flo P5, L29-30).</p>	<p>Women often blame themselves for AI, they are angry when professionals do not discuss or disclose information. fm 75</p>	<p>Sadness, shame, Anger, vulnerable, Professional avoidance</p>	
<p>It makes me feel like <u>they're hiding something</u>, like that <u>they've kept that locked away</u> and hoping that you know, I won't look into it any further (Heather P29, L15-16)</p>	<p>Professional silence is seen as avoidance, women sense there is more they aren't being told. fm 76</p>	<p>Emotional vulnerability, anxiety, Professional avoidance</p>	
<p><u>I wanted to make sure</u> they knew my position so that if I did need to go to the toilet <u>they could get me there as quickly as possible</u>, or direct me there as quickly as possible (Ella P2, L30 -32).</p>	<p>Young women speak out to find support with coping with AI. fm 77.</p>	<p>Needing to be heard, Support from others, Emotional support</p>	<p>Breaking the silence</p>

<p>You need to listen ,you need to listen like if someone had listened to me....there's <u>only one person that actually did...</u> ... the Midwife .(Anna P21, L5-6)</p>	<p>Women want to be heard but are frustrated people do not listen. fm 78.</p>	<p>Being heard Sole support, Emotional need</p>	<p>Breaking the silence</p>
<p>I think it was the time <u>that he started to understand</u> and he actually said to me, he said ... I actually didn't realize you know, and I'm like <u>this is what I have to live with every day</u>(Matilda P11, L7-9).</p>	<p>Talking to others brings a sense of relief and sharing helps to identify the devastating impact on life. fm 79.</p>	<p>Support, Hearing me, Emotional relief</p>	
<p>I think it's once you are <u>telling it out</u> it can help you... because <u>if you did not tell it out nobody knows...</u>I came here they found that I was incontinent... if I had denied it nobody would help me (Penny P13, L25-27).</p>	<p>Talking to others discloses the impact of AI and is a precursor to seeking and receiving help. fm 80.</p>	<p>Speaking out, Seeking help</p>	
<p>...it's <u>made it easier</u> because obviously <u>I don't have to ball it up all inside...</u> like coming and seeing the continence nurse has <u>been good</u> because she's been able to explain it to me... so now at least I know <u>there is something wrong, this is just not me being feral like</u> (Dianne P18, L 30; P19, L1-2).</p>	<p>Women find relief in talking to specialist's professionals who deal with AI, this interaction provides information and clarification that AI is not the woman's fault.fm 81.</p>	<p>Relief, Not to blame, effective information pathway</p>	
<p>She's asking you the right kinds of questions (Ella P20, L6)</p>	<p>Women feel their needs are met when professional listen fm82.</p>	<p>Being heard, relief</p>	<p>Breaking the silence</p>
<p>...you know <u>it'd be nice if you could talk to somebody</u> who's gone through it especially not that long ago as well because then <u>you don't feel like it's just you</u>, so it's silly I know but women do that to themselves that's just how we are.(Liz P21, L16-19</p>	<p>Women need to talk to people with similar experiences to identify they are not alone and to clarify their experience and not blame themselves.fm 83.</p>	<p>Wanting help</p>	

**Development of selected statements, formulated meanings, concepts and subthemes**

**Sub-themes: Retreating inside and compromise**

**Formulated meanings (fm) are numerically listed**

<b>Selected statements</b>	<b>Formulated meanings</b>	<b>Concepts</b>	<b>Sub-themes</b>
When you went out you tried <u>to look normal</u> like most people ... I used to <u>ignore the fact</u> that I had a problem ... (Flo P5, L 18-20)	In order to fit in women will deny they have AI with serious consequences.fm 84.	Wanting to be normal, denial	Retreating inside
It's been <u>five and a half years</u> and I'm still learning how to just <u>push it to the back of my mind</u> (Ella P3, L19-20)	The impact of AI is life-long and women try to cope by putting the thought of AI to the back of their mind.fm 85.	Lifelong burden, back of my mind	
I now <u>subconsciously just don't even try</u> and get myself involved ... because I'm not sure how its [Continence status] is going to go... (Ella P21, L11-12)	Women are fearful of the pending impact of AI on their life and try to avoid thinking of the future. fm 86.	Locked in subconscious, pending burden, fear	
I'd try and <u>avoid it</u> (move away from people) [very quiet voice] or nothing would really be said, nothing would be said, so I'd just try and I guess <u>cover it (AI) up</u> (Hallie P8, L6-7).	The silent shame of AI impacts on how women cope with AI, women will often move away from a situation or cover an accident up to avoid being found out. fm 87.	Silent affliction, concealment, avoidance	
... I try and just <u>forget about it (AI)</u> , just try and forget that it ever happened [still emotional] (Heather P 5, L14-15).	The impact of AI on a woman's life is devastating women just try to forget to cope. fm 88.	Forget it happened, mental impact, devastation	
... you just sort of <u>switch off and crawl into yourself</u> (Flo P 12, L7).	Women will retreat from society and themselves to cope with the negative impact on their lives.fm 89.	Emotionally and psychological devoid, need to escape/ hide	

