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Development and validation of a screening tool to identify anal incontinence in women of reproductive age

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Definition of key terms

Anal sphincter: Sphincter muscle of anus.

Anal incontinence (AI): Involuntary loss of solid, liquid stool, flatus and urgency from the anal sphincter.

Anus: Opening that excretes faeces.

Faeces: Bodily waste product.

Interpretative phenomenology: A qualitative research methodology, ontological in nature. A research method that does not bracket thoughts and feelings, but acknowledges that we have prior knowledge and beliefs. Through language (verbal and nonverbal), people are aware of their existence, challenged and reshaped through experiences.

Hermeneutic circle: Utilised in interpretative phenomenology to gain a deeper understanding of the experience. Through language, a cyclic process occurs where preconceived beliefs are challenged with new experiences and from this, new beliefs are derived.

Levator ani muscle (LAM): A muscle group of the pelvic floor, which provides support and assists to maintain continence.

Multiparous: A woman who has given birth more than once.

Neuropathy: Dysfunction of one or more peripheral nerves. Neuropathy following childbirth can lead to numbness in the pelvic floor and affect continence status.

Nulliparous: A woman who has never given birth.

Obstetric anal sphincter injury (OASIS): Damage to the anal sphincter muscle following vaginal birth. Also referred to as 3rd and 4th degree tears and severe perineal trauma.

Occult OASIS: Indirect damage to the anal sphincter muscles. Also referred to as obstetric anal sphincter injury (OASIS) and severe perineal trauma. Occult OASIS is considered rare.

Pelvic floor dysfunction: A collective term for urinary and faecal incontinence, pelvic organ prolapse as a result of damage to musculature and nerves of pelvic floor.

Phenomenology: A research methodology, which seeks to derive a deeper understanding of a person's world and experience.

Postnatal period: Days and weeks following birth until 6 weeks.

Post-partum: Refers to issues pertaining to the mother for a period following birth until 6 weeks.

Primiparous: A woman giving birth for the first time.

Pregnancy hand-held (PHHR): A written record held utilised by pregnant women worldwide and throughout Australia to assist in maintaining continuity of care and improving risk management.

Pudendal neuropathy: Damage to the pudendal nerve, which has a role in maintaining continence.

Quality of life: The term quality of life (QoL) defined by the World Health to include the multifaceted view of physical, emotional and social wellbeing and the perceptions of an individual which keep them engaged in every aspect of daily living.

Third and fourth degree tears: Also referred to as obstetric anal sphincter injury.

Van Manen: A phenomenological researcher, who built a framework of Martin Heidegger referred as the "the father of phenomenology". The Van Manen procedural framework guides data collection, analysis and interpretation.

Abstract

Anal incontinence is a debilitating condition projected to increase by 2030 to 1,835,340 Australian people, of which 1,122,749 will be women. Multiple risk factors are associated with anal incontinence. Pregnancy and childbirth are considered the main risk factors with subsequent pregnancies and childbirth compounding injuries and worsening symptoms. There is a high prevalence of incontinence but poor reporting across the lifespan for women of reproductive age. Furthermore, there is little evidence that specific screening or screening tools exist for pregnant or postnatal women especially in the first trimester of pregnancy, where the initial planning and management for care has commenced and can reduce worsening symptoms.

To address the gaps in clinical practice, this thesis used a mixed method research design, which included four stages of research to explore the factors that influence the disclosure of anal incontinence in women of reproductive age. This approach assisted in the development and validation of a bowel-screening tool (BSQ). Qualitative research methods complemented and informed quantitative research findings, identifying omissions or misunderstanding of terms within current screening tools and assisted in the development of the new tool.

The thesis findings established an overall high prevalence of anal incontinence. These findings are comparable to other studies that included rectal urgency. These findings differ to previous studies that report lower rates, largely because of the different clinical screening tools used, study sample and size, and how incontinence was determined.

The benefits of consumer participation in the development of the BSQ improved disclosure through the identification of symptoms and the transient nature of incontinence, which were important for women. Qualitative findings established further roadblocks for disclosure through the lack of screening by health professionals and difficulty comprehending screening tools. There was a significant disparity between the BSQ and clinical tools previously used, largely because of poor comprehension and symptom omission in tools.

The BSQ reported a high prevalence of anal incontinence across all stages of the research (range 26% to 68%). The screening tool identified that there was varied reporting of the symptoms of anal incontinence both in the past and during current screening of antenatal (68% vs 12.9%) and community women (5.1% vs 34.5%). Symptoms were less frequent in the current period for antenatal women suggesting that early pregnancy may alter the incidence of symptoms. The findings suggest that flatus, soiling and rectal urgency were predominant symptoms across both timeframes. These symptoms are known precursors for worsening function with subsequent births. Other obstetric factors, including caesarean section, second-degree perineal tear, intact perineum, ageing and increased body mass index, were also associated with incontinence. Ageing and increased body mass index were associated with incontinence and predominant factors in all stages of the research. The relative risk of experiencing anal incontinence increased with a yearly increase in age (OR = 1.02; 95% CI: 1.00, 1.05; P value = 0.0690). An increase by one unit on the body mass index further increased a woman's risk by 2% (OR = 1.02; 95% CI: 0.98, 1.05; P value = 0.3534). Over half the research participants (53%) were overweight with 32% of women with a BMI of 30 or more (obese). The risk of incontinence is heightened in obese women as they are more likely to have obstetric complications such as high blood pressure, gestational diabetes, larger babies, risk of instrumental delivery, perineal trauma and in particular, OASIS.

This work has identified a higher reporting of historical incontinence by antenatal women compared with women in the community. It has also reinforced that the aetiology of anal incontinence might be multifactorial, with factors other than birth trauma and direct injury to the anal sphincter, being associated with incontinence. These findings are similar to those reported in studies that recognise the influence of additional pre-pregnancy, and pregnancy factors, rather than just the consequences of labour and birth.

The prevalence of incontinence and the variability of symptoms is high in women of reproductive age. The BSQ can be used as a primary and secondary prevention strategy in clinical settings for early screening of at risk women through the identification of pre-existing symptoms, which may be overlooked in women who present with no current symptoms.

Declaration

I, Julie Marie Tucker, certify that this work contains no material, which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary setting. In addition, to the best of my knowledge and beliefs, contains no material previously published or written by another person except where due reference has been made in the text.

In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary setting without prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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I also give permission for the digital version of my thesis to be made available on the web, via the university's digital repository, the Library search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

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Julie Tucker Date 03/08/2020

Published literature and conference presentations during the course of this thesis

Published literature

Tucker J., Steen M., Edwards S., Clifton V. L. and Murphy E. M. A., Development and validation of a tool to identify anal incontinence in women of reproductive age: Mixed method research (in preparation for submission).

Tucker, J., Murphy, E. M. A., Steen, M. and Clifton, V. L. (2019). Understanding what impacts on disclosing anal incontinence for women when comparing bowels screening tools: A phenomenological study. *BMC Women's Health*, 19(1):142-50. https://doi.org/10.1186/s12905-019-0840-0.

Tucker J., Grzeskowiak, L., Murphy, E. M. A., Wilson, A. and Clifton, V. L. (2016). Do women of reproductive age presenting with pelvic floor dysfunction have undisclosed anal incontinence: A retrospective cohort study. *Women Birth*, 30(1):18-22, http://dx.doi.org/10.1016/j.wombi.2016.05.009.

Tucker, J. (2016). Improving communication around anal incontinence. *ANMF*, July, 24(1).

Tucker, J. (2014). Anal incontinence following Obstetric anal sphincter injury. *Australian Midwifery News*, Spring.

Invited & plenary conference presentations

Tucker, J. (2019) Bowel screening tools for women of reproductive age. [Invited Speaker] South Australian Continence conference Adelaide, Stanford Plaza North Tce. Adelaide South Australia, Australia, May.

Tucker, J. (2017). Nursing and Midwifery research (PhD progress research): development of a screening tool to identify anal incontinence in women of reproductive age. [Invited Speaker] Northern Allied Local Health Network (NALHN) Research Day. November.

Tucker J., Grzeskowiak L., Murphy E. M. A., Wilson A., and Clifton V. L. (2017). Retrospective review of anal incontinence in women of reproductive age. [Podium Presentation]. South Australian Health Research Day, University of South Australia, May.

Tucker, J. (2016). Identification of anal incontinence in women of reproductive age through active screening. [Plenary presentation] Perinatal Society Australian and New Zealand Conference, Townsville, Queensland, April.

Tucker, J (2015). Are we overlooking the importance of early identification of anal incontinence? [Plenary Presentation]. 24th National Conference On Incontinence, Melbourne, Australia.

Oral and poster conference presentations

Tucker, J., Murphy, E. M. A. & Clifton, V. L. (2019). Identifying anal incontinence in women of reproductive age in an antenatal and community setting (Oral Poster). Perinatal Society Australian and New Zealand Conference, Gold Coast Convention Centre, Gold Coast, Queensland, Australia, March.

Tucker, J., Murphy, E. M. A, Steen, M. & Clifton, V. L. (2019). Are we asking the right questions to identify anal incontinence in women of reproductive age? (Poster). Perinatal Society Australian and

New Zealand Conference, Gold Coast Convention Centre, Gold Coast, Queensland, Australia, March.

Tucker, J., Murphy, E. M. A. & Clifton, V. L. (2018). Anal incontinence in women of reproductive age in an antenatal and community setting (Oral Poster). National Conference on Incontinence, Hobart, Australia, October.

Tucker, J., Murphy, E. M. A., Steen, M. & Clifton, V. L. (2018). Disclosing anal incontinence in women of reproductive age in an antenatal setting [Oral Poster]. National Conference on Incontinence, Hobart, Australia, October.

Tucker, J. (2017). Contributor to Wounds Heath Innovations Australia teaching module perineal wound care in obstetric women [Online Module].

Tucker, J. (2015). Australian College of Midwives Webinar: anal incontinence following Obstetric Anal Sphincter Injury (OASIS) webcast, 5 August 2015.

Tucker, J. (2014). Screening women for incontinence [Oral Presentation]. Women and Children's Division of the Lyell McEwin Hospital, South Australia, Australia, 10 October 2014.

Tucker, J. (2014). Routine screening for anal incontinence [Poster]. Robinson Research Institute Symposium, University of Adelaide, South Australia, November.

Tucker, J., Wilson, A. and Clifton, V. L. (2014). Does routine screening of pregnant and postnatal women identify anal incontinence? [Poster Presentation - awarded best poster]. 23rd National Conference on Incontinence, Cairns, Australia, September.

Tucker, J., Wilson, A. and Clifton, V. L. (2013). Anal incontinence - who cares? [Poster Presentation - awarded best poster]. 22nd National Conference on Incontinence, Perth, Australia, October.

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My family were pivotal in the completion of my PhD. In six years, they have learnt so much about their bodily functions and am glad that I have now finished my research! I cannot thank you enough for your patience with reading, IT skills and support. I have grown as a person and learnt amazing skills from you all. It is not often in life that you humbly accept your children's ruthless grammar checking of your thesis. Thank you!

I dedicate this thesis to all the women who took part in its development, my colleagues who supported my journey, and most of all, my family (including Nigel) - without you I would not have made it.

Motivation and aims of this thesis

The control of faeces occurs for many at a young age and until that control is challenged through genetic cause, medical and surgical injury, trauma, health concerns and ageing, we take continence for granted and do not consider the effects of bowel incontinence. The inability to hold liquid and solid faeces and flatus has a debilitating effect on every facet of a person's wellbeing. It is not only a complaint of the elderly; it is evident across the lifespan. Aptly named the last taboo, anal incontinence (AI) is often only discussed with humour as this avoids any serious disclosure. Conversation around any bodily functions, especially excreta, often cause great distress and shame. Therefore, do we actually know the true prevalence of this debilitating condition? There is a lower reporting of AI compared to urinary incontinence; however, this is questionable, as both symptoms often coexist and occur in a young population, especially in pregnancy and childbirth, which are known risk factors for AI and urinary incontinence.

Twenty years of research has identified that women of reproductive age report flatus incontinence and rectal urgency, with these symptoms worsening with subsequent birth and ageing. There is variable reporting of the prevalence of AI and urinary incontinence in pregnant and postnatal women (between 1.7% and 65%), with limited screening of this at-risk group. Further, the screening tools for bowel incontinence often include a wide variety and different weighting of symptoms. As a result, these tools often under-represent the two most common symptoms reported by women - incontinence and rectal urgency.

The physical implications of AI are not the only factor to impact on a person's wellbeing. Research has identified the immense social impact of AI results in women isolating themselves from their family, friends and partners because of this devastating complaint. Women further retreat from their working environment, which increases the financial burden on their lives. The social mores surrounding AI keep this condition hidden. Health providers are in a unique position to enquire about a topic that is typically regarded as taboo; however, there appears a lack of enquiry by health professionals and this contributes to worsening mental health, isolation and financial hardship. The ramifications are not solely for the woman and her family but the burden impacts on the wider community and reliance on the health purse to manage the physical, financial and psychological impact. In effect, the wider community is significantly impacted.

Anecdotally, my clinical practice has shown that there is a lack of routine screening in obstetrics and gynaecology of young women unless presenting to a speciality clinic for treatment of AI or bowel concerns. Additionally, there is no current screening tool developed specifically for AI that is routinely used in pregnant and postnatal women. To reduce the physical, social, financial and psychological impact of this condition for women in the short and long term it would make good clinical reasoning to develop a tool, which could screen women. Screening with a specific tool during pregnancy and postnatally would allow for better assessment, care and management of women in the short term, and would also improve their long-term health. The early identification of incontinence and referral to specialist perineal clinics allows for a thorough review of birth plans to modify the factors that may increase the risk of demise to the pelvic floor.

The overarching aim of this thesis is the development and validation of a bowel-screening tool for the use in women of reproductive age. The development and validation of a specific bowel-screening tool for this group of women requires an understanding of what factors impact on disclosing AI. The identification of these issues may assist in providing a tool, which will show the true prevalence of this condition. This provides the basis to investigate our research hypothesis that improved screening tools for AI are required for this group of women for the early detection and intervention of the condition. A review of the literature is first required to gain an understanding of the current prevalence of AI, its impact on quality of life, and current screening tools used for this group of women.

Three specific aims were identified to investigate and develop a screening tool:

1. To determine whether routine screening of pregnant and postnatal women for anal incontinence utilising a modified St Marks Vaizey incontinence score (Vaizey score) improves identification of anal incontinence.

2. To identify and analyse the factors that impact on women of reproductive age disclosing anal incontinence to their health care providers.

3. To develop and validate a screening tool for anal incontinence in women of reproductive age.

These aims provide a stepwise process in confirming the development and validation of a specific tool to screen for AI. The nature of the mixed method research identifies that the aims are not separate but integral to each other.

Chapter Outlines

Chapter 1 provides a review of the literature and a discussion on the background, rationale, purpose and significance of this thesis. The literature review highlights a focus on the causation of anal incontinence but a lack of healt literature, which focuses on routine screening for anal incontinence in women of reproductive age. Paucity within the literature provides the impetus for which this research is based and development of the research study question and aims.

Chapters 2 describes the chosen methodology, materials and methods, which underpins the mixed method research study. Justification of the chosen methodology in stages 1 to 5 of the research is given.

Chapter 3 investigates whether women of reproductive age presenting with pelvic floor dysfunction have undisclosed anal incontinence. Retrospective research methods were adopted to identify if anal incontinence was ifentified at primary point of referral or after screening by the specialty service for pelvic floor dysfunction for women referred from obstetric care. The speciality service currently uses a generic bowel-screening tool (Vaizey score), which is utilised predominately in research settings, to actively screen women via phone consultations. A specifically designed data extraction sheet was utilised to identify anal incontinence and demographic details were also collected.

Chapter 3 is published as: Tucker, J., Grzeskowiak, L., Murphy, E.M.A., Wilson, A. & Clifton, V. L. (2016). Do women of reproductive age presenting with pelvic floor dysfunction have undisclosed anal incontinence: a retrospective cohort study. *Women Birth*, 30(1):18-22, http://dx.doi.org/10.1016/j.wombi.2016.05.009.

Chapter 4 highlights the paucity of screening tools available to identify anal incontinence in women of reproductive age. Accordingly, this chapter shifts the focus of the research to the development and validation of an effective bowel-screening tool (BSQ) in a pregnant population. The newly developed BSQ uses two screening tools (Vaizey and Wexner scores) in conjunction with an antenatal visit at a large tertiary centre. The findings of this research allow for a comparison of symptoms between the tools, and further validation of the BSQ. The chapter concludes with recommendations for further development of the screening tool.

Chapter 4 is under submission as: Tucker, J., Steen, M., Edwards, S., Clifton, V.L. & Murphy, E. M. A. Development and validation of a tool to identify anal incontinence in women of reproductive age: mixed method research. *Obstetrics and Gynaecology* (in submission, July 2020).

Chapter 5 identifies the importance of investigating possible causes of disparity between bowel screening tools, and is directly aligned with the second aim of this thesis. Qualitative methods are used to provide

insight into the barriers for disclosing anal incontinence in the pregnant and post-natal population. The findings assist in refining the research bowel-screening tool developed in Chapter 4 (stage 3 of the research). Chapter 5 presents a discussion on the Hermeneutic phenomenology framework that guides this research, and the study design, in order to answer the research question "*what factors impact on disclosure of anal incontinence in women of reproductive age?*". Ethical considerations, and the rationale for sample selection and recruitment strategies is also discussed. Van manen's procedural framework guides data collection, analysis and interpretation. Discussion of methodological trustworthiness and credibility enables validation of the findings and interpretations of this study.

Chapter 5 is published as: Tucker, J., Murphy, E. M. A., Steen, M. & Clifton, V. L. (2019). Understanding what impacts on disclosing anal incontinence for women when comparing bowels screening tools: a phenomenological study. *BMC Women's Health*, 19(1):142-50. https://doi.org/10.1186/s12905-019-0840-0.

Chapter 6 describes the use of a newly developed bowel-screening questionnaire (BSQ) to identify anal incontinence in a pregnant population attending their first antenatal booking at a large tertiary centre. Subsequent stages of the research describe utilisation of the BSQ in a community dwelling population. Findings from this research support the hypothesis that routine screening with a specific screening tool can effectively identify AI in pregnant and non- pregnant women. The results highlight the importance of recognizing the variability of symptoms of AI as evidence of probable existing pelvic floor demise in pregnancy and provides a basis for further research with the BSQ.

Chapter 7 concludes this thesis with a discussion of the key findings and an outline of recommendations for future research and clinical practice.