So unfortunately we do, if <u>we do put things back</u> , something simple like a haircut or <u>something huge like making it to the toilet.</u> (Liz P 23, L5-6)	Women will put then urgent need to go to the toilet back in their mind to deal with everyday family needs as a mother and wife. fm 90.	Put aside in order to cope with everyday needs of life, burden	Retreating inside
...so me thinking <u>I can hold it now</u> a little bit... has <u>backfired</u> on me... so I don't try and hold now...(Anna P8, L30; P9, L1)	Women desperately want to control AI and will often delude themselves they can and result in negative consequences.fm 91	Desperation denial	
I was <u>worried</u> that I would, you know, <u>make myself more</u> , you know <u>depressed</u> and so forth so <u>I would constantly try and not think about it</u> (Anna P12, L5-7)	The negative psychological and emotional impact of AI on a woman's life causes her to push any thoughts of AI to the back of her mind in order to cope. fm 92	Mental impact, Put it out of my mind	
<u>It is, it is</u> just a matter of learning <u>how to cope...</u> knowing you have to <u>change your life</u> to (pause) you have to <u>prioritize yourself</u> when it comes to that (AI), and you just have to <u>work around it</u> , because otherwise it ( <u>AI</u> ) <u>does get on top of you emotionally</u> and... as well as a physical thing, it's an emotional thing (Matilda P 14, L 24 -28).	AI is a physical and emotional burden to a woman's life, in order to cope women need to place themselves before others which results in emotional conflict and structure their life around AI. fm 93	Stressful, change life, dictated by AI, Emotional and physical impact	Compromise
<u>I won't go out anywhere until I've gone</u> , like used my bowels, just in case something happens (Dianne P 6, L20-23)	Women will structure their day around their bowel habits to avoid embarrassment fm 94	Planning to avoid accidents	
I guess it's <u>changed my diet</u> but I don't... live on food that may upset my stomach...so that's a good thing (Julie-Anne P 5, L14-15)	Women need to change their eating habits to avoid AI. fm 95	Changed diet to cope	Compromise
...just the balancing act, <u>making priorities, the stress</u> that it adds on top of everything else, I think that's pretty much it in a nutshell for me... because it hasn't happened a lot to me ... I got to the point where I got <u>more confident</u> and thinking I can do this (Liz P24, L 20-23)	Women prioritise their life around AI and these results in added stress to daily living. As women have less incontinence they become more confident at attempting activities of daily living. fm 96.	Prioritising to cope, Added stress, Gaining confidence	

I've got to <u>carry a pair of underwear</u> in my bag when I go to work just in case (Heather P4, L 29 -30)	Women put strategies in place to cope with AI, they have no choice due to the unpredictable nature of AI. fm 97	Forward planning, conflict role, sadness	Compromise
...I have to <u>wear the dark trousers</u> to help me. Like if I go in public, I know that I used to <u>sit where there's lot of loud noise</u> so that if anything did happen, nobody could hear (Penny P7, L28-30)	Women will dress in dark clothing to avoid disclosure of AI and women are constantly thinking where they will situate themselves in surroundings where the effects of AI will not be noticed. fm 98.	Changed dress, Planning outings, Planning locations	
When I was <u>dropping low</u> , I'd basically get up and go to <u>family</u> .. so I wouldn't get in that black hole (Anna P 7, L 17 –20)	Family are seen as a necessary support to cope with the psychological impact of AI on a woman's life.fm 99.	Support of families Scared of mental impact, disclosure	
I'd go to do the shopping ... you know <u>early in the morning when there are not many people</u> around, but many a time you had to <u>rush back to the car</u> cause you had had an accident ( Flo P 4, L14-16)	The pending physical and emotional impact of AI causes women to structure their day to avoid social interactions.fm 100.	Planning activities avoid people, park close	
it was a <u>joke</u> type thing, you know because <u>it's happened...</u> to people before like, it's happened to my brother when he's been out playing golf...mum's done it before...it was just a type thing (Dianne P5, L 2-4)	Humour helps women cope with the effects of AI. fm101.	Humour to cope, pending shame, changing role	
...it really could have meant the <u>end of either friendships or partnerships</u> ... but I think that's probably one of the things that it's one of my better sort of parts of my personality is that <u>I'm open and I think humorous</u> ...(Ella P4, L 10-14)	Humour is used to communicate the issues surrounding AI to potential partners and friend's. fm 102	Humour to communicate, avoid isolation	