Chapter 1

Literature Review

Literature Review

1.1 BOWEL CONTINENCE - INTRODUCTION

The pelvic floor maintains pelvic floor support, anal and urinary continence through the interplay of muscles, connective tissue and nerve pathways[1](Fig. 1A & B). The rectum terminates in the anal canal. Within the ischioanal fossae the anus is surrounded by loose adipose tissue both laterally and posteriorly, and the pudendal nerves pass over the ischial spines[2-4]. The perineal body separates the anal canal from the vagina anteriorly[2-4]. The anal canal consists of a inner epithelial lining, a vascular sub-epithelium (internal anal sphincter), and fibromuscular supporting tissue (external anal sphincter)[2]. The lining of the anal canal varies along its length the proximal end is lined with rectal mucosa (columnar epithelium) called the columns of Morgagni and contains a terminal radical of the superior rectal artery and vein. The wall of the anal canal contains the sub-epithelial tissues (known as anal cushions) which seal the anal canal and help maintain continence of liquid stools and flatus[2-4]. The area in the lower canal is supplied with sensory nerve endings and the upper canal lined by insensate columnar epithelium. The junction between the columnar and squamous epithelia is referred to as the anal transitional zone, which provides a sampling mechanism[2-4]. The anal sphincter complex is approximately 3-4 cm in length comprised of two types of muscle fibre, each responsible for specific bowel control[2](Fig.1.1). The internal anal sphincter is a continuation of the circular smooth muscle of the rectum[3]. Its role is to sample contents in the rectum and importantly contributes to approximately 75% of anal resting tone[2, 3]. The external anal sphincter (EAS) is comprised of striated muscle wrapped around the internal sphincter (IAS) and consists of a subcutaneous, superficial and deep layers[3]. The external anal sphincter is responsible for 25% of anal resting tone, and can increase in pressure under voluntary control to 60% of sphincter tone[3, 4]. Anal rest and squeeze pressures vary throughout the anal canal with rest pressures in women averaging

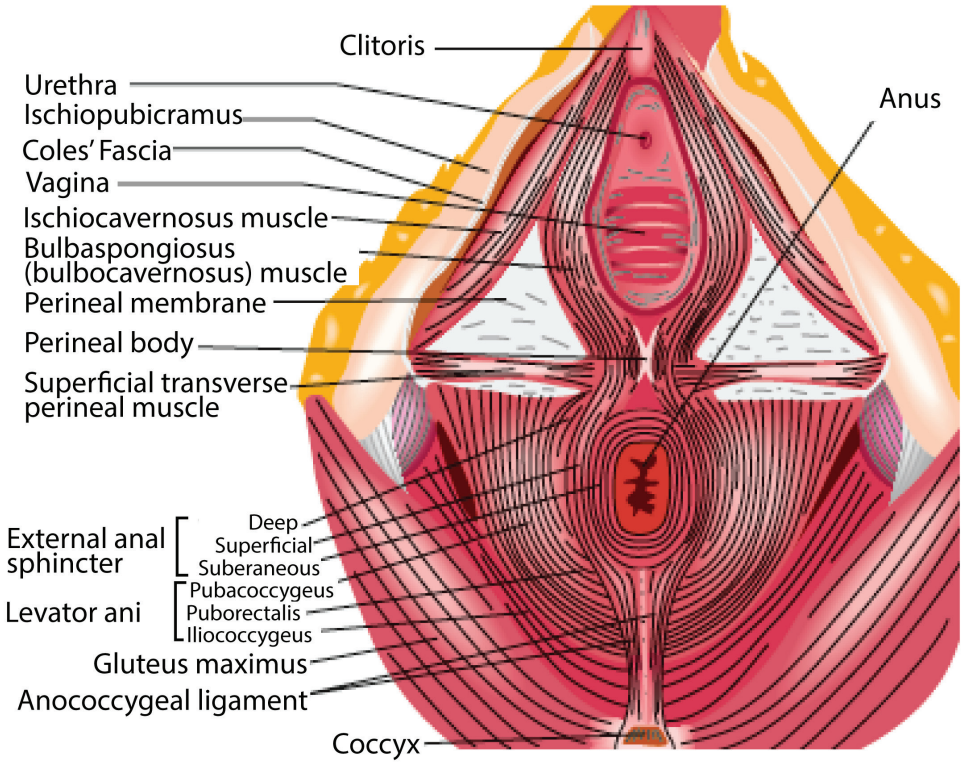

Figure 1A. Posterior view of the pelvic floor. Reprinted with permission from Springer Nature: Anatomy of the Perineum and the Anal Sphincter by Ranee Thakar and Dee E. Fenner. In: Perineal and anal sphincter trauma diagnosis and clinical management by Abdul H. Sultan, Ranee Thakar and Dee E. Fenner (editors) (2009).

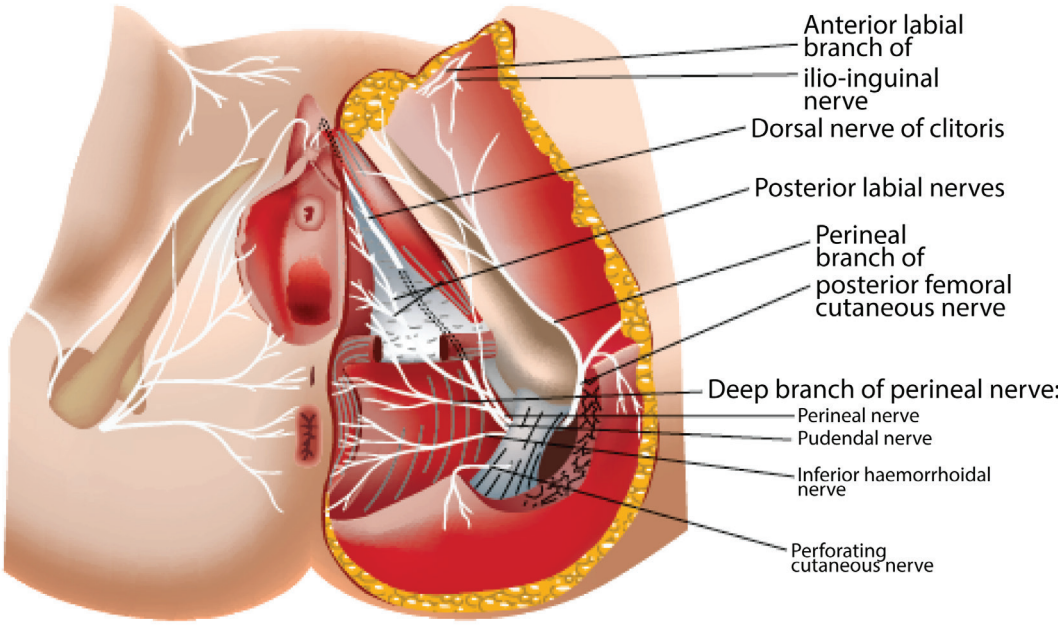

Figure 1B. Innervation of the pelvic floor. Reprinted with permission from Springer Nature: Anatomy of the Perineum and the Anal Sphincter by Ranee Thakar and Dee E. Fenner. In: Perineal and anal sphincter trauma diagnosis and clinical management by Abdul H. Sultan, Ranee Thakar and Dee E. Fenner (editors) (2009).

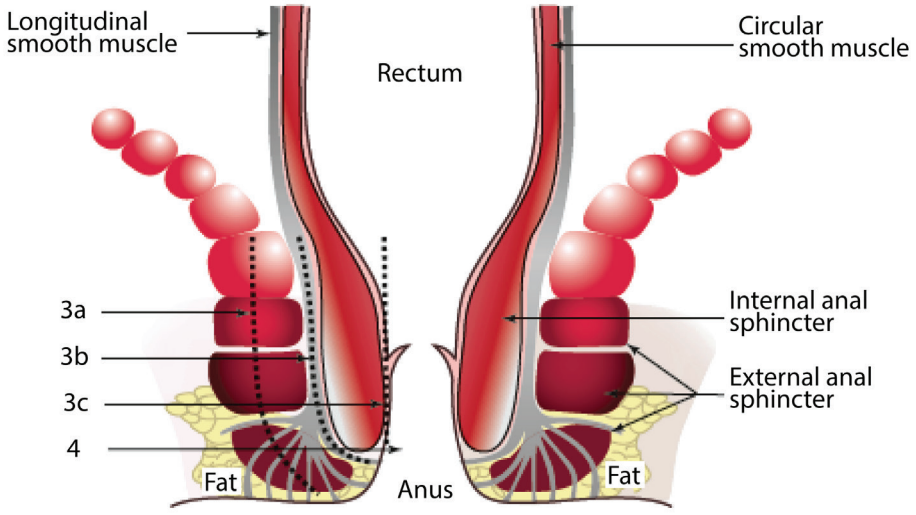

Figure 1.1. Schematic view of anal sphincter muscles. Reprinted with permission from Springer Nature: Anatomy of the Perineum and the Anal Sphincter by Ranee Thakar and Dee E. Fenner. In: Perineal and anal sphincter trauma diagnosis and clinical management by Abdul H. Sultan, Ranee Thakar and Dee E. Fenner (editors) (2009).

50 ± 13 mm Hg and squeeze pressures 159 ± 45 mm Hg[3]. Rest pressures higher in IAS compared to EAS with squeeze pressures higher in the EAS[3]. This can be altered due to mechanical and neuropathic changes to the muscles[2-4]. The sustainability of this action is shorter and notably the rest and squeeze pressures reduce with ageing. The puborectalis muscle forms a "u" shape from the pubic bone to the rectum and contraction of levator ani has a pivotal role in maintaining anal continence and controlling defecation[2, 5]. Rectal compliance is achieved through the action of muscles and nerve pathways until sensory stretch receptors signal rectal fullness[2]. This causes the IAS to initiate relaxation and the sampling process of faecal contents by sensory receptors[2]. The EAS and puborectalis muscles remain contracted to maintain continence until a place and time to evacuate the bowel is socially convenient[2]. The disruption to these muscles and nerves results in anal incontinence (AI) which is the involuntary loss of liquid, solid stool, flatus and rectal urgency[6]. Specific types of symptoms can identify muscle or nerve dysfunction, such as internal anal sphincter injury resulting in flatus incontinence and passive soling whereas external sphincter damage is associated with rectal urge or urgency[2].

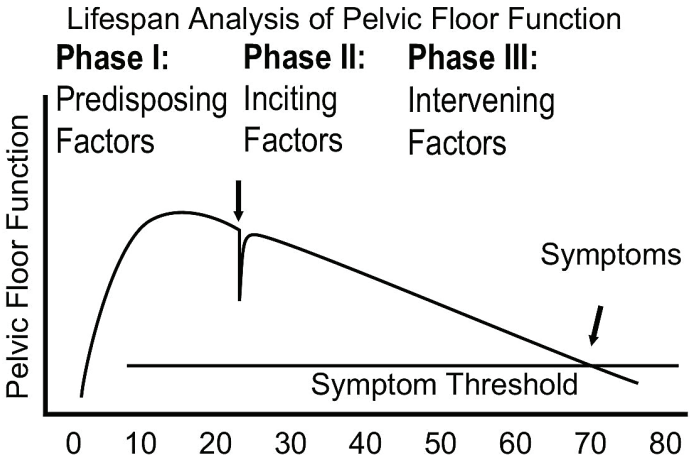

Figure 1.2. Integrated lifespan analysis of pelvic floor function. Reprinted from Am. J. Obstet. Gynecol. 2008 December; 199(6), De Lancey J, Low L, Miller J, Patel D, Tumbarello J., Graphic integration of causal factors of pelvic floor disorders: an integrated lifespan model, 7 (2009), with permission from Elsevier.

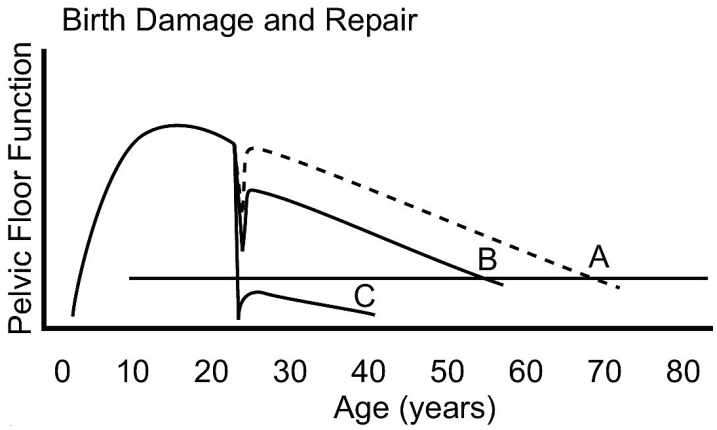

Figure 1.3. Variations of birth damage and repair across the lifespan. Reprinted from Am. J. Obstet. Gynecol. 2008 December; 199(6), De Lancey J, Low L, Miller J, Patel D, Tumbarello J., Graphic integration of causal factors of pelvic floor disorders: an integrated lifespan model, 9 (2009), with permission from Elsevier.

Deterioration of anorectal function and resultant AI is multifactorial however ageing is an important factor[2]. Understanding the causative influences which determine normal decline of the pelvic floor function across the lifespan improves the assessment, treatment and prevention of factors which negatively impact on pelvic floor reserve[1]. DeLancey and colleagues developed a lifespan model for women which identified the complexity of causation for pelvic floor dysfunction (PFD; Fig.1.2)[1]. This conceptual model described three phases including the predisposing, inciting and intervening phases that effect a woman's pelvic floor function, in this instance, bowel continence across her lifespan[1]. Early growth, genetic code, nutrition and physical development as a child determine pelvic floor function of a woman later in life[1]. For example, predisposing issues such as a collagen deficiency have been shown to contribute to weakening of the pelvic floor in women with no pregnancies or births (nulliparous) contributing to PFD[7, 8]. A large prospective study supported this view, where 874 nulliparous women were screened for PFD and AI with reported outcomes for PFD and or AI in 49% (n = 425) of women prior to pregnancy, compared to 57% (n = 429) post birth[7]. These findings were similar to a Chinese study which reported AI in 44% of nulliparous women in the first trimester, in 41.8% eight weeks postnatal and in 26.2% of women at 12 months postnatal[9]. Both studies suggested AI was multifactorial with predisposing factors prior to the first birth a precursor for further worsening symptoms in subsequent births.

De Lancey and Colleagues referred to this as the predisposing phase where" maximum capability" or "functional reserve" of the pelvic floor is achieved and continence maintained[1]. There are multiple causative factors associated with the inciting phase with pregnancy and childbirth noted as major risk factors for damage to pelvic floor structures[1]. A woman with optimal "functional reserve" may present with no symptoms conversely a woman with predisposing risk may have less "functional reserve" and this increased risk of incontinence following childbirth or even earlier across her lifespan[1, 10]. Birth damage and recovery detailed in figure 1.3, identified a woman with less "functional reserve" as "C" and a woman with maximum capability "A" where her rate of decline in pelvic floor function and risk of AI is less.The third stage the intervening phase influenced the rate of pelvic floor demise and varied according to co-morbidities, lifestyle and obesity[1, 11]. The three phases influenced pelvic floor structures differently and influence the potential onset of incontinence.

Table 1.1. Common aetiology of anal incontinence. ^OASIS (obstetric anal sphincter injury), †RMLE (right medial lateral episiotomy).

Mechanical	Neurological	Congenital	Inflammatory	Miscellaneous
1. Anal sphincter **Trauma:** OASIS^, RMLE†, forceps **Surgical:** haemorrhoidectomy, Sphincterotomy, anal fistula surgery, Dilation, Stretching injury **Direct trauma:** 2. Rectal prolapse 3. Neoplasms - rectal, brain, spinal 4. Chronic constipation 5. Impaction	1. Multiple sclerosis 2. Parkinson's disease 3. Spinal cord injury 4. Alzheimer's 5. Dementia 6. Cerebro-vascular accidents, 7. Brain or spinal injury	1. Congenital anomaly 2. Spinal Bifida 3. Sacral agenesis 4. Myelomeningocele 5. Imperforate anus	1. Pelvic radiation and radiation enteritis, 2. Inflammatory bowel disease	1. Collagen deficiency, 2. Ageing 3. Fragility and dependence 4. Poor cognition and dexterity 5. Poor toilet facilities 6. socialisation 7. Medications 8. Idiopathic 9. Obesity

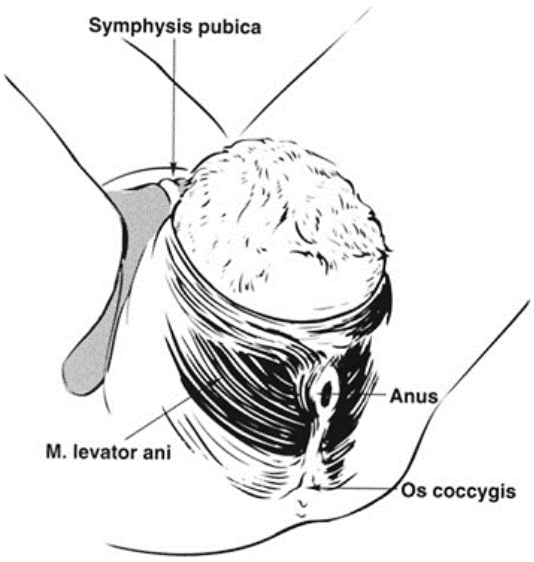

Figure 1.4. Pelvic floor distension late second stage of birth. Adapted and reprinted with permission from Springer–Verlag London Ltd., The effects of pregnancy and childbirth on the pelvic floor by Baessler K and Schussler B. In: Pelvic Floor Re-education, principles and practice by Baessler K, Schussler B, Laycock J, Norton P and Stanton S (editors) (1994).

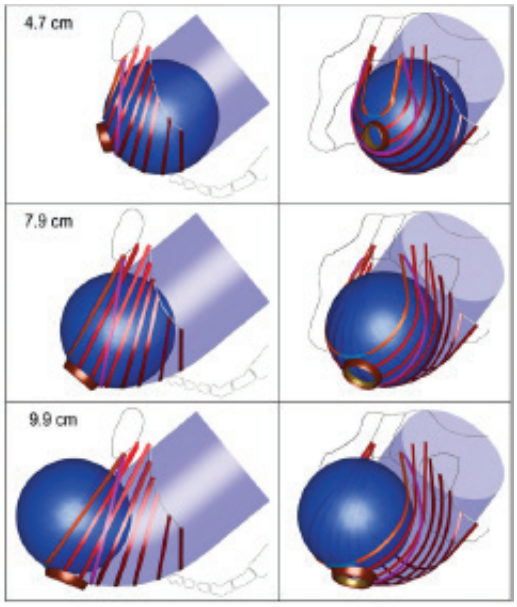

Fig. 1.5. A simulation of the head descending the pelvic floor during the second stage of labour. The top left photo shows the commencement of pushing; the bottom images show delivery. Adapted and reprinted with permission from Annual Reviews, Inc. provided by Copyright Clearance Centre from Annals of Biomedical Engineering. 2009 (11):163-76, Ashton-Miller J, DeLancey J. On the Biomechanics of Vaginal Birth and Common Sequelae, 291(2009).

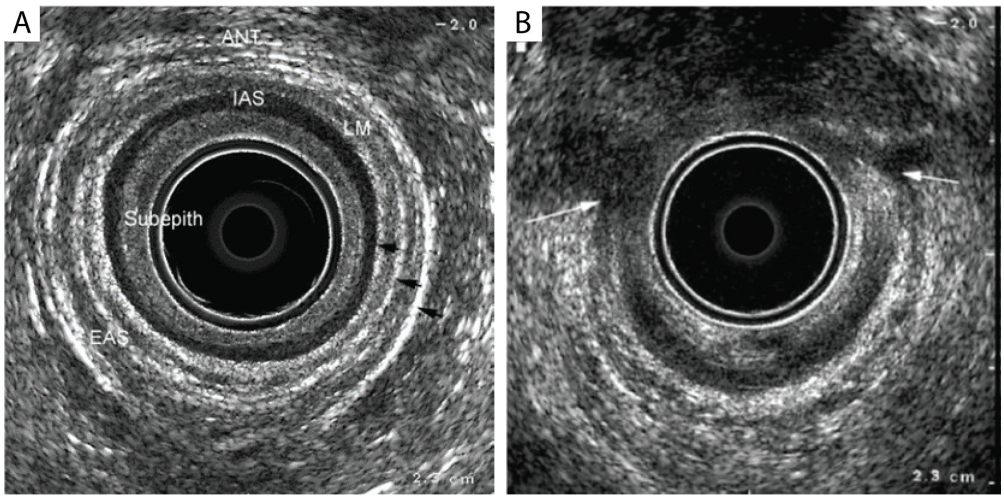

Figure 1.6. Endo anal ultrasound view of anal sphincter muscles. EAS (external anal sphincter) and IAS internal anal sphincter. (A) Normal sphincter; (B) Defect in both IAS and EAS, 9 to 2 o'clock. Reprinted with permission from Springer Nature. Imaging of the anal sphincter by Bartram C and Sultan A. H. In: Perineal and anal sphincter trauma diagnosis and clinical management by Abdul H. Sultan, Ranee Thakar and Dee E. Fenner (editors) (2009).

1.2 AETIOLOGY OF ANAL INCONTINENCE

Research literature identified the aetiology of AI as complex with persons afflicted often having a combination of causative factors (Table 1.1)[6, 12-14]. For women, hormonal changes in pregnancy and childbirth trauma are the main risk factors for PFD, which is a term used to describe symptoms of urinary or faecal incontinence, rectal and pelvic floor prolapse[15-17]. Changes to pelvic floor supports and structures in pregnancy, childbirth and ageing can pre-empt PFD symptoms with as many as 91% of women noting abnormal bowel function, including AI after delivery[18, 19]. During pregnancy and childbirth, the hormonal influence on maternal structures softens and elongates muscles and, ligaments to accommodate the growing foetus, and over distension of the pelvic floor muscles to assist in the birth of the baby (Fig. 1.4)[19-21]. The pelvic floor muscles can stretch 2 to 3 times their length, when noting maximal stretch tolerated by non-pregnant animal muscle tissue is only 1.5 times (Fig.1.5)[22, 23]. The over distension, compression and trauma to the anal sphincters, levator muscles and nerves leads to permanent scarring and injury resulting in neuropathy and risk of AI[19, 20].

1.2.1 Types of trauma

Obstetric anal sphincter injury

Trauma to the anal sphincter is cited as a major cause of AI in women of childbearing age resulting in two thirds of women being symptomatic for loss of solid or liquid stool, flatus incontinence and rectal urgency[1, 15, 24]. Disruption to the anal sphincter; obstetric anal sphincter injury (OASIS; Fig. 1.6) can be a result of direct or indirect trauma, with increased risk of PFD[7, 20, 25, 26]. Figure 1.6 represents a 3D endo-anal ultrasound image of the anal sphincters. Picture 'A' shows an intact IAS and EAS whereas picture 'B' identifies a defect in both sphincters between nine and two o'clock. This may result in incontinence in the short-term and worsening function with increased age.

Various risk factors are associated with OASIS many of which many can coexist at the birth[27]. Risk factors include parity[27-29], instrumental birth[30, 31], episiotomy[4, 17, 32, 33], maternal age[26, 34], ethnicity[35, 36], fetal macrosomia[30, 37, 38], and prolonged second stage for >1 hour[15, 39, 40].

Nulliparous woman are at increased risk of sphincter damage (4%) where the second stage of labour is greater than 1 hour (4%), or with an instrumental birth particularly with forceps (7%), or induction of labour (2%) and with a posterior position of the baby in the uterus (2%)[33, 38]. Longer labour are associated with women's request for epidural analgesia, and whilst not directly related to OASIS, this form of analgesia can slow the progress of labour and increase the risk of intervention and subsequent trauma to the sphincter (2%)[38]. This was consistent with a prospective cohort study of primaparous women which identified the association between OASIS, epidural anaesthesia (58%) and prolonged second stage[41]. An additional study by Simpson et al.[28] concurred with these findings and identified the coexistence of risk factors with the induction of labour, longer second stage, instrumental birth, epidural and episiotomy and thus increased risk of OASIS[28]. Smith et al.[42] observational study of 2,754 singleton vaginal births confirmed the high prevalence of OASIS with forceps delivery, longer second stage greater than one hour, and higher birthweight. Additionally, a retrospective review of perinatal data in an Australian study between 2001 and 2009 reinforced that the strongest risk factors for OASIS include primaparity, instrumental delivery, larger birthweight and Asian ethnicity[34]. The reported rate of OASIS in this study and association with episiotomy and forceps was lower when compared to other studies, which identified episiotomy as a significant risk factor for OASIS[15, 27, 34]. The authors suggested this was a result of improved training with placement and cutting of the episiotomy[34]. The rates of episiotomy differ worldwide and are often attributed to obstetric practices governing the medical centre[15, 33]. A systematic review identified avoidance of episiotomies in clinical practice reduced rates of OASIS[43]. On the other hand, there is considerable discussion within the literature that the rate of OASIS is dependent on the type and angles of episiotomy (midline versus medio lateral episiotomy)[44]. Kalis et al.[44] suggested the angle of episiotomy from the midline of the perineum and selective use of episiotomy was a determinant in reducing OASIS. These findings were consistent with a randomised controlled trial, which recommended that selective use of episiotomy might reduce OASIS. The second Australian Atlas of Healthcare[33] suggested increased rates of OASIS may be due to episiotomy rates and technique. This was consistent with Peleg et al.[45] reported that OASIS occurred in 2.1% of women where no episiotomy was preformed, in 11% with a midline episiotomy and in 21% of women with midline episiotomy and instrumental delivery[45]. Rates were lower in health settings which only utilised medio lateral episiotomy and reported (4.4%) compared to centres utilising midline episiotomy (11%) [45, 46].

Asian ethnicity was stated to be related to an increased risk of OASIS due to a woman's short stature and a perineal length less than 2.5 cm[15]. Deering et al.[47] compared the perineal length of 234 women prior to delivery and delivery outcomes. The findings suggested women with perineal length less than 2.5 cm had a significant risk of OASIS[47]. However, the relationship of perineal trauma and ethnicity remained unclear within the literature. Concerns the findings were not representative of Asian cultures and that additional factors may be attributable to perineal trauma other than perineal length[36, 48]. A systematic review of the literature undertaken on research published from 2000 to 2010 assessed if Asian ethnicity was a risk factor for OASIS and found evidence that cultural and social expectation, including language barriers may increase the risk of PFD and trauma[48-50]. The latter issue is vitally important and therefore needs consideration when screening all women for AI.

It is difficult to determine the true prevalence rates of recognised (direct) OASIS both in international or local settings with reported rates between 1.7% and 12%[4, 15, 33, 38, 51]. The advent of endo anal ultrasound (EAUS) in screening for OASIS has increased the reporting from 20% to 41% of women[4]. It is evident within Australia that further variation in reporting direct OASIS occurred across states and territories and within health institutions[33, 52, 53]. A review of eighteen maternal hospitals in South Australia, between 2002 to 2008 identified a wide variation in reporting which was attributed to poor recognition at birth and inadequate data collection methods[52]. Additional research conducted in 13,455 Australian women in New South Wales found rates of OASIS 1.7% to 1.9% in singleton births between 2001 and 2009[34]. The trend and variation in reporting direct OASIS was not unique to Australia but seen across the world. The United Kingdom reported a threefold increase (1.8% to 5.9%) over a decade[33]. However Australia had an above average rate of OASIS (2.4% to 7.3%) when compared to countries in the Organisation for Economic Co-Operation and Development (1.6% to 6.0%; OECD)[33]. The evidence highlighted that

the true prevalence of OASIS was unclear and thus the accurate prevalence of AI remained unknown[34].

Fear of a subsequent OASIS and AI, or worsening symptoms, remains the main concerns for birthing women[4, 54-56]. A systematic review by Dudding et al.[15] identified the risk of recurring OASIS was seven times greater in a woman with a previous history of OASIS compared to women with no history. Sultan et al.[4] recognised the repeated risk at 4.4% however this was influenced through the interplay of the risk factors as stated above. A study of 704 women with previous OASIS reported the risk of another OASIS as 2.1% (no episiotomy), 11% (midline episiotomy) and 21% (midline episiotomy and instrumental delivery)[45].

Levator muscle trauma

Levator muscles (LAM) contribute to the support and strength of the pelvic floor[20]. Trauma is associated with pelvic organ prolapse, urine incontinence (UI) and AI, however; it is often-unrecognised following vaginal delivery[20, 57]. This remains a concern as practice as early as the 1940's reported the importance of accurate assessment, management of PFD and provided preventative strategies to reduce LAM, yet this has not been adopted widely by health providers[20, 57]. This is a result of lack of awareness of the role of the LAM in pelvic support and care is fragmented, where women are seen by a single speciality[58, 59]. This is concerning as often UI and AI coexist[59].

Importantly, OASIS and LAM share similar risk factors and are associated with an increased risk of AI[60]. The significant relationship between this type of trauma and vaginal childbirth, episiotomy, perineal tears and length of second stage was demonstrated in a study of 513 women after their first baby[57]. This was consistent with other studies which reported trauma and vaginal delivery (21%), episiotomy (3.1%), forceps (14.7%), epidural (0.9%) , epidural and induction with oxytocin (0.8% to 0.9%)[61, 62]. The rate of LAM following first vaginal delivery (10% to 30%) tripled with age, and increased the risk of PFD[20, 63].

Neuropathy

The innervation of the IAS is from the lumbar (L5) and sacral (S2-S4) nerve roots and the inferior rectal branch of the pudendal nerve is responsible for innervating the EAS to enable rectal compliance to be maintained[4]. The LAM are innervated by the levator ani nerve, which originates in females in the S3-S5 sacral nerve roots[4].

The pudendal nerve is a mixed motor and sensory nerve where mechanical and neuropathic disturbances following birth can be associated neuropathy resulting in vaginal numbness or absent sensation to defecate resulting in AI[3]. The anal mucosa is also highly innervated and sensitive to touch, pain, temperature, and movement and stretch injury or direct trauma during pregnancy and childbirth increases the risk of neuropathy[3-6].

Risk factors for neuropathy are similar to OASIS or LAM. The prolonged second stage of labour, instrumental delivery and delivery of macrosomia babies associated with the greatest risk of denervation to the pelvic floor and resultant neuropathy[64, 65]. The pudendal nerves inability to stretch in labour increases the risk of denervation and resultant AI[66]. This was consistent with several studies. Zetterstrom et al.[67] whom reported nerve damage in 19% of women with OASIS but asymptomatic of AI, compared to 43% of symptomatic women with occult OASIS showing no nerve injury[67]. Snooks et al.[66] identified that occult denervation of the EAS in 33% of women, subsequently worsened over a 5 year timeframe the risk of UI and or AI and increased and reported in 58% of women with neuropathy. Whilst pudendal neuropathy was reported to improve in 60% of women by 6 months postnatal, the effects of further compounding injury and ageing may impact their continence status and thus screening for symptoms is paramount[68].

Occult injury

Thorough assessment and identification of pelvic floor trauma is critical, as clinically insignificant tears or undiagnosed anal sphincter injury (occult injury) results in underreporting. One study utilising EAUS in primaparous women before and after the first birth identified 33% occult injury[69]. Rieger et al.[71] utilised anal manometry and anal ultrasound in 53 primiparous women and identified vaginal birth adversely affected anal function in women with and without known OASIS. The advent of EAUS technology has increased the reporting of occult tears (20% to 41%)[70, 71]. It is questionable if the rate of reporting direct OASIS has been historically accurate as Sultan et al.[4] identified improved training in the assessment of perineal trauma, increased the accuracy in reporting at primary repair. This was apparent in two prospective studies where two clinicians, the second a more experienced clinician reviewed the perineal tears following women having their first birth[70, 72]. Both studies utilised EAUS to assess sphincter integrity postpartum, Andrews et al.[70] found an increase in OASIS detection rate from 11% to 25% of deliveries with a more experienced clinician. Whereas Groom et al.[72] found that 15% of small perineal tears were identified as OASIS when re-examined. Importantly many women who sustain either direct or indirect pelvic floor damage and maintain effective pelvic floor reserve may remain asymptomatic until later in life, therefore early recognition of trauma is paramount for future care and management[1, 19, 23, 73].

1.3 PREVALENCE OF ANAL INCONTINENCE IN AUSTRALIA

AI is common within the general community and not only restricted to the elderly in aged care facilities. In the Australian population, more than one million people reported symptoms[74, 75]. A recent Australian report in 2010 into the trend of AI within the Australian residential care and community settings reported 1.34 million people[74]. The report identified a projected increase of AI by 2030 to 1,835,340 people, of which 1,122,749 will be women[74]. The prevalence of AI is greater when compared to other major diseases which include heart disease (1.1 million), psychological stress (1.8 million), and mild asthma (2.3 million)[76]. The prevalence of AI increases with age and it is a common precipitating factor for admission to residential aged care, AI is not isolated to the elderly but is reported widely across the Australian community[26, 77]. The reported rates of AI within the community varied between 1.5% to 50%, and reporting dependent on the study population, tools utilised in screening and how AI was defined[74, 78].

In the general Australian population several Australian studies reported the rate of AI between 6.9% to 20.7%[77, 79]. Ho et al.[77] assessed the severity and prevalence of faecal incontinence (excluded rectal urgency) in an outpatient department in northern Queensland. The research included a specifically designed bowel questionnaire, which was pretested but not validated. The questionnaire included a severity scale and terms such as accidental bowel leakage and soiling, however it was difficult to differentiate between types of stool loss. The study included 435 male and female outpatients; overall 20.7% reported AI with a higher prevalence of in women. The median age for this study was 53 years with a range of 41 to 66 years. As 60% of the sample were gynaecology patients, it was difficult to assess if PFD was a result of previous pregnancy or childbirth as no obstetric data was evident. Therefore the causation for AI may be presentive of ageing only[77]. An additional cross sectional study undertaken in New South Wales by Kalantar et al.[79], included 990 male and females who completed a validated self-administered questionnaire with dichotomous yes or no responses to assess rates of faecal incontinence. This research included solid, liquid stool and rectal urgency but excluded flatus and soiling. The overall prevalence rates of incontinence to solid stool (2%) and liquid stool (9%) appeared similar between men (10.8%) and women (11.6%)[79]. Kalantar et al.[79] cite consistency between their findings and other Australian population studies such as that by Lam et al.[80] which reported 15% of men and women with faecal incontinence. These rates were higher than other community studies reporting 2% to 7%, however Kalantar et al. surmised the definition of bowel loss and the methods employed in these studies may have contributed to the disparity in reporting[79].

The prevalence of AI is often dependent on the population type studied. Chiarelli et al.[26] study which

included high risk birthing women identified that at least one symptoms of AI in 32.4%. This was a large cohort of 568 women whom received an initial structured interview with a validated questionnaire followed by a telephone review at 12 months[26]. Unlike Ho et al.[77], Chiarelli included only women of reproductive age (15 to 44 years) and assessed all types of stool loss, flatus incontinence, rectal urgency and soiling[26]. The findings suggested an association of high-risk delivery, with PFD and reported rates of flatus incontinence (24.4%), rectal urgency (14.8%), soiling (10.9%), liquid stool (4.9%) and solid stool (2.6%)[26]. The rates of liquid and solid stool loss were lower when compared to a multicentre study across New Zealand and the United Kingdom (8.2%). However the reporting flatus incontinence (18.8%) where similar between all studies. MacArthur et al.[31] study identified an increase in the reporting of symptoms (42.7%, all symptoms) over a 12 year period and of interest, of the 3456 women with no symptoms at 3 months post birth, 10.3% reported faecal incontinence (FI) at 12 years[31].

Additional research identified the relationship of gender and ageing, as women aged 45 years and over when compared to similar aged men were at eight times greater risk of AI than women[14]. These findings support the consensus within the literature as to the relationship between AI and gender, vaginal delivery and ageing. The impact of ageing on pelvic floor functional reserve previously discussed highlighted by the higher reporting of incontinence in women within aged care facilities[1, 74].The impact of pregnancy and childbirth is demonstrated with a higher rate of reporting of AI in pregnancy, the postpartum period and with ageing. The reporting of AI in gynaecology outpatients (16% to 28%) is higher when compared to the general population (4.4%)[11, 81, 82].

1.3.1 Prevalence of anal incontinence in women of reproductive age

The reported number of Australian women of reproductive age with anal incontinence was estimated to be approximately 359,876 in 2010 in a report from Deloitte Access Economics commissioned by the Continence Foundation of Australia[74]. The deterioration of the pelvic floor reserve following childbirth and resultant OASIS, as previously mentioned are main causes of AI in one to two thirds of women[15, 26, 54]. The reported prevalence of AI varying between 6.9% and 61% for women with known trauma, and 25% of women with no reported OASIS injury[17, 23, 54, 83, 84].

The reported literature highlighted the variation in the prevalence of AI in late pregnancy as between 30% and 50%, with 16 to 49 % of women reporting AI in the post-partum period[81, 85, 86]. The variation in reporting appeared to be a result of the different reporting tools used and how bowel incontinence was defined either AI or FI[86, 87]. FI excluded rectal urgency and studies, which used this definition, reported lower rates of bowel incontinence compared to higher reporting when the definition of AI was utilised[86, 88]. Slavin et al.[88] utilised the definition FI in late pregnancy and identified solid stool loss (0%), liquid stool (2.1%) and flatus (5.9%). The overall prevalence of bowel loss is much lower than Johannsson et al. who included symptoms of rectal urgency (13%) an identified an overall incidence of AI in 42% of women in late pregnancy[86]. Rectal urgency is the most commonly reported symptom and indicates external anal sphincter disruption and often the only symptom present, signalling a compromised pelvic floor[17, 19, 73, 86, 87]. However, symptoms are variably reported because of physiological changes following birth where the pelvic floor returns to the pre-pregnant state and symptoms in some cases are thus resolved until later in life[86].

Passive faecal soiling is a common and challenging problem within the general community and whilst the exact prevalence remains unknown, it was reported in 7% and 23% of women attending a hospital centre[89]. Predisposing factors for passive soiling included obstetric injury, yet these symptoms were not captured in current screening tools[89].

The importance of screening for a history of AI in women of reproductive age is paramount given the relationship between first birth and AI[14]. The cumulative effect of subsequent vaginal birth, obstetric trauma and ageing may compound symptoms[1, 90, 91]. A prospective Norwegian study utilised a validated bowel-screening tool (St Mark's faecal incontinence score, Vaizey score) to assess AI in 862 primaparous women. The findings identified that 22% of women were symptomatic of AI late in pregnancy with 18%

of this group still symptomatic at 12 months postpartum[92]. The study did not breakdown symptom type and it is difficult to determine type and frequency of bowel concerns. Furthermore, passive soiling was not investigated with this tool.

AI was also reported over a 5 to 10 year timeframe by Evers et al.[93]. The prospective study included 937 first-time mothers with 10% of women reporting a history of OASIS and AI. Women completed multiple questionnaires (Epidemiology of Prolapse and Incontinence questionnaire (EPIQ) and Colorectal-Anal Impact Questionnaire (CRAIQ-7)). The EPIQ a complex tool with multiple questions that assessed all pelvic floor concerns whilst the CRAIQ assessed quality of life[93]. There was an association between OASIS and a negative impact on quality of life 5 to 10 years after birthing[93]. Across three groups flatus incontinence was reported in 31% of women who sustained an OASIS, 23% of all women having a vaginal birth, and 15% of women having a caesarean section. Lower reported rates of incontinence to liquid stool in 17%, 8%, and 7% respectively, and to solid stool in 4%, 0%, and 1% respectively[93]. These trends were similar to other studies which suggested women with OASIS and who are symptomatic of AI in the postpartum period were eight times more likely to be at risk of persistent AI at five years[83]. Additionally a prospective study of 242 nulliparous women by Pollack et al.[83] identified incontinence at five, and nine months and then five years post birth. The study utilised a self-report questionnaire for faecal incontinence and constipation, which included questions to ascertain incontinence to solid, liquid and flatus[83]. These findings consistent with those of Evers et al.[93] and similar studies where the progression of worsening symptoms following OASIS were 44% at nine months and higher at five years (53%)[93].

Cornelisse et al.[94] recognised the impact of worsening AI over a 4 year timeframe for postnatal women. This study undertaken in the Netherlands, included 355 women and consisted of a control group with no history of OASIS (n = 194) and a group who sustained An OASIS (n = 141). Three questionnaires were utilised; Defecation Distress Inventory (DDI), Cleveland Clinic Fecal Incontinence Score, and Fecal Instrument Quality of Life (FIQOL)). This study identified that the reporting of AI was double for the OASIS group (40%) compared to the control group (20%)[94]. The latter an interesting finding that women with no known OASIS reported symptoms[94]. These findings were consistent with those of Pollack et al.[83] who reported AI in women with no sphincter trauma at 9 months (25%) and 5 years (32%). Additional studies, which evaluated the risk of AI for women with no history of OASIS, reported prevalence of flatus incontinence (11.7%), faecal incontinence (4.1%) and faecal urgency (12.3%) with no reported relationship to known risk factors for OASIS[73]. In the absence of a history of OASIS, AI symptoms may be a result of occult OASIS, levator ani trauma or chronic pudendal neuropathy[73]. However further evidence suggested that there are other predisposing factors which influenced pelvic floor function prior to first pregnancy and birth, and the outcome on continence status[1, 7].

A prospective study undertaken by Van Brummen et al.[95] investigated the impact of pregnancy and birth on defecation function utilising the DDI questionnaire. Defecation concerns reported in 487 nulliparous women in early pregnancy (3 months) and then at a further three time points. Flatus incontinence at 3 months gestation was 34.6% compared with 42.3% at 36 weeks gestation, 31.9% at 3 months post-partum, and 30.5% at 12 months post-partum. This study did not differentiate between liquid or solid incontinence, but overall FI was reported as 3.9% at 3 months gestation, 3.0% at 36 weeks gestation, 5.7% at 3 months post-partum, and 3.3% at 12 months postpartum. This further highlighted the importance for screening all women of reproductive age for AI and recognising women with no obvious trauma following vaginal delivery are at risk of PFD and AI[23, 73]. The onset of AI appeared to be variable occurring in pregnancy, after birth or anywhere from the third decade increasing in prevalence to the sixth decade with a moderate to severe impact on QOL[96, 97].

1.4 IMPACT OF ANAL INCONTINENCE ON QUALITY OF LIFE

Bowel control is assumed around 4 years of age and once attained the physiological aspects are often taken for granted[98]. Continence is a learnt behaviour which is influenced by the social and cultural beliefs and behaviours of the society in which we live[98]. How a person is socialised will influence their

attitude to continence matters. For example, a healthy attitude to excreta as a normal bodily function with no shame or disgust shapes how a person copes with incontinence[99, 100]. However, bodily functions are often viewed in society as taboo topics and elicit emotional disgust[99]. The thought, smell and sight of faeces places it uppermost on the list of disgust[100]. This is not a problem until there is a challenge or change to one's continence status, such as accidental soiling. A person struggles to cope with the physical impact of incontinence and challenges their self-image and identity within a social group[101, 102]. A persons experience of AI is unique and complex often influenced by many aspect of a person's life; the physical symptoms, emotional feelings associated with AI, social attitudes towards a person with AI, financial burden and isolation[103]. AI is referred to as the last taboo, AI as a result of societal rules it is avoided in conversations and remains hidden and negatively impacts on a person's quality of life[74].

Health seeking is complex involving a person's understanding that AI is a problem, social beliefs, motivation for help and receptiveness of health professionals[104]. Poor health seeking often associated with infrequent episodes of AI, or belief that AI was a normal consequence of birth whereas worsening symptoms a motivation for health seeking[56, 104, 105].