<p>I finally had, not that I didn't have his (partners) support, but <u>his understanding</u>, and I wasn't going to get, you've got to go to the toilet again, or, or I wasn't going to get frustration from him (Matilda P 11, L18-20)</p>	<p>The negative responses from significant others impacts on how a woman copes with AI, this is reduced when significant others truly understanding fm.103.</p>	<p>Understanding Relief, sharing, vulnerability</p>	<p>Compromise</p>
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**Appendix 10: Development of formulated meanings, concepts, sub themes and essential themes**

**Essential theme: Grieving for loss**

**Formulated meanings (fm) are numerically listed**

<b>Formulated Meaning</b>	<b>Concepts</b>	<b>Sub-themes</b>	<b>Essential theme</b>
There is an expectation that AI worsens with ageing, women are already compromised and sense the impending burden of AI.fm1	Loss of identity, impending burden	Near the edge	Grieving for loss
AI causes a woman to feel abnormal and question herself worth.fm2	Loss of identity, Worthless, Emotional devastation	Near the edge	
The effects of AI cause a woman to be depressed, questioning her worth and role in society and placing her at risk of suicide.fm3	No control, Low self esteem, Worthless, Questions living	Near the edge	
AI causes confusion between a woman's role as an adult and a childlike state, resulting in humiliation and shame.fm4	Shame, role confusion, loss of self, demeaning, disgust	Near the edge	
AI causes a woman to experience heightened anxiety, lack of self respect and grief as she is continually conflicted by the inability to control normal bodily function. fm 5.	Loss of identity, pending shame, sadness	Near the edge	
AI reduces a woman to a childlike state which impacts on her role as a parent/adult; there is little hope of improvement. fm 6.	Childlike, grief, resigned fate, sadness, vulnerability	Near the edge	
Adults should maintain continence; to be incontinent is humiliating. fm 7.	Emotional impact, Childlike, shame	Near the edge	

There is an expectation AI only happens to the elderly, yet young women are faced with the pending loss of their identity. fm 8.	Loss of identity, loss of freedom, disgust.	Near the edge	Grieving for loss
There is an expectation that AI shouldn't happen to young people, they don't deserve it and there is embarrassment and shame surrounding AI .fm 9.	Youth versus ageing, undeserving shame	Near the edge	
Women with AI question the impact of AI on their life and are faced with uncertainty of their future. fm10.	Fear of ageing, vulnerability of aging	Near the edge	
Women are faced with the sobering thought that AI is with them for life.fm11.	Loss of life, Sadness, loss identity	Near the edge	
Women find it difficult to cope with AI at a young age; they feel disgusted that AI happens to young people as it is viewed as an elderly complaint.fm12.	Fear of ageing, personal disgust, pending shame.	Near the edge	
Young women find it difficult to accept AI, AI is a complaint of the elderly.fm13	Age conflict, Not deserved, loss of life	Near the edge	
Women are angry and struggle with the being incontinent at a young age and they fear AI this will worsen with ageing.fm14.	Fear of ageing, life sentence, sadness. loss of life	Near the edge	
Women can rationalise the cause and impact of AI but as an adult, AI is not acceptable resulting in feelings of disgust and humiliation Fm15.	Conflict with role, Disgust, sadness	Near the edge	
As an adult there is an expectation that you should control bodily functions to lose control results in a range of emotions including disgust, anger, sadness and disappointment. fm 16	Conflict with role, Mental burden, sadness.	Near the edge	
AI reduces women to a childlike status, it's demeaning and humiliating. fm 17.	Loss of identity, shame, disgust	Near the edge	

AI causes a woman to feel vulnerable and lack control as an adult in everyday activities. fm 18.	Helplessness, loss of self, loss of control	Near the edge	Grieving for loss
Young woman are resentful of the random occurrence and impact of AI on their life, there is a fear with ageing AI will worsen; women just want to control AI. fm 19.	Fear of ageing, anger, Not deserved, sadness, mental impact	Near the edge	
There is immense physical, emotional and mental impact of AI on a woman's life. fm20.	Physical, emotional and mental devastation; isolation	Near the edge	
Coping with AI in public cause's anxiety and embarrassment for women with AI. fm 21.	Vulnerability, Loss of personal worth, mental impact	Near the edge	
Women do not have the luxury of controlling their bowel function, the unpredictable nature of AI results in urgency. fm 22.	AI dictates my life, No control, Anxiety	Near the edge	
AI makes a woman feel ostracised and there is sadness associated with the fact she is undeserving of this affliction. fm 23.	Loss of social mobility and acceptance, isolated	Near the edge	
The unpredictable nature of AI causes a woman to constantly fear having a bowel accident due to lack of appropriate services and brings into question the need for social interactions. fm 24.	Fear, Restricted lifestyle, ongoing anxiety	Near the edge	
The enormity of AI impacts physically and emotionally on woman, significant others and planning are essential for support. fm 25.	Restricted life, Anxiety, Mental strain	Near the edge	