The term quality of life (QoL) is utilised extensively within clinical practice and research, yet there is no consensus on what defines QoL. The World Health definition included the multifaceted view of physical, emotional and social wellbeing and the perceptions of an individual which keep them engaged in every aspect of daily living[106].

QoL questionnaires are utilised in clinical settings to assess for AI in all population groups. These tools provided a valuable insight into living with accidental loss of bowel control, and highlighted the detrimental impact on daily functioning[53, 54, 103, 107-109]. QoL tools have traditionally grouped concerns citing lifestyle, social functioning, financial burden, enforced social isolation, coping difficulties, depression, negative self-image, fear, embarrassment, anxiety due to unpredictability and sexual matters[55, 85, 110-114]. A quantitative scale included in the questionnaires identified symptom bother with higher scores relating to worsening impact on quality of life[94, 111].

There are limitations within QoL tools in the assessment of AI, largely due to their development. These types of tools were clinically derived and have little to no participation from those afflicted by AI[53, 113]. The lack of shared words or terms for AI are a barrier for health literacy and disclosure. Studies identified 60% to 70 % of women do not understand the term incontinence and suggested the use of common language used within communities should be utilised to describe stool loss[104, 115, 116]. Furthermore, clinical tools have a tendency to undervalue the incidence or severity of symptoms for women with AI[117]. Women often report rectal urgency, flatus incontinence and soiling as predominant symptoms noting a profound impact on their QoL. However, clinically derived tools,often excluded or underrated questions pertaining to symptoms which contributed to inaccuracies in reporting[78, 118]. The frequency and severity of solid stool incontinence often ranked higher by health professionals compared to other types of leakage, whereas those afflicted by AI, were conscious of all leakage and the associated embarrassment and negative impact on QoL[118-120]. Considering the main risk factors for PFD and AI are associated to pregnancy and childbirth, understanding the understanding the deterioration in QoL provided strong evidence of the need for routine screening women of reproductive age for AI[74].

Qualitative research methodology provided an in-depth understanding within this area however it remains limited[53]. Qualitative research identified that many women not only accept AI as a normal consequence of birthing but also learn to live with the negative consequences[118, 121, 122]. Women living with AI struggled with simple daily tasks of shopping, working, travel and outings[118, 123]. Often the unpredictable nature of AI heightened the anxiety associated with what were seen as simple every day activities[55, 56, 118, 123]. The daily planning of what to wear, fear of odour, where they were going, and accessibility to toilets resulted in avoidance or postponing events in case accidental bowel leakage occurred[118, 123].

Rasmussen et al.[54] revealed the compounding negative impact of enforced isolation as a result of AI

on a woman's mental health. Previous research by Tucker et al. concurred with these findings and has highlighted the fragility of young women's mental health as "teetering near the edge"[56]. The associated disgust and stigmatisation of AI in women of reproductive age has been shown to compound both the physical and mental burden which negatively affected their self-worth and how they conceptualise themselves as a sexual partner, woman, and wife[54, 56].

Women will not initiate discussion around this sensitive topic, and avoided intimacy for fear of accidents and the dissatisfaction of significant others[54, 56, 118, 124]. Fear of worsening symptoms in subsequent pregnancies and birthing further impacted on a woman's psychological fragility[54, 125].

Research identified incontinence was an independent risk factor for worsening mental health with variable reporting with different types of incontinence[118, 126-128]. Women with urinary incontinence reported both anxiety and depression, with lower rates of depression in 3% to 14% of women with stress urinary incontinence compared to 21 to 41% of women who reported urinary urge incontinence[127, 129]. Additional studies suggested there was a strong association between urinary incontinence and FI (double incontinence) and altered mental health[121, 130, 131].

A French study assessed the relationship of depression with the Edinburgh Postnatal Depression Score (EPDS) to FI and rectal urgency in 1632 post-partum women. Findings suggested that women who reported FI at 4 months post-partum were at greater risk of worsening mental health at 12 months with 36% of women with FI, and 23% with rectal urgency compared to 14.8% of women with depression at 12 months but no FI and rectal urgency[128]. The association of AI and mental health was reported by Brown et al.[132], who undertook a study of 5817 women which identified 1096 women with a history of bowel leakage. A third of women with bowel leakage identified feelings of depression and 40% of the total group reported a significant impact on QoL[132]. Treatment failures for AI were strongly associated with worsening depressive symptoms[118]. Meyer and Richter[118] concurred with these findings and noted psychological demise contributed to poor health seeking and treatment. The low rates of health seeking due to stigma in Meyer et al. study consistent with other research[79, 97, 132, 133]. However, studies which described the relationship between mental health and bowel incontinence remains limited and whilst further research is required in this area, there is a recognised need for early screening women for AI.[102, 128, 134].

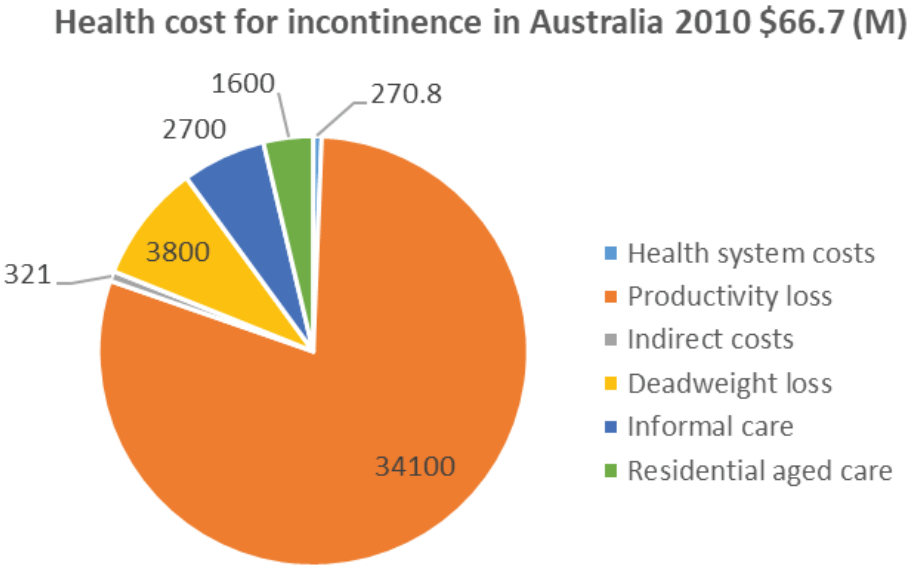

Figure 1.7. Total financial burden of incontinence in Australia for 2010. Source: Deloitte access economics-Continence Foundation of Australia. The economic impact of incontinence in Australia. ACT: 2011). †Indirect cost refer to living aids, pads, laundry and formal carer expenses. ‡Deadweight losses refer to lost revenue through transfers and lost taxation.

Non-disclosure of AI to health professionals is complex and citied as being due to stigma, and lack of enquiry by health professionals. Limited understanding of questions in tools utilised to identify AI further limits accurate assessment of the true prevalence of this condition hidden[53, 54, 103, 116]. The ability to comprehend questions within screening and assessment tools is paramount in the accurate identification of AI and improved QoL. Bartlett et al.[116] identified disagreement in terminology between two bowel screening tools, the Self-Administered Faecal Incontinence Questionnaire (SAFIQ) and the Cleveland Clinic Florida Faecal Incontinence Score (CCF-FI) as barriers to disclosure. Outcomes suggested direct enquiry by a health professional who utilised a questionnaire, which contained language women could understand could improve disclosure. Based on this information, this thesis aimed to address the gap in knowledge with the development of a novel bowel-screening questionnaire to identify AI.

1.5 ECONOMIC BURDEN OF ANAL INCONTINENCE IN AUSTRALIA

The economic burden of incontinence included not only the impact on the afflicted person, but consisted of carer support and costs to the wider community (Fig.1.7)[74]. Deloitte Access Economics on behalf of the Continence Foundation of Australia (CFA), estimated the total burden of incontinence in 2010 as A$ 66.7 billion dollars or A$14014 per person[74]. The projected increase for people living with incontinence by 2030 will be 6.2 million. Based on the daily individual cost (2010) A$14014 per person the burden on Australia equates to A$ 87 billion dollars[74]. The total cost burden of AI incurred by a person, included health system costs (A$270.8 million), continence aids (pads, clothing)(A$321million) productivity losses (A$34.1 billion) , informal carer costs (A$2.7 billion), residential care costs (A$1.6 billion) and dead weight loss from lost taxation (A$3.8 million) and burden of disease (A$23.8 billion)[74, 135].

Women living within the community represent the largest group suffering from incontinence, reporting AI in 44% and urinary incontinence in 47% of women under 50 years of age[74]. The impact on QoL apparent for women when the financial burden is considered. Women (73.5%) aged 15 to 64 years less financial earning capacity with lower workforce participation compared to men (83%)[136]. Additionally,

Table 1.2. Medicare costs for anal incontinence procedures. Source: MBS online, Medicare benefits scheme, Commonwealth of Australia, 2017, http://www9.health.gov.au/mbs/search.cfm?q=32216&sopt=S&=, accessed 21.6.2020).

Code	Surgery	Fee per item ($)	Code	Surgery	Fee per item ($)
2209	Anal or perineal graciloplasty with insertion of stimulator and electrodes	887	32213	Sacral nerve leads	635.95
2209	Anal or perineal graciloplasty with insertion of stimulator and electrodes	887	32214	Neuro-stimulator or receiver	321.3
2210	Gracilis neo-sphincter pacemaker	245.8	32215	Sacral nerve electrodes	120.65
32129	Anal Sphincter - direct repair	634.7	32216	Sacral nerve leads	571.1
32203	Anal or perineal gracilopasty	610.95	32217	Neuro-stimulator or receiver	150.4
32126	Anal incontinence Parks inter sphincteric procedure	465.65	32218	Sacral nerve leads	150.4
32051	Ileostomy reservoir	1,648.75	32220	Insertion of artificial bowel sphincter	869.65
32060	Ileostomy closure	2,228,80	32221	Removal or revision of artificial bowel sphincter	869.65
32063	Ileostomy closure with resection with long term follow up	2,045.65	32047	Perineal Proctectomy	
32066	Ilesotomy closure with resection	541.95			

women are more likely to be employed on a casual basis with less women working in full time employment (46.9%) this results in a 14.1% reduction in total earnings compared to male co-workers[136]. This is further compounded by persons living with incontinence who have a higher unemployment rate[137]. The burden of incontinence potentially resulting in higher absenteeism from paid employment[74, 137, 138]. The reduction in earnings directly impacts upon personal income, reduced disposable income decreasing the direct and indirect tax revenue for government budgets[74, 138]. The financial impact is not only personal but from a national perspective where the productivity losses from incontinence and subsequent loses in taxation revenue were reported in Australia in 2010 to be A$10.6 billion[74].

The financial impact of incontinence further disadvantaged women who are the predominant carers for others with incontinence. Two thirds of carers in Australia are women with 56% of carers aged 15 – 64 years in paid work compared to 80% in unpaid work[139, 140].

Whilst the cause of AI is multifactorial, extensive research identified known risk factors for AI as both pregnancy and childbirth worsening across the lifespan[1, 31, 90, 141]. As previously outlined, there is variable reporting of direct and indirect anal sphincter injuries (OASIS). In 2017, Australia women birthing for the first time sustained an average OASIS rate of 5.3%, however there was variation in different states and territories ranging between 5% and 6.2%[142]. National core maternity indicators reported an average of 3% for all women who birthed in 2016 and this is on par with state reporting of primary injury[142, 143]. Direct health care costs associated with anal sphincter at primary repair for each woman is A$634.70 for the anal repair alone (Table 1.2). The total cost for 3% of women with OASIS in 2016 would have equated to A$3,954,815.7, these figures do not include physician cost or facility cost for operating theatre, length of stay. There appears to be limited information on the lifetime financial costs for this group of women in Australia. An American study in 1996 undertaken by Mellgren et al.[144] identified the associated cost to the health facility following treatment for sphincter repair US$8555 per procedure with US$17,166 per woman with lifetime follow up.

Research literature identified the benefits of first line treatments including behavioural, biofeedback and conservative therapies in successful management of AI prior to further surgical interventions[145-147]. However, the implementation of therapies difficult because of the variable onset of symptoms and duration with many women not seeking assistance until later in the lifespan where a compounding of damage had occurred in subsequent childbirth. Additionally, AI symptoms often improve for many women in the postnatal period and are infrequent; women do not recognise the importance to disclose symptoms to a health provider. Furthermore, women presenting in a subsequent pregnancy are rarely screened for a history of AI unless they disclose previous symptoms[148, 149].

When there is no improvement in bowel symptoms in six or more months of behavioural therapies, further management options are discussed. Sacral neuromodulation (SNM) considered the gold standard of choice with a product cost of A$18000[150]. Failure rates of up to 5% to 20% and ongoing costs associated with battery replacement poses further financial strain for women[151]. Importantly SNM is not offered at many Australian major public hospitals and the cost of the procedure means that SNM is out of reach for many Australians.

Communicating a history of AI in subsequent pregnancy and delivery is vital for the preservation of the pelvic floor function across the lifespan[10, 152]. Active screening for AI by obstetricians, gynaecologist, general practitioners and midwives would promote early referral to services, which specialise in bowel management and allow obstetric care providers to assess and plan pregnancy care specific to a women's needs. This would improve her quality of life in the short and long term[118, 148, 153].

1.6 ROUTINE ASSESSMENT AND SCREENING OF ANAL INCONTINENCE IN WOMEN OF REPRODUCTIVE AGE

The assessment and screening for AI in women of reproductive age requires a strategy that includes primary, secondary and tertiary approaches. A primary approach focuses on modification of risk factors

such as obesity, surgical and obstetric cause which increase the risk of trauma and resultant AI[118]. It was evident within the literature that there are risk factors for PFD, and OASIS and relationship of AI following childbirth is clear. However, there are limited studies that provided a strategy for the reduction of perineal trauma, OASIS and screening for AI. Dietz (20) supported this view, stating there has been a hiatus over 40 years in the development of therapeutic and clinical approaches for PFD especially in the disciplines of obstetrics and gynaecology.

There is evidence of clinical strategies to reduce OASIS in multicentre studies[154]. A care bundle of evidenced based interventions which included angle of episiotomy and application, massage, warm packs, recognition and repair of perineal trauma have been enlisted to bring about change in practice thus reducing the risk of OASIS[154, 155]. Each of the interventions were used as standalone strategies however; the advantage of the bundle is that it brings about change through consistency of application in clinical practice with each episode of care to reduce OASIS[155]. Nevertheless, the strategy does not provide any evidence as to the importance of routine screening for AI. This omission inhibited the secondary screening approach and tertiary approach minimising risk and worsening impact on QoL. The scope of this thesis focuses on the secondary approach.

The secondary approach in the prevention of AI included screening women of reproductive age with a simple, quick easy to use tool[118, 148, 153]. However, disclosure is reliant on both women disclosing symptoms and active screening by health professionals. Disclosure of AI as previously outlined is complex with the nature and severity often influencing health-seeking behaviour[87, 118, 148, 156]. This was consistent in a study by Bharucha et al.[97] which reported the severity of symptoms influenced reporting in women (48%). This is of concern and indicated there are potentially more women who are symptomatic in the community who have not disclosed symptoms thereby affecting their care and management especially in a subsequent pregnancy. This was consistent with a study by Cornilesse et al.[94] which identified the overall rate of flatus incontinence in women with OASIS (44%) and women with no OASIS (22.6%), was higher when compared to women citing severe bother in the OASIS (12.1%) and no OASIS (4.6%) group.

Research identified that the receptiveness of a health provider can influence discourse, with women preferring a general practitioner as they were perceived as receptive and non-blaming[56, 116, 118]. Bharucha et al.[97] identified a pathway for reporting for women which included the general practitioner (56%) who appeared to be the preferred option to report compared to the junior doctor (19%), gynaecologist (27%), uro-gynaecologist (7%) and colorectal surgeon (7%)[97]. However, many women rarely seek care more likely disclosing to a friend (51%) when compared to a doctor (10% to 30%)[97, 118, 121]. This preference for reporting was consistent with research by Fatlin et al.[157] who utilised a self-report questionnaire in 1435 women attending outpatient appointments in a uro-gynaecology and maternity department. AI was reported in 4.4% to 15.9% of women, however only 20% of the overall group reported symptoms to a health provider[157].

The lack of health provider enquiry identified in research negatively influenced disclosure, with women citing that health professionals lacked clinical knowledge and skill in screening, care and management of AI[54, 56, 148]. Tucker et al.[56] qualitative study investigating women's experiences following OASIS and AI, highlighted that the inattentiveness of health providers as a roadblock to disclosure. Inattentiveness was viewed as lack of knowledge and skill in the management of AI[56]. Disclosure further discouraged by health providers who appeared to minimise the importance of AI[13, 158].

An additional roadblock in screening for AI lies in the discordance in ranking of symptoms between health professional and person afflicted[118]. Clinical history, bowel diaries, QoL, screening tools are utilised to identify AI, yet patient symptoms are often undervalued by health professional, with specific disciplines placing greater significance on solid stool loss compared to liquid, flatus incontinence and rectal urgency[54, 56, 118, 148]. Additionally, Rusvay et al.[148] international survey of 143 clinical specialities identified that, specialities involved with women of reproductive age; obstetricians, gynaecologists and uro-gynaecologists rarely routinely screen women for AI[148].

There is limited evidence within research, which identified the routine use of screening tools in women of reproductive age. A review of the literature identified two groups: clinical practice and clinical research.

1.6.1 Clinical practice

There was paucity within the literature as to the routine use of screening tools in the pregnant and postnatal population. The pregnancy hand-held (PHHR), a written record held utilised by pregnant women worldwide assists in maintaining continuity of care and improving risk management[159-161]. Whilst similarities are evident between the PHHR, it was obvious that no consistent format existed (Table 1.3)[162-166].

Four of the six Australian state and territory PHHR contained no prompt for bladder or bowel status (Table 1.3). Queensland and Western Australia PHHR contained questions about continence status utilising words such as incontinence[162, 163]. The Queensland PHHR was superior as it included questions on types of bladder function however bowel questions were limited to constipation and anal incontinence[162].

The ability to read and understand health literature and decipher AI questions for the health professional and woman may also be a barrier in eliciting information[56, 116]. The lack of a shared vocabulary was evident in a prospective research by Bartlett et al.[116] which compared reporting of AI between a Self-administered Faecal Incontinence Questionnaire (SAFIQ) and the Wexner Score (CCF-FI) in 262 men

Table 1.3. Comparison of pregnancy hand held records in Australian and the United Kingdom.

Origin	Document name				
NHS UK	NHS Pregnancy notes	National Health System United Kingdom	A4 Booklet	Medical history	Incontinence (urinary / faecal)
WA	National woman held pregnancy record	Department of Health and Ageing	A4 booklet	Personal history Obstetric problems No PFD nor OASIS	Incontinence (urine or faeces, stress or urge)
QLD	Pregnancy health record	QLD Government	A4 booklet	Medical history No Oasis	Bladder function: Frequency, urgency, dysuria voiding problems; Incontinence: stress or urgency; Bowel function: constipation, incontinence
SA	Pregnancy record	SA health	A4 booklet	Medical history No incontinence No PFD	No
ACT	Maternity Record	ACT government	A3 card	No continence	No
NT	Pregnancy Health record	NT	A3 card bifold	No continence No PFD	No
Victorian	Maternity record	Vic	A4 booklet	Postnatal going home No incontinence in pregnancy	Urine bowel function

The WEXNER SCORE
A Frequency Assessment Tool

Type of Incontinence	Never	Rarely	Sometimes	Usually	Always
Solid	0	1	2	3	4
Liquid	0	1	2	3	4
Gas	0	1	2	3	4
Wear Pad	0	1	2	3	4
Lifestyle altered	0	1	2	3	4

Table 1.4 (left). Cleveland Clinic constipation score - the Wexner score. Reproduced from Dis Colon Rectum, Aetiology and management of faecal Incontinence by Jorge JMN & Wexner SD, 36:77–97, 1993, with permission BMJ Publishing Group Ltd.

Table 1.5. St Mark's fecal incontinence score - Vaizey score. Reproduced from Dis Colon Rectum, Aetiology and management of faecal Incontinence by Jorge JMN & Wexner SD, 36:77–97, 1993 with permission BMJ Publishing Group Ltd and Dr Carolynne Vaizey.

Vaizey Fecal Incontinence Score					
Type of Incontinence	**Frequency**				
	Never	**Rarely**	**Sometimes**	**Weekly**	**Daily**
Incontinence for solid stool	0	1	2	3	4
Incontinence for liquid stool	0	1	2	3	4
Incontinence for gas	0	1	2	3	4
Alteration in lifestyle	0	1	2	3	4

	No	**Yes**
Need to wear pad or plug	0	2
Taking constipating mechanisms	0	2
Lack of ability to defer defecation for 15 minutes	0	4

and women attending colorectal and gynaecology outpatients in Queensland. The findings reported misinterpretation of questions as a major reason for nondisclosure[116]. Brown et al.[115] concurred with these findings and suggested disclosure is enhanced through the type of screening tool (self-report versus clinician) and the use of terminology. The study involved 5817 women over the age of 45 years in the United States, and included an online questionnaire adapted from a validated bowel screening tools Faecal Incontinence Severity Index (FISI) and the Wexner score. Whilst the self-report format of the questionnaire enhanced reporting with 97% of women noting a history of AI in the last 12 months, there were issues surrounding terminology with 31% of women never had heard the term FI[115].

The use of clinical terminology and absence of questions to assess AI within the PHHR are limitations for the screening and assessment in women of reproductive age. Enquiry only apparent if a women presents with symptoms or the health care provider recognised the importance for screening in this group of women[167].

Social more's influence enquiry by health professionals as discussed in previous sections and this can limit discussion. Shame and embarrassment are common reasons for the concealment of stigmatised conditions[158]. Non-disclosure is further compounded through the misguided acceptance by society that AI is a normal consequence of birthing and this negatively impacts on women's management, compounding current PFD and poorer QoL[56, 168].

A search of the literature over a 20-year timeframe revealed only three papers, which reported the use of screening tools in clinical practice to identify AI. The clinical areas included perineal clinics to review perineal trauma and OASIS. Each clinical setting utilised a different screening tool to identify incontinence however, each tool contained similar parameters to review type (solid, liquid, flatus incontinence and or rectal urgency) and severity of AI.

The Modified Cleveland clinic score (Wexner score, Table 1.4) was utilised in an Irish population of 399 women, referred for perineal concerns over a 2 year timeframe[169]. The primary intention in the establishment of the clinic in 1995 was to review and treat women who sustained OASIS at 3 months postpartum but it had since grown to include other perineal complaints and therefore findings also reflected older women (range 18 to 77 years)[169]. The referral pathway to this clinic followed the Royal College of Obstetrics and Gynaecology recommendations for health professionals to establish perineal clinics for the early identification and management of incontinence in women with OASIS[38]. The

main pathway for referrals were maternity hospitals (79%), general practitioners (10%), other hospitals (7%) and self-referrals (4%). Fifty three percent of women with a history of OASIS reported FI at 3 months postpartum with flatus incontinence the main symptoms[169]. However, the authors provided no breakdown of symptoms for the OASIS group. Discussion was provided for 56 (50%) of symptomatic women with rectal urgency which was interesting as the Wexner score does not include questions for rectal urgency, hence the definition of FI compared to AI[169].

An additional study by Pretlove et al.[170] reported on the first 18 months of a perineal clinic, established for perineal trauma and OASIS in the United Kingdom. Initial referral for women with OASIS was from the maternity setting. Referrals were initially low due to lack of awareness by staff and women failing to attend appointments. Referrals increased as staff and women saw the potential benefits.

The St Marks Faecal Incontinence Score (Vaizey score, Table 1.5) a validated screening tool was utilised to screen women for AI. However, the authors only identified incontinence with a Vaizey score of three or more, which is contrary, to the Vaizey scoring system where a score greater than zero identified symptom bother. During 2001 and 2002, 71 women attended the clinic, including 41 women with a history of OASIS, and 14 with no history of OASIS but a history of AI. The remaining women had other perineal concerns. The mean timeframe to report AI was 2 years. Forty-one women who sustained OASIS reported an overall prevalence of AI at 61%. This included nine women (22%) with solid and liquid stool compared with fourteen women (80%) with no history of OASIS reporting solid and liquid stool[170].

Given the authors utilised the Vaizey score and included only a score greater than three; there was difficulty in reviewing the findings to ascertain the true prevalence of AI and symptoms of flatus or rectal urgency. Hypothetically, the additional 20% of women with no OASIS reported symptoms of AI. Omission in the discussion of these symptoms by the authors adds weight to comments within literature that health professionals put more importance in the reporting symptoms of solid and liquid stool[118].

Brincat et al.[171] American research details the experiences of the first four years of a postnatal clinic where 247 women presented with a range of perineal concerns. Referral patterns included a combination of maternity settings, obstetric doctors, general practitioners and self-referral. Numbers for referral had increased over the four years with the authors attributing this to recognition of early assessment and management and enhanced collaboration between professional bodies[171]. The authors supplied no patient demographics or type of screening tool. Findings suggested 154 women with OASIS (63%) reported multiple symptoms (52%) with transient symptoms of FI (12.3%) reported in women attending their first appointment[171]. As the authors referred to FI rather than AI, there was an assumption that rectal urgency was not included in their findings.

Brincat et al.[171] clinic was modelled on the Mayday clinic in the United Kingdom . The Mayday clinic provided not only clinical reviews for women's perineal concerns at 3 months postnatal but also antenatal review for subsequent mode of delivery[172]. From July 2002 to July 2005, the Mayday clinic received 433 referrals of which 50 were antenatal women and 373 postnatal women. 67% of women with OASIS were reviewed over this timeframe with 23 women who identified AI and urgency (6.2%)[172]. Whilst the authors detailed the diagnosis and management of AI there was no reference to an initial screening tool only ongoing diagnostic testing with manometry and endo anal ultrasound[172].

The review of the perineal clinics identified that the primary aims were early assessment and management for women with OASIS. The importance of early referral through education and collaboration between health professionals and women resulted in increased referrals to the clinics. Whilst screening for AI and FI occurred, there was no uniform screening tool. The implementation and use of the various tool was reliant on the operator and in cases where the symptoms score was adjusted to meet the clinicians expected outcomes, AI was potentially is underreported.

The routine screening of pregnant and postnatal women in everyday clinical practice is limited. This

view is supported by the study of Rusavy et al.[148] which identified the use of AI scoring systems by 143 researchers and clinicians in north America, Asia and Europe. The findings revealed obstetricians and gynaecologists often neglected screening[148]. The preferred tool identified by obstetricians and gynaecologists, were the Wexner score and Vaizey score[148]. The lack of screening by these professional groups was alarming given the association of pregnancy and birth to PFD.

The assessment of AI requires sensitive questioning to elicit a detailed history from those afflicted and whilst there was evidence within the literature as to the development and refinement of many tools to assess bowel incontinence, there was minimal evidence of tools specifically developed for women of reproductive age[156, 173]. Multiple screening tools are utilised to assess bowel incontinence (FI or AI) and are applied to pregnant and postpartum populations in clinical research[7, 19, 31, 73, 83, 86, 87, 90, 109, 114, 171, 174-181].

1.6.2 Clinical research

Questionnaires and screening tools utilised in research often focused on the relationship of pelvic floor compartments including bladder, bowel, prolapse and QoL. Whilst they are comprehensive in nature they have limitations as there is no standardisation of questions and often time consuming for both clinician and person afflicted[156]. Zuchelo et al.[149] assessed tools utilised for PFD in the post-partum period, noting that the tools were not developed for this specific group of women, having been borrowed from other disciplines or developed for the general population[149]. Thirty-three articles identified PFD questionnaires across the pregnancy continuum, of which one looked at nulliparous women before pregnancy and nine validated tools reviewed the postnatal period from three days to five years[149]. Pelvic floor questionnaires included the Pelvic Floor Inventory-20 (PFDI-20), the Pelvic Floor Impact Questionnaire-7 (PFIQ-7), the Australian Pelvic Floor Questionnaire (FPFQ), the International Consultation on Incontinence Questionnaire (ICIQ-VS), the Electronic Personal Assessment Questionnaire(eQAQ-FF), the Pelvic floor Bother Questionnaire (PFBQ) the Pelvic Floor Distress Index-46 (PFDI-46) and the Impact Questionnaire-31 (PFIQ-31)[149].

The most frequently tools utilised to assess PFD were PFDI-20, PFIQ-7 and ICI-VS. Each tool focused on a specific domains of PFD citing limitations of the ICIQ-VS as having no bowel questions and the PFIQ-7 focused only on QoL and not symptom identification or bother[149]. The tools were complex and included a range of non-standardised sets of symptoms including bladder, bowel, prolapse, sexual function, vaginal and postpartum symptom bother and or QoL. Questions ranged from 14 to 118 with an average of 31 questions[149].

Research, which specifically assessed bowel function in women of reproductive age, identified 15 frequently used questionnaires and screening tools (Table 1.6). These consisted of tools which addressed all pelvic floor compartments and included the PFDI-20,PFIQ-7[182], FPFQ[183], and symptom severity and QoL tools which included the Birmingham Bowel and Urinary Symptom Score (BBUSQ)[184], the Faecal Incontinence Quality of Life Tool (FIQoL- Rockwood scale)[111], the International Consultation on Incontinence Questionnaire Bowel (ICIQ-B)[185], Manchester Health Questionnaire (MHQ)[173]. Whilst tools which had a primary focus on symptoms severity include the Danish Anal Sphincter Rupture Questionnaire (ASR)[186], the Faecal Incontinence Severity Index (FISI)[119]; St Marks Incontinence Score (Vaizey Score)[187], Modified Miller Score (Rothenberger)[188], Cleveland Clinic Score (Wexner Score) [14], Parks Score[189, 190], Pescatori Scale[191], and Rapid Assessment Faecal Incontinence Score (RAFIS[192].

The benefits of the QoL questionnaires are outweighed by their inherent weaknesses when utilised to screen for AI in women of reproductive age. Many are utilised in a known symptomatic population and there is a tendency to underestimate the true nature of the phenomenon at hand[53, 111]. Importantly the formulation and validation of questionnaires requires the perspective of those afflicted, yet few tools have focused on the importance consumer participation in their development. Two QoL questionnaires, FIQoL scale and ICIQ-B included consumer participation in the pilot test and re-testing of their questionnaires[113, 119, 185]. The development of these tools included men and women who were symptomatic of AI from the gastroenterology clinics, and were therefore limited to the wider population.

However the outcomes from these QoL tools detailed the negative impact of AI on lifestyle, depression, self-perception, embarrassment, social functioning and self-image[111, 113, 185].The ICIQ-B included 21 questions to identify bowel control, pattern and quality of life and was used in clinical practice[113, 185]. The tool superior to other QoL tools as it also included fear of leaving home, the shame and embarrassment of living with AI, not captured by other questionnaires[113]. The importance of these types of questionnaires in the assessment of symptoms and impact on QoL should not be underestimated. Their length and complexity of these questionnaires however limit their usefulness as a quick and easy screening tool in the primary health care setting.

The RAFIS was a unique tool, which assessed the frequency of symptom loss in relation to the patients emotional response to AI using a visual analogue scale[192]. Whilst a simple tool the RAFIS underestimates the frequency, severity and type of incontinence. Additionally the small sample size used in the development of the tool limits its useability.

The validation of a questionnaire by Reilly et al.[193] which measured FI and risk factors within the general community was a positive step to active screening for AI. The questionnaire's usability was enhanced by being written at a sixth grade reading level, utilising lay terms and being formatted in large print[193]. However, the intention of the questionnaire was not to solely screen and thus the length and complex nature of the questionnaire limits its usefulness in the primary screening and identification of AI in pregnant and postnatal women.

Alternatively Bugg et al.[194] developed the Manchester Health Questionnaire for screening AI in postnatal women. The questionnaire was successful in identifying 9.1% of postnatal women with AI[173]. However, not unlike the ICIQ-B , the MHQ was limited by its purpose and length as it was designed with 32 questions for the assessment of AI and impact on quality of life[174].

Symptom severity scores often contained fewer questions than QoL tools and objectively evaluated symptoms, yet in the past, these tools have often excluded the consumer perspective in their development. Whilst current development of screening tools have been in either male or female populations or community dwelling women, there appeared to be few tools developed specifically for women of reproductive age (Table 1.6). The Danish Anal Sphincter Rupture (ASR) questionnaire was the only tool which used women with a known history of OASIS in the development[186]. The ASR, a validated questionnaire which specifically targeted women with known 3rd and 4th degree tears (OASIS) and included screening for quality of life, sexual and physical complaints such as anal pain[186]. The benefits of the ASR was its simplicity, taking only 15 minutes to complete, however it was only utilised in a cohort with known sphincter damage, and does not include women who have had occult damage and limits its usefulness in the screening for AI in all women of childbearing age. Furthermore, the ASR has no frequency scale, which limits the ability to identify symptom severity.

Simple screening tools for AI have evolved through time and included similar parameters to identify type of loss, frequency and severity[148, 195]. Disappointingly there was no standardisation of AI symptoms (156). The Parks scale is the simplest tool containing four questions with a total score of one (continence) to 4 (incontinence)[189]. This scale was limited as it excluded a frequency and severity scale, and importantly excluded rectal urgency[156]. The Pescatori Scale included three questions including solid stool, liquid stool and flatus/mucous loss[191]. A basic frequency and severity scale zero (continence) to six (incontinence) were included to assess symptom impact. The tool was limited as it omitted rectal urgency and only assessed frequency daily to less than once per week[191]. The variable nature of AI in women of reproductive age limited the ability of this tool to capture a history of AI.

The strengths of summary scoring systems like the Modified Miller score and FISI (Table 1.6) included questions on type of incontinence (solid, liquid stool and flatus), frequency and severity scale[119, 195]. The severity grading scale allowed for comparisons between previous scores to assess improvement or correlate QoL[156, 195]. However, both tools are limited with the exclusion of rectal urgency and greater weighting of solid and liquid stool over flatus loss. The uneven weighting of symptoms was reflected

Research instrument	Number questions	liquid	solid	flatus	urge	frequency scale	other	Timeframe in weeks
APFQ	70 (12 Bowel)	✓	✓	✓	✓	✓	×	not specified
ASR	33(12 FI)	✓	✓	✓	✓	×	×	not specified
FIQoL	29	×	×	×	×	×	QoL	not specified
FISI	4	✓	✓	✓	×	✓	Mucous	4
ICIQ-B	21	✓	✓	✓	✓	✓	Staining	12
MHQ	31 (12 Bowel)	✓	✓	✓	✓	✓	passive soiling	not specified
Vaizey score	8	✓	✓	✓	✓	✓	QoL	4
Modified Miller	4	✓	✓	✓	×	✓	×	not specified
Parks score	4	✓	✓	✓	×	×	×	not specified
Pescatori scale	3	✓	✓	✓	×	✓	mucous	1
RAFIS	6	Not stated	Not stated	Not stated	Not stated	Not stated	Only leakage frequency	4
Wexner score	5	✓	✓	✓	×	✓	QoL	not specified
PFDI-20	20 (8 Bowel)	✓	✓	✓	✓	✓	×	12
PFIQ-7	21 (7 Bowel)	x	x	x	x	x	QoL	12

Table 1.6. Symptom scoring system for bowel incontinence. Pelvic floor inventory questionnaire (PFIQ-7; includes colorectal anal impact questionnaire 7 CRADI-7). Pelvic floor distress inventory (PFDI-20, includes Colorectal Anal distress inventory CRADI-8). Wexner score (Cleveland clinic score). Rapid assessment faecal incontinence score (RAFIS). Modified Miller score (Rothenberg score), St Marks faecal incontinence score (Vaizey score), Manchester Health Questionnaire (MHQ), International consultant on incontinence questionnaire- bowel (ICIQ-B), Faecal incontinence severity index (FISI). FIQoL. Danish anal sphincter rupture questionnaire (ASR). Australian Pelvic floor Questionnaire (FPFQ).

in the literature, which revealed significant disparity in reporting symptoms comparing the clinician perspective to clients[118]. This is of concern as there was significant evidence in the literature that a woman's perspective of impaired flatus control, soling and rectal urgency resulted in a debilitating impact on QoL[56, 118].

The Wexner score or Vaizey Score are tools frequently used in clinical practice and research to assess AI[148, 196]. Whilst there was a wide variation in screening tools used to identify AI in research in women of reproductive age, these two tools appeared to be the preferred tool[19, 86, 87, 90, 92, 174-176, 181].

1.7 TOOLS FREQUENTLY USED FOR ASSESSMENT AND SCREENING OF ANAL INCONTINENCE IN WOMEN OF REPRODUCTIVE AGE

The Wexner score and Vaizey score quantified and assessed the impact of AI. Both tools are superior to other AI tools as they are quick to use with five to seven questions on the type of incontinence and included a lifestyle impact, frequency and severity scale[14].

The Wexner score used frequently in clinical practice, postnatal and longitudinal research was preferred for its simplicity and ease in implementation[148, 156]. The scoring system cross tabulates symptom frequency to a total score between zero (no incontinence) to twenty (incontinence) (Fig. 1.4). There was equal weighting of symptoms however; a timeframe for symptom bother and rectal urgency are not included[148, 156, 195]. The latter is interesting as rectal urgency may be the only symptom women of reproductive age present with[148]. Whilst the Wexner score was commonly utilised in clinical practice the tool has not been formally validated, unlike the Vaizey score[148].

The Vaizey score is a validated and reliable tool and easy to implement which makes it superior to other symptom severity tools[176]. The use of the Vaizey score in research was evident in late pregnancy, postnatal and longitudinal research[156]. A cross sectional study which included 1500 postpartum primiparous women utilised the Vaizey score to identify AI[85]. The results identified rectal urgency (37%), loss of flatus (16%) , more than 2 symptoms of AI (21%) and three or more symptoms (5%)[85]. The recommendations from this research emphasised the importance of routine screening in women during pregnancy to identify the risk of PFD to improve outcomes in the postpartum period and across the lifespan[85].

The Vaizey score correlated highly to the health professionals clinical impression of patient symptoms when compared to the Wexner score and Pescatori scale[176]. Unlike the Wexner score, the Vaizey score included additional items such as rectal urgency, pad use, constipation medications and a timeframe of last four weeks for symptom bother (Fig. 1.5)[156, 187]. The scoring system assessed liquid, solid stool, flatus incontinence and lifestyle impact and included a five point system which ranks frequency of symptoms (never, rarely, sometimes, weekly, daily) from zero to four[187]. A dichotomous scale with a scale of zero (no bother) or two (bother) assessed pad use, constipating mechanisms and zero (able to defer defecation for 15 minutes) or four (unable to defer for 15 minutes) with the combined score ranging between zero (no incontinence) to twenty four (total incontinence)[187]. However the dichotomous items are not weighted evenly and there is a lack of a frequency scale for rectal urgency, which undervalued its importance on QoL and its recognition as a precursor for worsening AI across the lifespan[148, 156]. Furthermore, the timeframe of four weeks limited an accurate assessment of current versus historical reporting of symptoms. The review of literature within this thesis has identified the variable nature of AI in women. Additionally, the inclusion of wearing pads is a further limitation for the Wexner score and Vaziey score to simply screen for AI, as pad use may be for urine incontinence and not for faecal loss.

Passive soiling often variable in nature is known to impact negatively on Qol yet the Wexner and Vaizey scores do not include passive soiling of mucous or faeces in symptom screening[113, 195]. Whilst the inclusion of these symptoms are only noted within the ICIQ-B, MHQ, FISI and Pescatori scale the limitation of these tools as a quick and easy screening tool have also been outlined.

1.7.1 Strengths and limitations of the Wexner score to the Vaizey score

The preferred screening tools within clinical research in women of reproductive age included the Wexner and Vaizey scores. However, there appeared to be discrepancies between the tools as suggested by Rusavy et al.[87] study which investigated AI in 790 women with a history of episiotomy following childbirth. The research utilised both Wexner score and Vaizey score at 3 and 6 months postpartum. Both tools contained similar wording and scale for liquid, solid stool and flatus and therefore scores should have reflected similar outcomes. Additionally, the researchers graded the severity of incontinence by assigning limits to the Vaizey scores. A Vaizey score greater than four identified incontinence and greater than eight equated to severe incontinence. Findings for the mean and standard deviation for the Wexner score at 3 months (0.7 ± 1.2) and 6 months (0.4 ± 0.9) were lower when compared to the Vaizey score for the same timeframe (1.0 ± 1.9), (0.6 ± 1.6)[87]. The Vaizey score reported AI in 48 (7.3%) women at 3 months and 29 (4.4%) women at 6 months postnatal[87]. It is difficult to refine the symptoms as the authors had only provided rectal urgency as an individual symptom prenatal (5%) and denovo at 3 months (7.8%) and 6 months (4.6%)[87]. Disparity in reporting was identified in Sorensen et al.[90] study which reviewed 360 women with OASIS (n = 125) and without OASIS (n = 235) for FI utilising the Wexner score and the Vaizey score. Whilst there were no statistical significance differences found between the tools, the mean Wexner scores were lower in women with OASIS 1.7 (95% CI 1.3-2.1) and no OASIS women mean 1.1 (95% CI 0.7-1.4) compared to the mean Vaizey score 2.8 (95% CI 2.1-3.4) in the OASIS group and women with no history of OASIS, mean 1.4 (95% CI 1.0-1.9). The Vaizey score only reported rectal urgency in OASIS group (13%) compared to no OASIS (14%). The limitation of the Wexner score was the inability to screen for urgency. The Vaizey score was also limited in assessment of rectal urgency due to the dichotomous scoring of urgency.