AI impacts on a woman's ability to feel confident with social outings. Women prefer to isolate themselves and will only venture out if they feel they have supports in place. fm 26.	Imposed social isolation, restricted lifestyle, grief	Near the edge	Grieving for loss
The unpredictable nature of AI and lack of control impacts on a woman's freedom. fm 27.	Loss of freedom, restricted lifestyle, anxiety	Near the edge	
Women feel the need to escape and hide due to the impact of AI on their lives. fm 28.	Need to hide, embarrassment, sadness	Near the edge	
AI has a negative emotional impact on how young women perceive their right to procreate and worsening impact of AI with further childbearing. Fm 29.	Loss of right to procreate, Fear of childbearing, anxiety	Near the edge	
The fear of worsening AI with future birthing causes a great deal of anxiety for woman. fm 30.	Loss of right to procreate, Fear of worsening AI, anxiety	Near the edge	
The reality of further bowel damage with vaginal deliveries causes fear and vulnerability for women. Fm 31.	Loss of bowel function, Fear, anxiety, devastation, mental impact	Near the edge	
Fear of AI is always in a woman's mind and restricts a woman's ability to engage in and enjoy sexual relations. fm 32.	Fear of sexual relations, Loss of sexual freedom, in my head	Near the edge	

AI has a negative impact on a woman's personal relationship Fm 33.	Relationship breakdown, sadness, ongoing grief	Near the edge	Grieving for loss
AI is a constant worry for woman during intercourse, impacting on a woman's self concept and relationship. fm 34.	loss of intimacy, shame, mental impact	Near the edge	
The fear of AI is always on a woman's mind, it is consuming and stressful dictating her life. fm 35.	Always in my head, Consuming, No confidence	Near the edge	
The reality and impact of AI is unknown within the community as there is limited discussion on this topic, leaving affected women feeling isolated and depressed. fm 36.	Mental impact, Loss of networks, alone	Near the edge	
Women feel vulnerable about the unpredictable nature of AI. fm 37.	Anxiety Vulnerability, mental strain	Near the edge	
AI impacts on relationships, to cope women isolate themselves for so long they have no social networks. fm 38.	Alone, Sadness Emotionally bare, Isolated on the edge	Near the edge	
Women feel angry that they have to suffer from the effects of AI; it impacts negatively on their lifestyle and self concept. fm 39.	Anger, Intimacy versus isolation, Loss self worth	Loss young adulthood	Grieving for loss
The unpredictability of AI impacts on sexual relations, women continually worry AI will negatively impact on their relationship. fm 40.	Fear of sexual Activity, lack of sexual freedom, loss of intimacy, anxiety	Loss of young adulthood	

A woman is faced with the constant fear and vulnerability that AI will occur during sexual relations and there is an uncertainty of how her partner will respond.fm 41.	Lack of sexual freedom, Vulnerability	Loss of young adulthood	Grieving for loss
Home is a safe place where others are unaware of AI and associated embarrassment.fm 42.	Safety of home, Forced isolation	Loss of young adulthood	
Women with AI find the home environment a sanctuary, to lose control of bowel function anywhere else is humiliating.fm 43.	Safety of home, Loss of independence	Loss of young adulthood	
Young woman with AI are isolated from participating in everyday activities.fm 44.	Social isolation, restricted mobility, sadness	Loss of young adulthood	
Young women with AI are forced to isolate themselves due to the vulnerability in social settings, this lasts for many years.fm 45.	Social avoidance, loss of social life, restricted mobility, anxiety	Loss of young adulthood	
Women are angry that they are unable to achieve basic bowel control like their children.fm 46.	Loss of control, Poor negative role modelling as a parent, sadness	Loss of middle adulthood	Grieving for loss
As an adult it is frustrating and embarrassing having no control over what is considered controllable.fm 47.	Anger at lack of control as an adult, embarrassment sadness,	Loss of middle adulthood	
A woman with AI has increased anxiety and emotional turmoil due to the loss of control as an adult reducing a woman to a childlike state.fm 48.	Loss of parent role, childlike, Negative emotion	Loss of middle adulthood	

As an adult there is an expectation you can control your bowel actions, to lose control causes conflict with the parenting role and expectations.fm 49	Poor role modelling, Childlike, public shame	Loss of middle adulthood	Grieving for loss
The lack of control of AI has a negative impact on a woman's physical and mental wellbeing.fm 50.	Physical loss devastation, shame, loss of control	Loss of middle adulthood	
Women are not only faced with the negative physical and emotional impact of AI, but are challenged by their role as a parent with AI, disclosing their urgent needs to their children.fm 51.	Physical urgency, desperation, no control, demoralised	Loss of middle adulthood	
There is a point of desperation where women are faced with the urgent need to find a toilet and are faced with the vulnerability of disclosing AI to others fm 52.	Physical loss, devastation, lack of control	Loss of middle adulthood	
The unpredictable nature of AI makes a woman feel vulnerable, impacted lack of control and resultant anxiety and negative physical sensations.fm 53.	Negative physical sensation, urgency, sadness	Loss of middle adulthood	
Women with AI grieve their loss of life and normality.fm 54.	Restricted life, loss of normality, vulnerability	Loss middle adulthood	
AI has a devastating impact on a woman's life, women will retreat from social interactions to feel safe.fm55	Safety of the home, restricted lifestyle, sadness	Loss of middle adulthood	
The consuming nature of AI has negative implication for a woman's sex life.fm 56.	Deterrent to sexual activity, loss of intimacy	Loss of middle adulthood	

Lack of control with AI results in personal emotional devastation.fm 57.	Lack of control, Loss of personal self worth, shame	Near the edge	Grieving for loss
AI dictates a woman's life, woman choose social isolation over the unpredictable nature of AI and the burden of carrying personal items.fm 58.	Restricted lifestyle, Lack of control, demoralised	Loss of middle adulthood	
AI controls every aspect of woman's lives.fm 59.	Lack of control	Loss of middle adulthood	
Women are frustrated by the lack of control they have over AI .fm 60.	No choice to control, denial, sadness, vulnerability	Loss of middle adulthood	
Women are frustrated that they have no control of AI.fm 61.	Frustration, Lack of control	Loss of middle adulthood	
AI negative impacts on a woman's sexual relationship, woman are constantly in fear that AI will occur they are unable to relax and enjoy sexual relations.fm 62.	Fear of sexual enjoyment, anxiety, loss of sexual pleasure	Near the edge	



**Development of formulated meanings, concept, sub themes and essential theme**

**Essential theme: Silence**

**Formulated meanings (fm) are numerically listed**

<b>Formulated meanings</b>	<b>Main Concept</b>	<b>Sub-themes</b>	<b>Essential theme</b>
Nondisclosure helps women to cope with the impact of AI fm 63.	Concealed Vulnerable, Anxiety, Pending shame	Keeping silent	Silence
Women don't divulge information about AI; they wait for others to prompt conversation due to their embarrassment of AI and fear of rejection.fm 64.	Hidden Embarrass- ment Vulnerable, Fear of disclosure	Keeping silent	
Women wait for health professionals to discuss AI as they see AI as a normal process following delivery and cope with the consequences.fm 65.	Normality, Waiting to be asked	Keeping silent	
AI cause women to have feelings of disgust about themselves and reinforces not to share with others. fm66.	Bad feelings, Hiding, pending shame	Keeping silent	
Social rejection of AI makes woman feel worthless lack of social support results in isolation.fm67.	Avoidance, Mental devastation. socially devoid, Grief	Keeping silent	
Women choose not to share their struggle of AI with significant others, they find it embarrassing. fm68.	Hidden from others, Embarrass- ment, Sadness	Keeping silent	
Women only disclose what they feel they need to in order to protect and care for others resulting in under informed support networks.fm69.	Isolation, Protecting others, fear	Keeping silent	

Women will not openly disclose AI as it is not acceptable to openly discuss in society.fm70.	Not acceptable, Hidden, disgust	Keeping silent	Silence
AI has devastating emotional impact on a woman's life, women are careful of whom they disclose information too.fm 71.	Emotional devastation, Avoidance, Vulnerability	Keeping silent	
Women believe nondisclosure by health professionals is due to fear of client anger and dissatisfaction.fm72.	Professional avoidance, client anger, Vulnerability, Uncertainty	Professional silence	
Women believe professional silence is due to avoidance resulting in anger and frustration.fm 73.	Isolated Anger, Frustration	Professional silence	
Women want to be referred to appropriate services are dumfounded and angry that professionals don't know or support other networks.fm74.	Frustration, Anger, Professional avoidance	Professional silence	
Women often blame themselves for AI, they are angry when professionals do not discuss or disclose information.fm 75.	Sadness, shame, Anger, vulnerable, Professional avoidance	Professional silence	
Professional silence is seen as avoidance, women sense there is more they aren't being told.fm 76.	Emotional vulnerability, anxiety, Professional avoidance	Professional silence	
Young women speak out to find support with coping with AI. fm 77.	Needing to be heard, Support from others, Emotional support	Breaking the silence	

Women want to be heard but are frustrated people do not listen.fm 78.	Being heard Sole support, Emotional need	Breaking the silence	Silence
Talking to others brings a sense of relief and sharing helps to identify the devastating impact on life.fm 79.	Support, Hearing me, Emotional relief	Breaking the silence	
Talking to others discloses the impact of AI and is a precursor to seeking and receiving help.fm 80.	Speaking out, Seeking help	Breaking the silence	
Women find relief in talking to specialist's professionals who deal with AI, this interaction provides information and clarification that AI is not the woman's fault.fm 81.	Relief, Not to blame, effective information pathway	Breaking the silence	
Women feel their needs are met when professional listen.fm 82.	Being heard, relief	Breaking the silence	
Women need to talk to people with similar experiences to identify they are not alone and to clarify their experience and not blame themselves. fm 83.	Wanting help Not alone	Breaking the silence	