Traditionally these tools are utilised in clinical areas with implementation by a health professional, the Wexner score preferred by clinicians for ease of use and lacked confusing terminology which are two

Table 1.7. Strengths and limitations of the Wexner score and Vaizey score. †QoL, quality of life.

Wexner score		Vaizey Score	
Strengths	**Limitations**	**Strengths**	**Limitations**
Frequently used in research includes women of reproductive age		Frequently used in research includes women of reproductive age	
Frequently used clinical practice		Frequently used clinical practice	Wexner score preferred over Vaizey score by clinicians and researchers
Not validated	Not validated	Validated tool	
Incontinence defined	Faecal incontinence (FI) Excludes rectal urgency	Incontinence defined Anal Incontinence (AI)	
5 point scale easy to use		7 point scale easy to use	
Frequency scale evenly weighted 0-4		Frequency scale for 4 items weighted 0-4	Rectal urgency only weighted as **either** 0 or 4 compared with a **range** of 0-4 for other symptoms
Scale range 0-20		Scale range 0-24	
QoL† Lifestyle and pad use	Misinterpretation of pad use	QoL† Lifestyle and pad use	
No rectal urgency	Underscores importance of rectal urgency	Includes rectal urgency	No frequency range
		3 item dichotomous scale, zero (no bother) or 2 (bother)	Limits interpretation of frequency severity especially of urgency
No timeframe		4 week timeframe	Excludes variable nature AI
No passive soiling/ mucous/staining	Potential impact on QoL†	No passive soiling/ mucous/staining	Potential impact on QoL†
Development	Clinically derived	Development	Clinically derived and validated

common factors that limit disclosure[116]. As discussed, the reporting of FI was lower when utilising the Wexner score in both studies, and the discordance between screening tools can be attributed to the fact that the tools were posted to participants and utilised as self-reporting tools.

The Wexner score is preferred in clinical practice for its simplicity desspite that it is not a validated tool[148, 156]. However, a major limitation of the Wexner score in the assessment of FI is that it excludes rectal urgency, whereas the inclusion of this important symptom in the Vaizey score better quantified AI (Table 1.7). Neither tool assessed the frequency of rectal urgency or passive soiling which are precursors for worsening function. These two symptoms of the three (flatus incontinence, rectal urgency and soiling) commonly reported symptoms within the literature over the past 20 years however; screening tools have not changed to include the frequency and severity of all of these symptoms.

Language utilised in both the Wexner score and Vaizey score are similar with the additions of plug and defer defecation in the Vaziey score (Tables 1.4 & 1.5). Given that both scores were clinically derived with limited consumer participation, the terminology within these tools has been identified as a potential barrier to a person's health literacy further impacting on the disclosure of AI[168]. The Wexner score contains no timeframes and therefore captures the historical perspective and given the variable reporting of AI in young women, this is an advantage compared to the Vaizey score, which is limited by a timeframe of the last four weeks.

1.8 CONCLUSIONS

The review of literature has identified that AI is multifactorial, however; pregnancy and childbirth are main risk factors. There appeared to be a lack of opportunist screening for AI in this at-risk group. The risk of compounding injury with subsequent pregnancy, childbirth and ageing emphasises the need to develop a quick and easy screening tool for AI in women of reproductive age, which would improve the identification of AI, assist in access to clinical care and improve quality of life

Findings have established the benefits and limitation of screening tools for bowel incontinence. There was a preference for the Wexner score for its simplicity and ease of use over the Vaizey score. However, it was evident that there is a need for the development of screening tool specific for women of reproductive age, which embraced the strengths of each of the current tools, whilst acknowledging crucial inclusions of rectal urgency, soiling, and no timeframe and consumer participation in the development.

The lack of mutually agreed definitions, complex language and terms ascribed to AI, are barriers in disclosure[103, 116, 123]. It is crucial that the development and validation of a new screening tool for AI involves participation of those afflicted. A screening tool is required to be sensitive to a specific health group and utilisation of common terminology for bowel problems would be advantageous in improving the disclosure of symptoms in the screening and identification of AI[103, 116, 123].

Therefore, this research thesis asks two questions, firstly; what factors influence the disclosure of AI in women of reproductive age? Secondly, would the identification of these issues assist in the development and validation of a bowel-screening tool to identify AI in this group of women? The research hypothesises that the development of a screening tool for this cohort would improve the early detection and intervention for bowel incontinence in women of reproductive age.

1.9 RESEARCH AIMS

The aim of the research is threefold. Firstly, to determine whether routine screening in a pregnant and postnatal population identifies AI. Secondly, analysis of the factors that affect disclosure of symptoms to health care providers. Thirdly, the development and validation of a screening tool for AI within a group of treating specialists and women of reproductive age. Further validation of the tool undertaken in a population of pregnant women and non-pregnant reproductive aged women to determine if the screening tool improves identification of AI within different populations.

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CHAPTER 2

Materials and Methods

Materials and Methods

2.1 METHODOLOGY

A mixed method sequential design was utilised within the five stages of the research. Combining the quantitative and qualitative perspectives assisted in answering the research questions and the stated aims of the research as mentioned in Chapter 1.

2.2 RESEARCH DESIGN

There was insufficient information available within the literature regarding factors that influenced disclosure of anal incontinence (AI) for women of reproductive age when utilising bowel-screening tools. The sequential design of the research allowed for an exploratory and integrative approach to address the research question, where a single quantitative or qualitative approach would not have provided a comprehensive understanding of factors influencing disclosure and negatively affected the development of the screening tool.

The strengths and perspectives of both quantitative and qualitative approaches was important at each stage of the research and enhanced the reliability and validity of the findings[1, 2]. The reconfiguration and interpretation of both the objective and subjective findings in the initial tool development subsequent phases of the research informed the subsequent stage in the development of a screening tool[2, 3].

Quantitative research methodology allowed for the investigation of an at risk population for; women of reproductive age, to determine the incidence of screening and prevalence of AI[3, 4]. The lack of clinical screening and wide variation in reporting of AI in prevalence studies provided an impetus to review local prevalence rates. For the purpose of this research, AI was defined as the accidental loss of any loss of liquid or solid stool, flatus, and rectal urgency. Whilst clinical terminology has been used throughout the discussion, the bowel screening tool-utilised language which women were familiar and preferred terms which included; liquid and solid poo, wind or gas and cannot hold on (need to rush to the toilet).

The first stage of the thesis included a review of the literature and a retrospective study (stage 1). The retrospective study determined whether a disparity existed in reporting AI by health professionals who referred women to a specialist perineal clinic compared to screening undertaken within the speciality clinic. Prospective studies (stages 2, 4 and 5) determined if a newly developed screening tool for this research identified AI within women of reproductive age (Fig. 2.1).

The development and validation of the screening tool (stages 1 to 3) included participation from both health professionals involved in the care of pregnant and postnatal women, and women who were symptomatic of AI. Whilst few bowel screening tools have utilised women's involvement in their development, this research was unique as it included qualitative methodology to elucidate the phenomenon at hand[5, 6]. The qualitative interviews provided a deeper understanding for the complex nature of disclosing AI when using screening tools. This differed to previous studies where a single method approach provided one perspective of the research focus that being development of a screening tool[3, 5]. Phenomenological qualitative interviews informed by Van Manen methodological framework[5] was an appropriate framework as this assisted in the interpretation of the lived experience of AI from a person perspective of everyday life where otherwise it may be concealed[7, 8].

2.3 STUDY SETTING

South Australia is the fourth largest state in Australia with 1.7 million population, of which 1.2 million live in the capital city of Adelaide[9]. Areas of disadvantaged populations in the outer northern suburbs of Adelaide reflect high levels of unemployment (22%), low levels of completion of secondary education (40%), sole female parenting (22%) and a reliance on public housing (27%)[9]. The poor

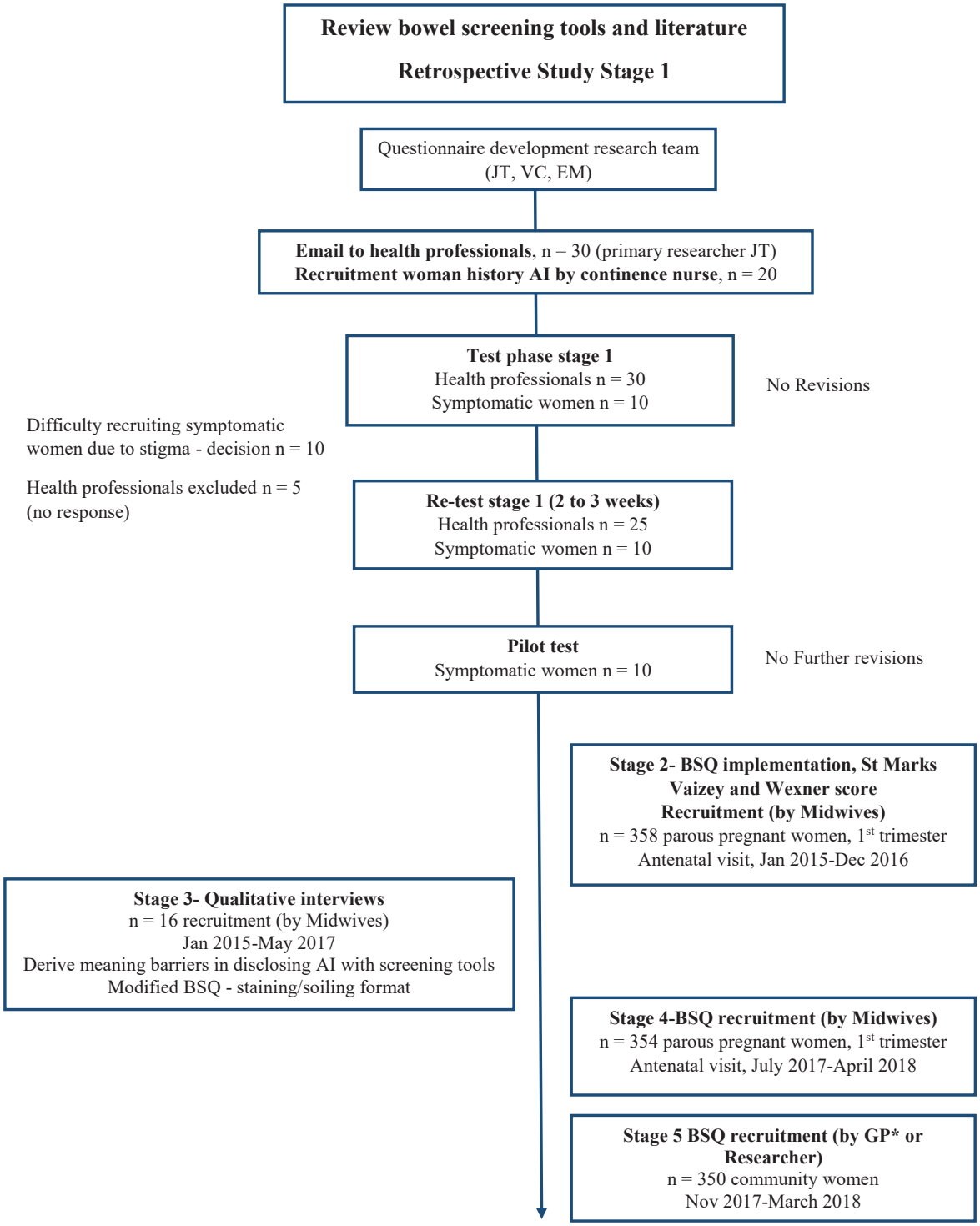

Figure 2.1. Development of screening tool flow chart. *GP (General Practitioner).

social determinants of health disadvantage for this population and contributes to poor health seeking behaviour and access to services[10, 11]. The socially unacceptable nature of AI and stigmatisation within communities may further limit disclosure for these groups[12, 13]. The importance of health literacy and comprehension of information was paramount for the development of the screening tool[11, 14]. The mixed method approach and inclusion of qualitative interviews addressed these concerns.

The place of research for stages one to four of this study was in the northern suburbs of Adelaide, one of three largest tertiary centres in South Australia. The total birthing population in 2013 for South Australia

was reported to be 20,263 births of which 3333 (16.5%) women birthed at the third largest maternity unit[15]. The birth numbers have increased overtime within the maternity unit and in 2016 births recorded as 3837 (19.2%) of births in this metropolitan area[16]. The fourth stage of the research also included a large community medical clinic within the same geographical area.

This mixed method study occurred between May 2014 to April 2018. Where relevant, the following subsections in this chapter provided additional information on of specific theoretical frameworks, research sites, population samples, data collection and analysis. A detailed explanation of each stage is provided in chapters three to six.

2.4 ETHICS

The University of Adelaide Human Research Ethics Committee and the Human Research Ethics Committee (HREC/14/TQEHLMHMH/58) approved ethics. The research commenced on successful granting of ethics from both ethics committee and participants (stages 2 to 5) obtained written consent (Appendices 1A, 1B, 2 & 5A). Participants through both written participant information forms and verbal discussion with the researcher, that their anonymity and confidentiality were assured. All information was de-identified through the removal of all information that could link a person's information and a code assigned to individual data maintained confidentiality and anonymity.

Information was stored on a Universal Serial Bus (USB) accessed only by the primary researcher (JT) and kept in a located filing cabinet in the Robinson Research Unit, Elizabeth South Australia. Retention and destroying data complied with the University of Adelaide data management plan and the State Records Act 1997 and the Australian Standard AS ISO 15489[17].

Participants were aware of their rights and responsibility when consenting to participate within the study. Additionally how to contact the research team if they had any concerns and or wanted to withdraw from the research at any point, without any impact on their care (Appendices 1A, 1B & 5A). Each of the following subsections address further ethical considerations where relevant for each stage of the study.

2.5 DO WOMEN OF REPRODUCTIVE AGE PRESENTING WITH PELVIC FLOOR DYSFUNCTION HAVE UNDISCLOSED ANAL INCONTINENCE: A RETROSPECTIVE STUDY (STAGE 1)

2.5.1 Rationale for theoretical framework

Extensive literature has identified the relationship of pregnancy and childbirth with pelvic floor dysfunction (PFD)[18-20]. Symptoms of PFD are often interrelated resulting in urinary and AI and pelvic organ prolapse (18, 20). Clinics, which specialise in PFD, may assess women for symptoms of PFD[21-23]. A Midwifery and Nurse led continence clinic (CNS) specialising in PFD within the research study setting routinely screened all women with PFD for AI, with a bowel-screening tool known as the St Marks Incontinence Score (Vaizey score).

The Vaizey score; a symptom severity score consisted of two scoring systems with a five-point scale, which evaluated type and frequency of solid or liquid stool loss, flatus incontinence and impact on quality of life and scored 0 (never) to 4 (daily)[24, 25]. Additionally, the Vaizey score addressed rectal urgency and use of pad or constipating medications utilising with a dichotomous scale (0 = no; 2 or 4 = yes). The scores from both scales added together and denoted continence (0/24) and incontinence (>0/24). The Vaizey score assessed AI symptoms over the four weeks; however, given the variable history of AI in pregnancy and postnatal periods, it was common practice for all CNS staff to omit the four-week timeframe[26, 27].

Selection of the retrospective design allowed for a comparison between women with known PFD who were assessed in the CNS clinic to determine whether midwives and obstetric doctors at the time of

referral did not identify AI and whether routine screening by the CNS identified AI. The advantage of utilising a retrospective design was the small sample size, ease in collecting data and a cost effectiveness[3, 4].

2.5.2 Research sample

The research sample involved a retrospective cohort study of 288 women referred to a CNS clinic with PFD from January 2011 until December 2013.Women who identified a minor PFD issue to a health professional while receiving antenatal or postnatal care (<6 weeks) were routinely referred to the CNS for telephone consultation. A review of 288 case notes during May 2014 until June 2015 was undertaken.

2.5.3 Inclusion/exclusion criteria

Women referred to the CNS with a generic hospital referral noting PFD for antenatal or postnatal women (<6 weeks) during January 2011 to December 2013 were included in the study. Women were excluded who were non-obstetric or obstetric referrals where women were non-contactable by telephone.

2.5.4 Data collection

Data extraction from the case notes utilised a systematic data collection tool (Appendix 1). Data collected included: socio-demographics, obstetric history, primary reason for referral, assessment of AI and attendance to CNS appointment. The primary researcher (JT) conducted extraction of data from the case notes, with a 10% sample also extracted by another researcher (JD) to evaluate for repeatability and reproducibility.

2.5.5 Specific ethical considerations

Ethical considerations are discussed in ethics section (2.4).

2.5.6 Data analysis

Descriptive statistics were utilised to describe the frequency of AI and its relationship to urinary incontinence (UI). Comparison of means for continuous data between two groups utilised the independent sample's t-test. The chi-square test compared categorical background data. Mean utilised Statistical software package IBM SPSS version 20.0 (SPPS Inc. Chicago. Illinois. USA).

The Cohen's Kappa measure of agreement was utilised to estimate the proportion of agreement between researcher's findings. The Kappa Measure of Agreement value was 1.00, with a significance of $P<0.0005$ and represents good agreement.

2.6 DEVELOPMENT AND VALIDATION OF SCREENING TOOLS FOR ANAL INCONTINENCE IN WOMEN OF REPRODUCTIVE AGE: A PROSPECTIVE COHORT STUDY (STAGE 2)

2.6.1 Rationale for theoretical framework

The retrospective review (section 2.5, chapter 3) of case notes identified a disparity in reporting AI by health professionals and the need to screen women. There are a number of tools utilised in clinical areas and research designed to identify AI[6, 28, 29]. However, these tools are not specifically designed for pregnant and postnatal populations and often developed without consumer participation and may be a confounding factor in nondisclosure of AI[6, 30]. The tool length and omission of symptoms including, rectal urgency, soiling and range of symptoms precluded the use of current designs as a quick and easy screening tool in women of reproductive age in clinical practice. The prospective framework assisted to answer the research question on what affected the disclosure of AI, and tested the research hypothesis.

The research recruited women afflicted by AI to help inform the development and validation of a screening tool (bowel screening questionnaire, BSQ).

The initial steps included a review of the literature, identification of current screening tools utilised in women of reproductive age; to identify commonalities, and differences in type, frequency, scales utilised in the assessment of AI. The intent of stage two of the study was to develop a quick, easy to understand objective tool to identify a history of AI in this population of women and no quality of life questions were included.

Initial items included solid, liquid stool, flatus and rectal urgency. The literature identified the variable nature of AI and the research team questioned the use of a timeframe, as this may have precluded identification of symptoms; as such, no period was included.

The research setting was in a disadvantaged area with low levels of secondary school completion. Therefore, the content of the initial questionnaire was assessed for the years of education required to understand the content by undertaking a Simple Measure of Gobbledygook (SMOG) test. The SMOG test of the BSQ achieved grade 5 (age 8 to 9 years of age) readability[31, 32]. Questionnaire items subsequently reviewed for readability and relevance by researcher (JM) supervisors (VC, EM). The initial version of the pre-test BSQ (Appendix 3B) and copies of two clinical bowel screening tools used frequently in hospital settings; the St Marks fecal incontinence score, (Vaizey score; described in section 2.5.1) and Cleveland Clinic incontinence score (Wexner score). The inclusion of the Vaizey score and Wexner score in the current study was to compare the readability, and validity in the assessment of symptoms with the BSQ. The Vaizey score was derived from the Wexner score and whilst similarities existed between the tools, the Wexner score is a non-validated tool that is reported by clinicians as being easier to implement[29]. The Wexner scoring system cross tabulated a lower symptom frequency to a total score between zero (no incontinence) to twenty (incontinence), however it was limited with the exclusion of rectal urgency[33].

Items generated for the initial questionnaires resulted from a review of literature and opinion from purposive sampling of 35 participants, which included health professionals, involved in the care of pregnant and postnatal women, and women symptomatic of AI (Fig. 2.1).

The sequential research design promoted identification of barriers to disclosing AI and importantly answered the research question “what factors impact on disclosing AI in women of reproductive age with AI[30]. The research framework included three sections; firstly test and re-test questionnaire stage, secondly test questionnaire phase and thirdly qualitative interviews. Respective chapters (section 2.7, chapter 5) provided detailed discussion on the qualitative findings.

2.6.2 Research sample

Recruitment for each stage of the research included flyers and patient information sheets (Appendices 1A, 1B, 2 & 3A). The primary researcher (JT) emailed information to all health professionals who provided care of antenatal and postnatal women for the test and re-test phase, whilst speciality midwives working within a continence team recruited women for the test and re-test questionnaire phase.