**Development of formulated meanings, concepts, subthemes and essential theme**

**Essential theme: Striving for normality**

**Formulated meanings (fm) are numerically listed**

<b>Formulated meanings</b>	<b>Concepts</b>	<b>Sub-themes</b>	<b>Essential theme</b>
In order to fit in women will deny they have AI with serious consequences.fm 84.	Wanting to be normal, denial	Retreat inside	Striving for normality
The impact of AI is life-long and women try to cope by putting the thought of AI to the back of their mind.fm 85.	Lifelong burden, back of my mind	Retreat inside	
Women are fearful of the pending impact of AI on their life and try to avoid thinking of the future. fm 86.	Locked in subconscious , pending burden, fear	Retreat inside	
The silent shame of AI impacts on how women cope with AI, women will often move away from a situation or cover an accident up to avoid being found out.fm 87.	Silent affliction, concealment, Avoidance	Retreat inside	
The impact of AI on a woman's life is devastating women just try to forget to cope.fm 88.	Forget it happened, mental impact, devastation	Retreat inside	
Women will retreat from society and themselves to cope with the negative impact on their lives.fm 89.	Emotionally and psychological devoid, need to escape/ hide	Retreat inside	
Women will put then urgent need to go to the toilet back in their mind to deal with everyday family needs as a mother and wife.fm90.	Put aside in order to cope with everyday needs of life, burden	Retreat inside	
Women desperately want to control AI and will often delude themselves they can and result in negative consequences.fm 91	Desperation, Denial	Retreat inside	

The negative psychological and emotional impact of AI on a woman's life causes her to push any thoughts of AI to the back of her mind in order to cope.fm 92	Mental impact, Put it out of my mind	Retreat inside	Striving for normality
AI is a physical and emotional burden to a woman's life, in order to cope women need to place themselves before others which results in emotional conflict and structure their life around AI.fm 93	Stressful, change life, dictated by AI, Emotional and physical impact	Compromise	
Women will structure their day around their bowel habits to avoid embarrassment.fm 94	Planning to avoid accidents	Compromise	
Women need to change their eating habits to avoid AI.fm 95	Changed diet to cope	Compromise	
Women prioritise their life around AI and these results in added stress to daily living. As women have less incontinence they become more confident at attempting activities of daily living.fm 96.	Prioritising to cope, Added stress, Gaining confidence	Compromise	
Women put strategies in place to cope with AI, they have no choice due to the unpredictable nature of AI.fm 97	Forward planning, conflict with role, sadness	Compromise	
Women will dress in dark clothing to avoid disclosure of AI and women are constantly thinking where they will situate themselves in surroundings where the effects of AI will not be noticed.fm 98.	Changed dress, Planning outings, Planning locations	Compromise	

Family are seen as a necessary support to cope with the psychological impact of AI on a woman's life.fm 99.	Support of families Scared of mental impact	Compromise	Striving for normality
The pending physical and emotional impact of AI causes women to structure their day to avoid social interactions.fm100.	Planning activities avoid people, park close	Compromise	
Humour helps women cope with the effects of AI. fm 101.	Humour, Normalising, changing role	Compromise	
Humour is used to communicate the issues surrounding AI to potential partners and friend's. fm102.	Humour, avoid isolation	Compromise	
The negative responses from significant others impacts on how a woman copes with AI, this is reduced when significant others truly understanding. fm 103.	Relief, sharing, vulnerability	Compromise	

### Appendix 11: Formulation of essential themes

Formulated statements	Main Concept	Sub-theme	Essential theme
<p>There is an expectation that AI <u>worsens with ageing</u>, women are already compromised and sense the <u>impending burden of AI</u> fm1. AI causes a woman to <u>feel abnormal and question herself worth</u> fm2. AI causes <u>confusion between a woman's role as an adult and a childlike state</u>, resulting in <u>humiliation and shame</u> fm4. AI causes a woman to experience heightened <u>anxiety, lack of self respect and grief</u> as she is continually conflicted by the <u>inability to control</u> normal bodily function fm 5. AI reduces a woman to a <u>childlike state</u> which impacts on her role as a parent/adult; there is <u>little hope of improvement</u>.fm 6. <u>Adults</u> should maintain continence; to be <u>incontinent is humiliating</u>.fm 7. There is an expectation AI only happens to the <u>elderly, yet young women</u> are faced with the <u>pending loss</u> of their identity fm 8. There is an expectation that AI <u>shouldn't happen to young people, they don't deserve it</u> and there is <u>embarrassment and shame</u> surrounding AI fm 9. Women with AI <u>question</u> the impact of AI on their life and are faced with <u>uncertainty of their future</u> fm10. Women find it difficult to cope with AI at a young age; they feel <u>disgusted</u> that AI happens <u>to young people</u> as it is viewed as an <u>elderly complaint</u> fm12. Young women find it <u>difficult to accept</u> AI, AI is a complaint of the <u>elderly</u> fm13. AI reduces women to a <u>childlike status</u>; it's <u>demeaning and humiliating</u>.fm 17. AI causes a woman to feel <u>vulnerable</u> and lack control as an adult in everyday activities.fm 18. Women do not have the luxury of controlling their bowel function, the unpredictable nature of AI results in urgency fm 22.</p>	Loss of identity	Near the edge	Grieving for loss
<p>Women are faced with the sobering thought that AI is with them <u>for life</u> fm11. Women are <u>angry</u> and struggle with the being incontinent at a <u>young age</u> and they fear AI <u>this will worsen with ageing</u>.fm14 AI makes a woman feel <u>ostracised</u> and there is</p>	psychological burden vulnerability	Near the edge	Grieving for loss