The antenatal triaging midwives in the maternity unit at the tertiary centre assisted with recruitment of pregnant women in their first trimester appointment for the pilot testing of the questionnaire and qualitative interviews.

2.6.2.1 Questionnaire design: test and re-test phase

There appeared to be no standardised number of persons required in the development of tools. Based on previous literature reporting questionnaire development for women, it appeared advantageous to achieve a broad scope of persons and 10 or more persons required for test and re-test phases of the questionnaire

development[26, 30, 34]. All health professionals (n = 30) received a generic email in the maternity unit, professionals who responded and completed all the phases were included in the analysis (Fig. 2.1).

Women attending a CNS appointment in the maternity unit outpatient setting were invited to participate in the questionnaire development by the CNS midwife. Women who were of reproductive age, and had a history of AI and completed all phases of the study were included. The number of women recruited for the initial stage was lower than study expectations (n = 10). As there were no changes to the questionnaire at test and re-test phase the research team decided 10 woman would suffice with a further 10 women recruited for a pre-pilot test the questionnaire.

2.6.2.2 Test questionnaire phase: pilot test antenatal setting

Invitation to participate in the research was offered to women who attended a first trimester antenatal appointment at the antenatal clinic, within the hospital maternity unit. Recruitment then occurred at the antenatal appointment by a midwife. The previous year's birth rate (2013) estimated the sample size of 350 pregnant women using a power of 80% and $\alpha = 0.05$.

2.6.2.3 Qualitative interviews

Participation in qualitative interviews was available for women who took part in the pilot test phase (section 2.6.2.2) of the research. The recruiting midwife provided women with members of the research team to contact for further information about the study. This allowed the potential participant time to reflect on their willingness to participate[35-37]. Qualitative interviews by nature seek to derive a deeper understanding of the issue at hand and thus recruiting a purposeful sample provided a group of women with a history of previous birth and AI and opportunity to discuss issues[3, 5]. There was no set recruitment target for qualitative interviews as recruitment continued until there was saturation of data where no new themes occurred[5, 37].

2.6.3 Inclusion/exclusion criteria

2.6.3.1 Questionnaire design: test and re-test phase

Health professionals

Eligibility for inclusion in the test and re-test phase (section 2.6.2.1) included only health professionals who provided antenatal and postnatal care of women and included consultants and registrars from the disciplines of Obstetrics and Gynaecology and Colorectal, shared care, antenatal, postnatal and domiciliary Midwives.

Symptomatic women

Women attending a CNS appointment in an outpatient setting of the maternity unit and of reproductive age with a history of AI and previous birth were included. The decision to include only multiparous women allowed for the recruitment of a homogenous group who may have been predisposed to PFD in a previous birth and increased the risk of AI.

Health professionals and symptomatic women were excluded if they had not completed a consent form, had incomplete questionnaires and or failed to return questionnaires.

2.6.3.2 Test questionnaire phase: pilot test antenatal setting

Women were included in the pilot test phase (section 2.6.2.2) if they were pregnant, had a previous birth and completed a consent form, and returned all completed questionnaires. Exclusions occurred if women were nulliparous.

2.6.3.3 Qualitative interviews

Eligibility for qualitative interviews were as stated for the test and re-test phase and pilot test. Women were only included if they had completed the BSQ during a first trimester antenatal appointment.

2.6.4 Data collection

2.6.4.1 Questionnaire design: test and re-test phase

Health professionals

This research incorporated a specifically designed questionnaire to gain an understanding of the relevance of items, readability, and clarity of the tool. This was a large tertiary setting and logistics of face-to-face feedback from health professionals was not practical. The BSQ and copies of the Vaizey score and Wexner score (Tables 1.4 & 1.5) which allowed for detailed comments were emailed to health professionals with a subsequent re-test at a 2 to 3 week interval (Appendix 3B)[38]. Completed questionnaires returned to the researcher by internal hospital mail or email.

Symptomatic women

Women recruited by the CNS midwives completed their initial questionnaire and copies of the Vaizey score and Wexner score at a subsequent time within the CNS appointment. A subsequent re-test of all study material posted by mail and followed with a phone call from the CNS midwife at 2 to 3 weeks.

All questionnaires were de-identified and allocated a number by the researcher. Data collection and coding entered into a secure database only accessible by the primary researcher (JT).

Two cycles of test and re-test phases over two to three week intervals reviewed responses and changes made to the BSQ. Following no further amendments the pre-pilot test BSQ was completed by a further group of symptomatic women (n = 10).

2.6.4.2 Test questionnaire phase

The antenatal midwives in the tertiary centre implemented the pilot version of the questionnaire (BSQ; Appendix 4). The questionnaire collected socio-demographic, obstetric history, health-seeking behaviours whilst the bowel section assessed simple binary (yes or no) questions related to AI. The women completed the Vaizey score and Wexner score at the same point in time. Coding undertaken on each questionnaire with a number anonymising responses.

2.6.4.3 Qualitative interviews

Open-ended interviews, which were tape recorded and transcribed verbatim-facilitated data collection. A semi-formal interview guide with general statements assisted with the interview process and data collection (Appendix 5). Tape recording interviews allowed the researcher and woman to immerse in the discussion[5]. Interviews where undertaken at a length, time and place convenient for the woman which allowed her time to discuss her story and provided a deeper understanding of information not previously uncovered[5, 37, 39]. Women completed all three bowel-screening tools (BSQ, Vaizey score and Wexner score) prior to the interview. Journaling a method utilised in qualitative research provided meaningful information to the findings through noting verbal and nonverbal cues often missed[5, 39]. Participants were aware the researcher transcribed all texts.

2.6.5 Specific ethical considerations

Participants provided a written consent prior to commencing the research (Appendicies 1A & 3A)

following the provision of research study information (Appendicies 1A & 2). Each form of documentation was anonymised using a coded sequence; this information was accessed by the primary researcher (JT) and password protected. Qualitative transcribed texts were assigned a corresponding numerical code and participants were assigned a pseudonym, and there was no reference to participants within the thesis.

Ethical consideration addressed above in ethics (2.4).

2.6.6 Data analysis

2.6.6.1 Test and re-test questionnaire phase and test questionnaire phase

Descriptive statistics were utilised to describe the frequency of AI and its relationship between symptomatic and asymptomatic groups. Comparison of means for continuous data between two groups utilised the independent sample's t-test. Statistical analysis was undertaken on quantitative data using SPPS version 24 (Chicago Illinois) Measures of central tendency (mean, median, and mode) and variability (standard deviation, variance). Convergent validity of the initial questionnaire (BSQ) compared to the two bowel-screening tools (Vaizey score and Wexner score) used in clinical practice areas.

2.6.6.2 Qualitative interviews

Van Manen's thematic analysis was utilised in the research[5]. Data collection, analysis and interpretation was simultaneous so analysis begins at the first interview (Fig. 2.2)[5]. Van Manen's procedural framework required the researcher to stay in touch with the research questions and aims. The backwards and forwards process of the hermeneutic circle within the research process assisted in the reflection and uncovering the essence of women's experiences of AI[5]. The repetitious reading and writing of data from journaling, audio and transcribed texts further developed meaning. The sententious, highlighting and line by line analysis approach (thematic analysis) uncovered themes and sub themes[5]. Specific data analysis considerations for qualitative interviews discussed in Chapter 5 (section 2.7).

2.7 UNDERSTANDING WHAT IMPACTS ON DISCLOSING ANAL INCONTINENCE FOR WOMEN WHEN COMPARING BOWEL SCREENING TOOLS: A PHENOMENOLOGICAL STUDY (STAGE 3)

2.7.1 Rationale for theoretical framework

Interpretive phenomenology was adopted as a framework for this research[5]. This type of research was beneficial as it allowed research into an area not well understood[3, 5]. Seeking to derive a deeper understanding of human beliefs, values and cultural experiences often omitted in quantitative research[5, 39-41]. To have excluded these experiences would have affected the true meaning of the phenomenon for both participants and researcher[41]. Interpretative phenomenology recognised the researcher as an active participant in the research process, and as someone who holds their own beliefs, values and experiences[8, 41]. The relationship of the person and their world (beliefs and values), which is referred to as co-constitution, continues to change through daily interactions[8, 41, 42]. Interpretive phenomenology required the researcher not to put aside preconceived ideas but to make prior assumptions known throughout the research process to assist with reflection on women's experiences[41]. The overarching research was the development of a screening tool to identify AI in women of reproductive age. The research question stated factors might affect the disclosure of AI when utilising screening tools. The stated assumption within this research enhanced the research validity[8].

Van Manen's hermeneutical approach was consistent with the philosophical underpinning of interpretive phenomenology[5, 40]. Van Manen framework both reflexive and reflective in nature and as new information had been derived the researchers assumptions questioned, reformulated and new meaning derived[5, 40]. This allowed for both descriptive and interpretive aspects of the experience identify the

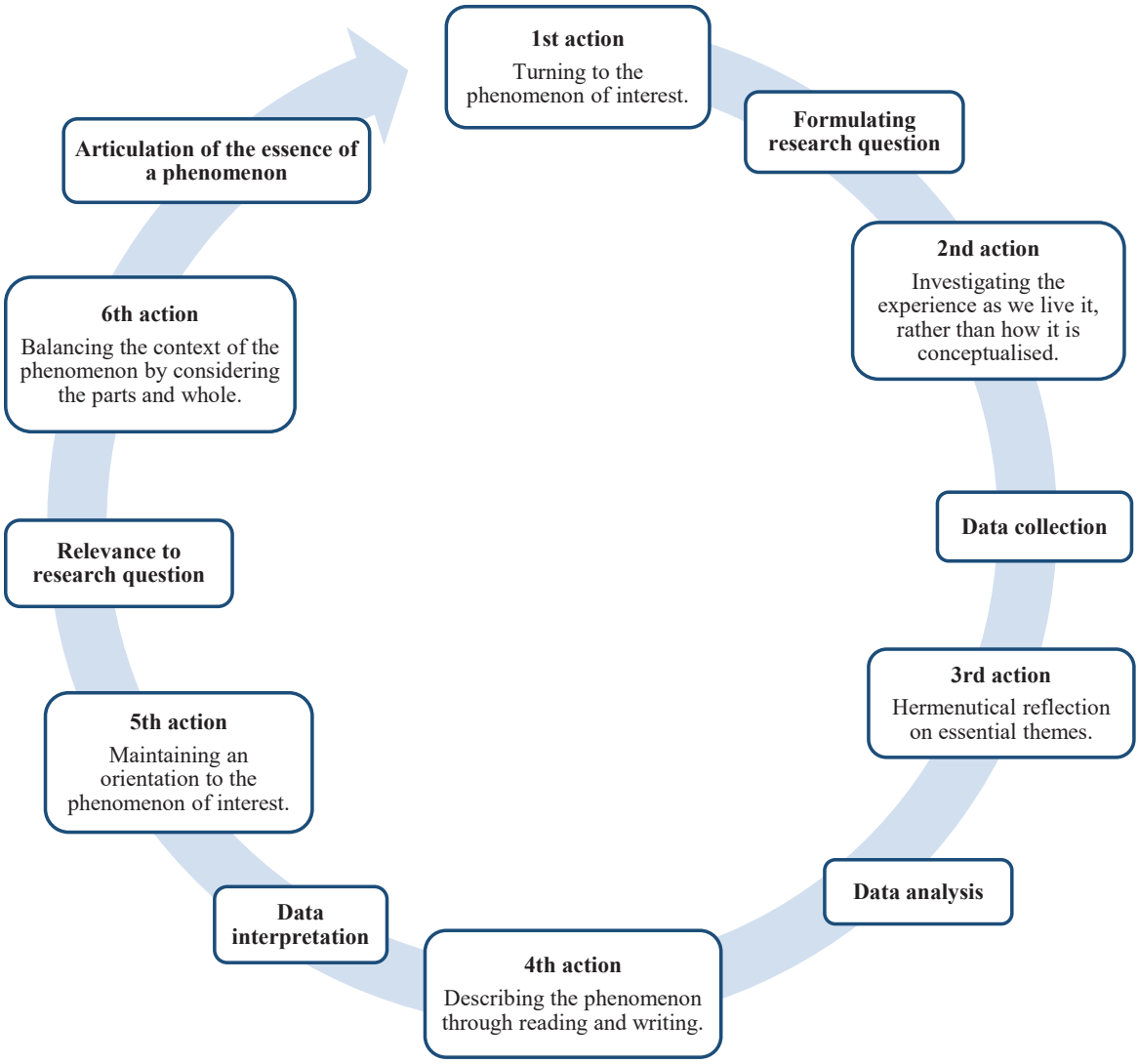

Figure 2.2. Van Manen procedural framework. Adapted from: Van Manen M. Researching the lived experience human science for an action sensitive pedagogy. USA: The state University of New York, University of Western Ontario; 1990.

inhibitors and enablers in disclosure and answered the research question. This methodology added flesh to the bones of the development of the final version of the BSQ and answered the research question "would identification of what impacted on disclosure assist in the development and validation of a tool to identify AI in women of reproductive age?" Research methods such as open-ended interviews enabled the contextual characteristics of the research issue to be illuminated[3, 5, 39].

2.7.2 Research sample

Purposeful sampling a common method used in interpretative research provided a group of women with a history of AI to recount an in-depth description of their experiences disclosing AI using screening tools[36]. Recruitment occurred through flyers and information sheets (Appendices 1A & 2) and verbal recruitment by triaging midwives at the pilot test questionnaire phase (Appendix 4).

Research interviews were undertaken at a place and time that was convenient for the woman. Prior to the interview, women completed three bowel assessment tools including pre-test BSQ, the Vaizey score and Wexner score.

Sample size within this type of research are often small due to the volume of information generated by

the participants[43]. The review of research literature identified no previous studies to guide recruitment numbers. However, qualitative research, which identified AI in women on reproductive age, contained less than ten participants[44, 45]. We aimed to derive deeper understanding of what affected disclosure therefore recruitment continued until no new themes were evident and saturation of data occurred.

2.7.2.1 Inclusion/exclusion criteria

Women were included if they had completed the test questionnaire phase and contacted the researcher to participate. Nulliparous and asymptomatic were not included.

2.7.3. Data collection

Van Manen's six procedural stepped framework underpinned the research. The procedural framework guided data collection, analysis and interpretation (Fig. 2.2). Van Manen described these actions as interconnecting, as such they are not lineal steps but seen as an ongoing cyclic process informing each stage[5]. For the purpose of thesis format, data collection section will detail the first two procedural actions and the final four procedural actions described in data analysis.

2.7.3.1 Van Manens' procedural framework: turning to the phenomenon of interest

An important step in the research process was acknowledging an area of interest, making known any prior beliefs and then immersing oneself into the experience[5]. The researcher's current clinical practice included women of reproductive age with PFD and AI. This area provided a strong interest for the current research and led to the development of the research questions. As the researcher acknowledging and bringing to the foreground preconceived ideas that disclosure of AI may be limited by screening tools in current clinical practice, allowed for those beliefs to be challenged, refined and develop a deeper understanding of women's experiences[46]. Stating preconceived ideas at the commencement of the research enhanced confirmability of the research[8, 39]. Confirmability including credibility, dependability and transferability were important aspects to judge rigor in qualitative research[39].

2.7.3.2 Investigating the experience as we live it rather than how it is conceptualised

The second procedural action investigated the 'lived experience' through semi-structured open-ended interviews, verbatim-transcribed text and journaling utilised to explore and develop an understanding of women's experiences of disclosing AI[3-5, 39]. This type of research required the researcher to be an active participant immersing in the interview process, semi structured interviews facilitated the process[47]. The credibility of the research enhanced though the recruitment process where women approached the researcher to participate in the research. Semi structured interviews were undertaken where women felt comfortable to disclose their stories and validity of the research enhanced through the reflexive and reflective process of the hermeneutic circle (Fig. 2.2).

Interview process

Audio taping interviews enabled the researcher and women to immerse themselves within the conversations, and to record the realm of emotions and depth of the women's individual experiences[5, 39]. Recording interviews enhanced the accuracy and trustworthiness of data collected[8]. A semi-formal interview guide assisted interview progress (Appendix 5) and guided questions by asking the woman to describe what it was like living with AI and to share what factors influenced or inhibited the disclosure of AI when using the three screening tools.

The style of the interview encouraged rapport and empathy through a conversational nature, with interviews, which typically lasted between 30 to 50 minutes. Journaling by the researcher provided further depth to information in the interview and included non-verbal body language and written information provided on screening tools by participants (Appendix 6)[5]. In the interviews, copies of the

screening tools (BSQ, Vaizey score and Wexner score) made available to women to assist in clarification and allowed women to describe the enablers and inhibitors in disclosure.

2.7.3.3 Specific ethical considerations

General ethical consideration addressed above in ethics (2.4).

Participants were required to provide written consent prior to commencing the research (Appendix 1A) following the provision of research study information (Appendices 1A & 2).

Prior to consenting for interviews, all women were aware that the researcher would transcribe all digital recordings. Sixteen women consented for interviews.

Women were aware that confidentiality maintained through the de-identified texts and research information stored on a secure password protected universal serial bus. Women distressed by the research were aware referral to appropriate services or withdraw from the research without penalty.

2.7.4 Data analysis

Data analysis and interpretation occur simultaneously with data collection, commencing at the first interview[5]. The remaining four procedural actions of Van Manen framework are outlined as follows; hermeneutical reflection on themes, describing the phenomenon through writing and re-writing, maintaining an orientation to the phenomenon and balancing the research context by considering the parts and whole.

2.7.4.1 Hermeneutical reflection on essential themes

Transcribed texts, audio recordings and journaling provided a depth of information in qualitative research[8]. Cues from verbal and nonverbal body language added further meaning to what was uncovered.

The backwards and forwards process of the hermeneutic circle (Fig. 2.2) within the research process assisted in the reflection and uncovering the essence of women's experiences. The repetitious listening, reading and writing of data further developed meaning through the identification of keywords, phrases and commonalities[5]. Isolation of themes stemmed from this process. Themes are complex and often interconnected in order to derive meaning an excel spreadsheet recorded all phrases and concepts. Van Manen utilised three approaches in thematic analysis. The first approach, sententious approach looked at the overall understanding of the text[5]. This required multiple reading of the text, as interpretation would vary between readers; however, the researcher continually revisited the findings asking the question do the findings represent women's experiences in disclosing AI? Initial interpretations were refined as the researcher immersed themselves within the literature elucidating and overall meaning which described the text.

The second approach, highlighting approach focused on selective reading of the text to isolate phrases, statements and repetitious words which stood out to describe the experience[5]. Audio and journal entries provided the verbal and nonverbal cues missing from the transcribed text (Fig. 2.2). Statements compared between interviews for commonalities.

The line-by-line approach was the final step in Van Manen thematic analysis and identified key word and concepts from the highlighting phase[5]. At the initial interview, emerging concepts and subthemes became evident. However, through reading, writing and further interviews commonalities were identified with main concepts and sub-themes.

2.7.4.2 Describing the phenomenon through writing and re-writing

The Hermeneutical process was a cyclical process and required attention to reading and writing multiple times to redefine and clarify meaning. The findings reviewed by the researcher's supervisor (VC & AW) to establish trustworthiness of data. The fourth procedural action included not only an overall reading of the text but a meticulous line by line approach which derived the core meaning of the experience. Journaling identified the researcher's preconceived beliefs, followed the documentation of the research process, and provided rigor for the qualitative research.

2.7.4.3 Maintaining an orientation to the phenomenon of interest

Van Manen fifth procedural action maintaining an orientation to the phenomenon of interest guided the researcher in reflection and remaining true to the research question[5]. Journaling provided information of thoughts, feelings throughout the research and questions the relevance of the research question and credibility of information collected[5].

2.7.4.4 Balancing the context of the phenomenon by considering the parts and whole

The sixth procedural action in Van Manes hermeneutical framework considered the parts and wholes of the phenomenon[5]. The cyclic nature of data collection, analysis and interpretation considered the parts in context with the whole of the experience. Thematic analysis uncovered words, phrases and concepts and described the multiple meanings of the whole experience. The individual interviews and experiences considered in relation to each other to gain a deeper understanding of the overall research question.

2.8 SCREENING WOMEN OF REPRODUCTIVE AGE WITH A NEWLY DEVELOPED SCREENING TOOL TO IDENTIFY AI (STAGES 4 & 5)

2.8.1 Rationale for theoretical framework

Findings from stage three of the research suggested revision to the BSQ format would enhance its useability. The addition of both historical (greater than four weeks) and recent history (within the last four weeks) would capture the variable nature of AI. Repeating the research in a first trimester antenatal population would identify if the BSQ produced similar findings to stage four. Additionally, the hormonal influences on the pelvic floor in pregnancy and childbirth have been associated with an increased risk of AI. Undertaking research in women of reproductive age in a similar demographical area population would identify if the BSQ produced similar prevalence rates of AI (stage 5).