<p>sadness associated with the fact she is <u>undeserving of this affliction</u>.fm 23. The <u>unpredictable nature</u> of AI causes a woman to <u>constantly fear</u> having a bowel accident due to lack of appropriate services and brings into question the need for social interactions.fm 24.AI impacts on a woman’s ability to feel confident with social outings. Women prefer to <u>isolate</u> themselves and will only venture out if they feel they have supports in place.fm 26. The unpredictable nature of AI and lack of control <u>impacts on a woman’s freedom</u>.fm 27. Women feel the need to <u>escape and hide</u> due to the impact of AI on their lives.fm 28. AI has a <u>negative impact</u> on a woman’s <u>personal relationship</u> fm 33. AI impacts on relationships, to cope women <u>isolate themselves for so long they have no social networks</u>.fm 38. A woman with AI has increased <u>anxiety and emotional turmoil</u> due to the loss of control as an adult reducing a woman to a childlike state fm 48. The lack of control of AI has a <u>negative impact</u> on a woman’s <u>physical and mental</u> wellbeing.fm 50. The unpredictable nature of AI makes a woman feel vulnerable, impacted lack of control and <u>resultant anxiety and negative physical</u> sensations.fm 53. Lack of control with AI results in personal <u>emotional devastation</u>.fm 57. AI negative impacts on a woman’s sexual relationship, woman are constantly <u>in fear</u> that AI will occur they are <u>unable to relax</u> and enjoy sexual relations fm 62.</p>			
<p>Women feel <u>angry</u> that they have to suffer from the effects of AI, <u>it impacts negatively on their lifestyle and self concept</u>.fm 39. The unpredictability of AI impacts on sexual relations, women <u>continually worry AI will negatively impact on their relationship</u>.fm 40. A woman is faced with the <u>constant fear</u> and <u>vulnerability that AI will occur during sexual relations</u> and there is an uncertainty of how <u>her partner will respond</u> fm 41. Home is a safe place where <u>others are unaware of AI and associated embarrassment</u> fm 42.Women with AI find the home environment a sanctuary, to <u>lose control of</u></p>	<p>Loss of Intimacy</p>	<p>Loss of young adulthood</p>	<p>Grieving for loss</p>



<p><u>bowel function anywhere else is humiliating</u>.fm 43. Young woman with AI are <u>isolated from participating</u> in everyday activities fm 44. Young women with AI are <u>forced to isolate</u> themselves due to the <u>vulnerability</u> in social settings, this lasts for <u>many years</u> fm 45</p>			
<p>Women are <u>angry</u> that they are unable to achieve <u>basic bowel control like their children</u> fm 46. As an <u>adult</u> it is <u>frustrating and embarrassing</u> having no control over what is considered controllable fm 47. Women are not only faced with the negative physical and emotional impact of AI, but are <u>challenged by their role as a parent with AI</u>, disclosing their urgent needs to their children fm 51. There is a point of <u>desperation</u> where women are faced with the urgent need to find a toilet and are faced with the <u>vulnerability of disclosing</u> AI to others fm 52. Women with AI <u>grieve their loss of life and normality</u> fm 54. AI has a devastating impact on a woman's life, women will retreat from social interactions to feel safe fm 55. The <u>consuming nature</u> of AI has negative <u>implication for a woman's sex life</u> fm 56. AI <u>dictates a woman's life</u>, woman choose <u>social isolation</u> over the unpredictable nature of AI and the burden of carrying personal items fm 58. AI <u>controls every aspect of woman's lives</u> fm 59. Women are <u>frustrated by the lack of control</u> they have over AI fm 60. Women are <u>frustrated that they have no control</u> of AI fm 61.</p>	<p>Lack of control, Negative values</p>	<p>Loss of Middle adulthood</p>	<p>Grieving for loss</p>

**Essential theme: Silence**

**Formulated meanings (fm) are numerically listed**

Formulated statements	Main Concept	Sub-theme	Essential theme
<p><u>Nondisclosure helps women to cope</u> with the impact of AI fm 63. Women <u>don't divulge</u> information about AI; they wait for others to prompt conversation due to their <u>embarrassment</u> of AI and <u>fear of rejection</u> fm 64. AI cause women to have <u>feelings of disgust</u> about themselves and reinforces <u>not to share</u> with others fm 66. <u>Social rejection</u> of AI makes woman feel <u>worthless</u> lack of social support results in isolation fm67. Women choose not to share their struggle of AI with significant others, they find it <u>embarrassing</u> fm68. Women only disclose what they feel <u>they need to</u> in order <u>to protect and care for others</u> resulting in under informed support networks fm69. Women will <u>not openly disclose</u> AI as it is <u>not acceptable to openly discuss</u> in society fm70</p>	<p>Pending shame</p>	<p>Keeping silent</p>	<p>Silence</p>
<p>Women believe <u>nondisclosure by health professionals</u> is due to <u>fear of client anger and dissatisfaction</u> fm72. Women believe professional silence is due to <u>avoidance resulting in anger and frustration</u> fm 73. Women want to be referred to appropriate services are dumfounded and angry that professionals <u>do not know or support</u> other networks fm 74. Professional silence is seen as <u>avoidance</u>, women sense there is more <u>they aren't being told</u> fm 76. Women often <u>blame themselves</u> for AI, they are <u>angry when professionals do not discuss or disclose information</u> fm 75</p>	<p>Professional avoidance and fear</p>	<p>Professional silence</p>	<p>Silence</p>
<p>Young women speak out to <u>find support</u> with coping with AI fm 77. Women <u>want to be heard</u> but are <u>frustrated people do not listen</u> fm 78. Talking to others brings a <u>sense of relief</u> and sharing helps to <u>identify the devastating impact</u> on life fm 79. Talking to others <u>discloses the impact</u> of AI and is a precursor to <u>seeking and receiving help</u> fm 80. Women find <u>relief in talking to specialist's</u></p>	<p>Need to be heard, support, help, relief</p>	<p>Breaking the silence</p>	<p>Silence</p>

professionals who deal with AI, this interaction provides <u>information and clarification</u> that AI is not the <u>woman's fault</u> fm 81. Women feel their <u>needs are met</u> when professional <u>listen</u> fm 82. Women need to talk to people with <u>similar experiences to identify they are not alone</u> and to clarify their experience and <u>not blame</u> themselves fm 83.			
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**Essential theme: Striving for normality**

**Formulated meanings (fm) are numerically listed**

<b>Formulated statements</b>	<b>Main Concept</b>	<b>Sub-theme</b>	<b>Essential theme</b>
<p>In order to fit in women will deny they have AI with serious consequences fm 84. The impact of AI is life-long and women try to cope by putting the thought of AI to the back of their mind fm 85. Women are fearful of the pending impact of AI on their life and try to avoid thinking of the future fm 86. The impact of AI on a woman's life is devastating women just try to forget to cope fm 88. Women will retreat from society and themselves to cope with the negative impact on their lives fm 89. Women desperately want to control AI and will often delude themselves they can and result in negative consequences fm 91. The negative psychological and emotional impact of AI on a woman's life causes her to push any thoughts of AI to the back of her mind in order to cope fm 92.</p>	Pushed to the back of my mind	Retreat inside	Striving for normality
<p>The silent shame of AI impacts on how women cope with AI, women will often move away from a situation or cover an accident up to avoid being found out fm 87. Women will put then urgent need to go to the toilet back in their mind to deal with everyday family needs as a mother and wife fm 90.</p>	Avoidance	Retreat inside	Striving for normality
<p>AI is a physical and emotional burden to a woman's life, in order to cope women need to place themselves before others which results in emotional conflict and structure their life around AI fm 93. Women will structure their day around their bowel habits to avoid embarrassment fm 94. Women need to change their eating habits to avoid AI fm 95. Women prioritise their life around AI and these results in added stress to daily living. As women have less incontinence they become more confident at attempting activities of daily living fm 96. Women put strategies in place to cope with AI, they have no choice due to the unpredictable nature of AI fm 97. Women will dress in dark clothing to avoid disclosure of AI and women are constantly thinking where they will situate themselves in surroundings</p>	Need to change lifestyle, No choice	Compromise	Striving for normality

<p>where the effects of AI will not be noticed fm 98. Family are seen as a necessary support to cope with the psychological impact of AI on a woman's life fm 99. The pending physical and emotional impact of AI causes women to structure their day to avoid social interactions fm 100. Humour helps women cope with the effects of AI fm 101. Humour is used to communicate the issues surrounding AI to potential partners and friend's fm 102. The negative responses from significant others impacts on how a woman copes with AI, this is reduced when significant others truly understanding fm 103.</p> <p>.</p> <p>.</p>			
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