2.8.2 Research sample

Antenatal setting

Recruitment for the research included flyers and patient information sheets (Appendices 2 & 5A). The triaging midwives at the tertiary centre assisted with recruitment of pregnant women. Invitation to participate in the research was open to women attending their first antenatal booking at a large tertiary centre. Recruitment occurred at the first trimester antenatal booking by the antenatal midwife. The previous year's birth rate 3333 (2013) estimated the sample size of 350 pregnant women using a power of 80% and $\alpha = 0.05$. Antenatal midwives provided with education from the researcher (JT) on research and bowel screening tool.

Community setting

Recruitment for each stage of the research included flyers and patient information sheets (Appendices 2 & 5A). Doctors and researcher (JT) recruited women of reproductive age in a large general practitioner community health centre in the northern suburbs of South Australia (Adelaide Unicare, The University

of Adelaide). The community sample size based on the sample utilised in the antenatal setting for the BSQ in sections 2.6, 2.7 and 2.8.

2.8.2.1 Inclusion/exclusion criteria

Antenatal setting

Women were included if they were pregnant and had a previous birth. Exclusions occurred if women were nulliparous. Participants were only included if they had completed a consent (Appendix 5A) form and returned completed questionnaires (Appendix 7).

Community setting

Women were included if they were of reproductive age (15 to 50 years) and had a previous birth and not pregnant. Exclusions occurred if women were nulliparous. Participants were only included if they had completed a consent form (Appendix 5A) and returned completed questionnaires (Appendix 7).

2.8.3 Data collection

Antenatal setting

The antenatal midwives in the tertiary centre implemented the final version of the questionnaire (BSQ) (Appendix 7). The questionnaire sort to elicit demographic and obstetric history, whilst the bowel section asked five simple questions related to AI. Coding of each questionnaire with a number anonymising responses. Reliance on participant recall increases the risk of inaccurate reporting therefore extraction of data from the case-notes by the same researcher (JT), with a 15% sample also extracted by another researcher (JD) to evaluate for repeatability and reproducibility.

Community setting

Women attending a community health centre for their general practitioner appointment completed the BSQ (Appendix 7) Data collection; coding and anonymising responses completed as outlined above in the antenatal setting (2.8.3). Additional data obstetric, demographic characteristics and body mass index (BMI) were identified and assessed probable causation for AI. Participants recalled their weight and height to calculate BMI.

2.8.4 Specific ethical considerations

Ethical consideration addressed above in ethics (2.4).

2.8.5 Data analysis

Descriptive statistics were utilised to describe the frequency of AI and its relationship between symptomatic and asymptomatic groups. Comparison of means for continuous data between two groups utilised the independent sample's t-test. Statistical analysis was undertaken on quantitative data using SPPS version 25 (Chicago Illinois) and SAS 9.4 (SAS Institute Inc., Cary, NC, USA). Measures of central tendency (mean) and variability (standard deviation, variance), ordinal logistics generalized estimating equation (GEE) models for historical and current reporting of AI. Odds ratio (ORs), 95% confidence intervals (CIs) and P values. The associations between a history and current AI were analysed in relation to ethnicity, delivery mode, perineal outcome, age, BMI, gravida and parity using binary logistic regressions and results reported as odds ratios (OR) with confidence intervals (95% CI) and P values.

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Chapter 3

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Overall percentage (%)	100
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By signing the Statement of Authorship, each author certifies that:
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Do women of reproductive age presenting with pelvic floor dysfunction have undisclosed anal incontinence: a retrospective cohort study

ABSTRACT

Background: Indirect and direct trauma following vaginal birth can negatively impact on the pelvic floor function increasing the risk of anal incontinence. It is often difficult for women to openly disclose that they have anal incontinence and there are limited data collection tools available for the identification of these women in a clinical setting.

Aim: This study aims to describe the prevalence of undisclosed anal incontinence in antenatal and postnatal women with pelvic floor dysfunction.

Methods: Retrospective cohort study of 230 antenatal and postnatal women referred to a Continence Nursing Service in a large tertiary hospital in South Australia, Australia, with pelvic floor dysfunction. A criteria list was utilised to access the primary reason for referral, anal incontinence assessments and attendance to an appointment.

Results: Anal incontinence was identified in 26% of women (n = 59). Anal incontinence was the primary reason for referral amongst 8 women, with the remaining 51 women identified as having anal incontinence following clinical screening via phone consultation. Eighty six percent of women stated they had not previously disclosed anal incontinence to health professionals. Overall, 71% of symptomatic women (n = 28 antenatal and n = 14 postnatal women) attended appointments to a service specialising in pelvic floor dysfunction.

Conclusion: Women presenting with urinary incontinence or other markers of pelvic floor dysfunction should be actively screened for anal incontinence, as the prevalence of this condition is high amongst childbearing women.

Keywords: Anal incontinence, women, reproductive age, clinical screening.

Summary of relevance

Problem	Anal incontinence is underdiagnosed in pregnant and postnatal women.
What is known	Direct and indirect trauma to nerves, muscles and pelvic floor structures for two-thirds of first time mothers following vaginal birth contributes to pelvic floor trauma and pelvic floor dysfunction on the pelvic floor resulting in increased risk of anal incontinence. Disclosure of incontinence is difficult for women experiencing this problem and there is no routine screening in most clinical settings for this condition.
What this paper adds	Routine clinical screening for anal incontinence identified a significant amount of symptomatic women. Once identified women are willing to attend clinical appointments for assessment and management of this condition, indicating that appropriate measures to encourage disclosure of this problem can lead to improved care of these women.

3.1. INTRODUCTION

An intact perineum following vaginal childbirth is not a true indicator that a pelvic floor is undamaged[1]. There is growing evidence that direct and indirect trauma to nerves, muscles and pelvic floor structures occur in 66% of first time mothers following vaginal birth contributes to pelvic floor dysfunction[2-5]. Pelvic floor dysfunction symptoms include bladder prolapse, vaginal prolapse, rectal prolapse and urinary and faecal incontinence[6, 7]. The aetiology of pelvic floor dysfunction is multi-factorial and includes genetic background, nutrition, hormonal changes to the pelvic floor in pregnancy and medical

co-morbidities[8]. However, mechanical and neural trauma can follow vaginal birth and are major risk factors pelvic floor dysfunction[4, 7, 8]. Pelvic floor dysfunction symptoms are interrelated and the risk of worsening symptoms are compounded through subsequent childbirth and ageing[5, 6].

Obstetric anal sphincter injury (OASIS) and neural damage are risk factors for anal incontinence (AI)[6, 9-11]. AI is defined as the accidental loss of solid or liquid stool and flatus[12]. The prevalence of OASIS is reported between 0.6% and 9% of women, however ultrasound findings suggest this is underreported, with 20% to 41% of women presenting with missed or occult sphincter damage on endo-anal ultrasound[6, 13, 14]. In women with a documented OASIS, the prevalence of AI is variable and reported between 7% and 74% of women[14-16]. Disclosure of AI to health professionals is often complex for women as it is a debilitating condition which negatively impacts on the physical and psychological wellbeing of young women's lives and results in underreporting of this complaint[17]. Research identifies routine clinical screening could identify women who have not previously disclosed AI, but current evidence suggests there is no universal, routine screening for AI in pregnant and postnatal women[1, 10, 16, 18, 19].

The early identification of AI can result in the improvement of short and long-term health outcomes for those afflicte[d1, 18, 20, 21]. Once identified, then appropriate clinical approaches can be introduced and reduce the deterioration of this condition over time and providing women with options of care to improve their quality of life[20, 22, 23]. However, there appears to be no routine clinical screening for AI in this group of women. We have retrospectively examined whether pregnant and postnatal women referred to a Continence Nursing Service (CNS) for any pelvic floor dysfunction (PFD) had a complication of AI using a validated screening tool, the St Marks faecal incontinence score (Vaizey score)[24]. The purpose of this analysis was to determine whether AI was unidentified at the time of referral by health professionals, which may explain why it is underreporting in at risk women. Additionally we assessed how many symptomatic women who were offered further assessment at a service, which specialised in bowel control attended appointments.

3.2. METHODS

Ethics approval was received through two Human Research Ethics Committees; University of Adelaide Human Research Ethics Committee and the Adelaide Health Service Human Research Ethics Committee.

This retrospective cohort study was completed during May 2014 to May 2015 and involved a review of 288 case-notes for women referred to the Continence Nursing Service (CNS) at a Level 2 tertiary centre in Adelaide, Australia, during January 2011 to December 2013. The CNS specialises in behavioural management of pelvic floor dysfunction (PFD) and routinely screens women with the St Marks Vaizey incontinence score for AI. Women (n = 230) were eligible for review if the referral was for antenatal and postnatal women (<6 weeks postpartum; Fig.3.1). Women of non-reproductive age (n = 22), and non-contactable phone consults (n = 36), were excluded.

A systematic data collection tool specifically designed for the research extracted data from case notes (Appendix 1). Data collected within this research included: demographics, obstetric history, primary reason for referral, assessment of AI and attendance to CNS appointment. Data extraction from the case-notes by the same researcher (JT), with a 10% sample also extracted by another researcher (JD) to evaluate for repeatability and reproducibility.

Indication for primary referral was identified from the generic hospital referral within case-notes. Health care providers do not routinely question women about continence status and referrals are often generated as a result of women initiating a concern. A primary health care provider at antenatal or postnatal contact completed referrals. Referrals were actioned by CNS within 1-3 days of receipt. Referrals were grouped as urinary incontinence (UI), AI, UI and AI; other complaints. Other complaints included constipation, obstructed defecation, pelvic floor laxity and haemorrhoids. Demographic details were included to describe the profile of the women. Age, previous pregnancies and births were collected to identify correlation to AI.

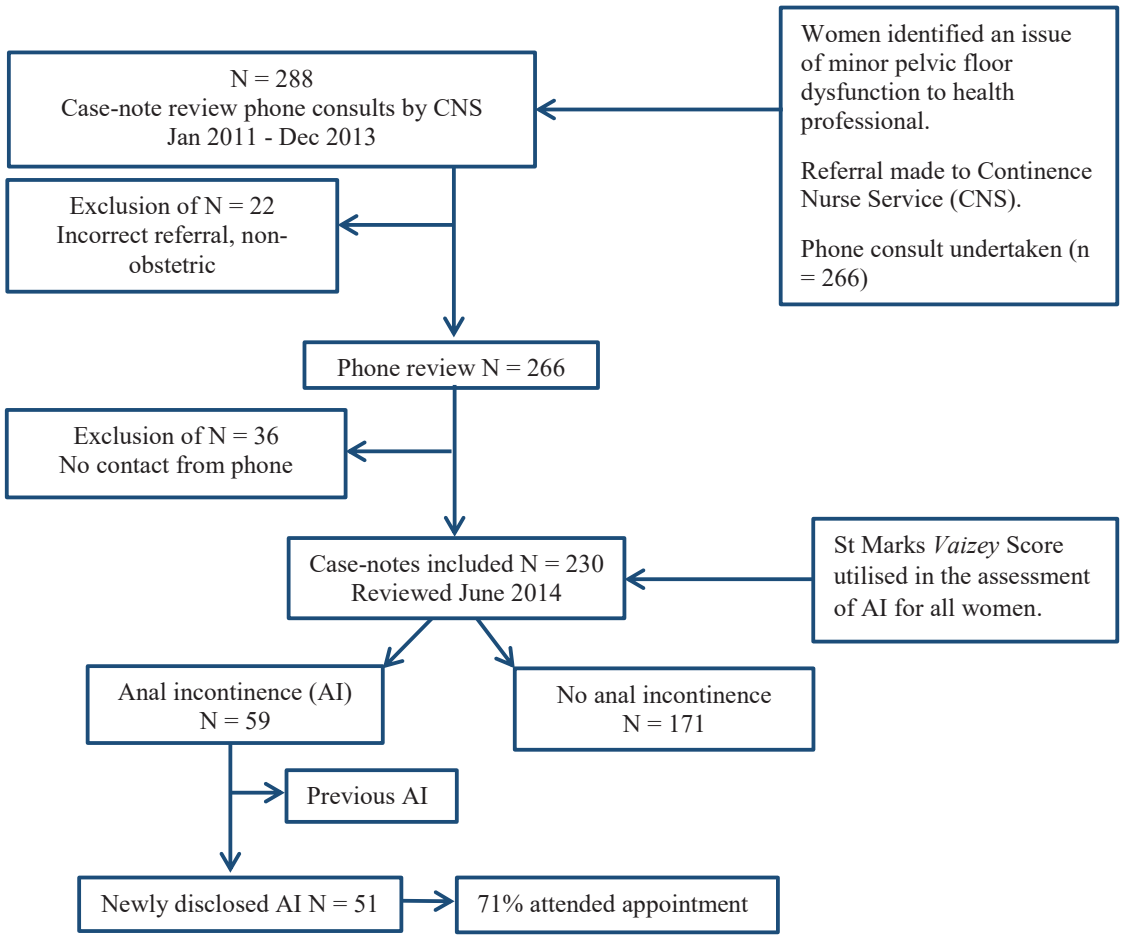

Figure 3.1. Flow chart of study participants (n = 230).

AI was defined as the involuntary loss of liquid, solid stool and flatus[12]. AI symptoms were identified by the CNS during initial phone consultation, utilising a validated assessment tool, the Vaizey score[24]. The Vaizey score consists of two scoring systems with a five point scale which evaluates type and frequency of solid/liquid stool loss, flatus incontinence and impact on quality of life[24, 25]. Additionally, the Vaizey addresses rectal urgency (no = 0; yes = 4) and use of pad or constipating medications (no = 0; yes = 2). The scoring system denotes continence (0/24) or incontinence (>0/24). The Vaizey score assesses AI symptoms over the past month; but given the variable history of AI in pregnancy and postnatal periods, it is common practice for all CNS staff to omit the month timeframe[10, 18]. If symptomatic, women were also asked whether they wished to be referred to a service which specialised in pelvic floor dysfunction (Fig. 3.1).

3.2.1 Statistical methods

Ten percent of data collection utilising the systematic data collection tool assessed for inter-rater agreement reliability between the researchers (JT) and assisting researcher (JD). The Kappa measure of agreement was utilised to estimate the proportion of agreement between researcher's findings. The Kappa Measure of Agreement value was 1.00, with a significance of $P<0.0005$ and represents good agreement

Descriptive statistics were utilised to describe the frequency of AI and its relationship to UI. The independent sample's t-test compared means of continuous data between two groups. Categorical background data compared utilising chi- square test. Mean or median scores where appropriate were derived for age, parity, Vaizey score. Statistical analysis utilised Statistical software package IBM SPSS version 20.0 (SPPS Inc. Chicago. Illinois. USA).

3.3 RESULTS

A total of 288 referrals were made to the CNS specialising in pelvic floor dysfunction (Fig. 3.2). Women were excluded if they were of non-reproductive age (n = 22) or not contactable by phone (n=36) leaving 230 women for analysis. Women were referred to the CNS by antenatal and postnatal midwives (82%, n = 188), obstetric and colorectal doctors (11%, n = 26) and other health providers (physiotherapists, mental health nurses) (7%, n = 16). Referrals included antenatal (53%, n = 122) and postnatal (47 %, n = 108) women. Antenatal referrals (69%) were predominately within the late 1st or early 2nd trimester. The range of pregnancies and births for antenatal women were reported between 1and 15 respectively with a mean of 3.6 pregnancies and 1.8 births. Postnatal women reported between 1 and 8 pregnancies and births with a mean of 2.7 pregnancies and 1.9 births. Women were predominantly Caucasian, married and/or in a defacto relationship. Within the cohort, the median number of previous pregnancies was 3.2 (Table 3.1). The mean age of the women was 28 years, and the mean number of births was 1.9.

The primary reason documented on the initial referral for the phone contact group (n = 230) included subgroups UI; 67.9% (n = 156), AI; 1.7% (n = 4), AI/UI; 1.7% (n = 4) and other complaints 28.9% (n = 66; Table 3.1). It was difficult to further define the type of UI as stress, urge or both, given the inaccuracy of reported case-note data and referrals.

Following the phone consultation, disparity existed between the initial reason for referral and what women identified as the primary problem where UI was confirmed in 52.1% of women (n = 120), AI identified in 8.3% of women (n = 19), AI/UI identified in 17.4% of women (n = 40) and other complaints reported in 22.2% of women (n = 51; Fig. 3.2).

The incidence of pelvic floor dysfunction was higher in women (n = 120) with UI symptoms (Table 3.2). AI was reported by 26% of women (n = 59) of which dual incontinence was reported by 17.4% of women (n = 40). Women with AI and AI/UI were more likely to be pregnant with a third pregnancy (SD 2.4– 2.5) with parity >2.1 (SD 1.4-1.6). However, these parameters were not statistically significant. Women with both AI/UI had a higher mean Vaizey of 5.5 (SD 3.7) whereas women with AI alone had a mean Vaizey score of 3.4 (SD 3.1). There was a significant difference (t-test P = 0.001) between Vaizey scores for AI/UI relative to women who reported AI as a sole complaint.

AI symptoms consisted of non-specified AI (n = 9), rectal urgency (n = 6), flatus incontinence (n = 23) and flatus and urgency noted often as dual complaints (n = 21). Fourteen percent (n = 8) of women were primarily referred with a history of AI and 86% of women (n = 51) had not disclosed a history of AI, and were identified following clinical screening.

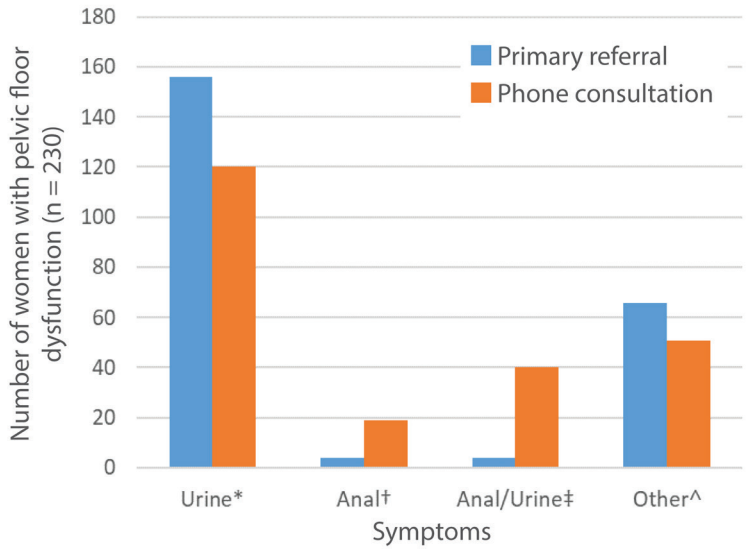

Figure 3.2 (left). Reason for referral to CNS service pre- and post phone screening (n = 230). Abbreviations: †AI, anal incontinence; ‡AI/UI, anal and urinary incontinence; *UI, urinary incontinence; ^Other, complaints consisted of constipation, haemorrhoids and pelvic floor laxity.

Table 3.1. Demographic details of contactable study participants (n = 230). Abbreviations: †AI, anal incontinence; ‡AI/UI, anal and urinary incontinence; *UI, urinary incontinence; ^Other, complaints consisted of constipation, haemorrhoids and pelvic floor laxity. ˇSD, standard deviation.

Criteria	Number of contactable participants
Number (n)	230
Mean age in years (SD)ˇ	28 (5.9)
Ethnicity	
Caucasian, n (%)	192 (83.5)
Other	38 (16.5)
Marital status, n (%)	
Married/de facto	223 (97)
Other	7 (3)
Employed, n (%)	93 (40.4)
Pregnancy, mean (SD)	3.2 (2.3)
Births, mean (SD)	1.9 (1.3)
Referral, n (%)	
Antenatal	122 (53)
Postnatal	108 (47)
Vaizey score, mean (SD)	1.2 (2.8)
Indication for referral, n (%)	
AI†	4 (1.7)
AI/UI‡	4 (1.7)
UI*	156 (67.9)
OTHER^	66 (28.7)

Table 3.2. Patient characteristics according to type of incontinence identified following phone consultation (n = 230). Abbreviations: AI, anal incontinence; UI, urinary incontinence, other complaints consisted of constipation, haemorrhoids and pelvic floor laxity.

Criteria	AI†	AI/UI‡	UI*	Other^	P value
Number (n)	19	40	120	51	
Mean age (SD)ˇ	30(6.1)	29 (6.1)	28(6.3)	27.5 (4.1)	0.661
Ethnicity, n (%)					
Caucasian	16 (8.3)	32 (16.7)	104 (54.2)	40 (20.8)	0.572
Other	3 (7.9)	8 (21.1)	16 (42.1)	11 (28.9)	0.572
Marital Status, n (%)					
Married/defacto	16 (7.2)	39 (17.5)	117 (52.5)	51 (22.9)	0.860
Other	3 (42.9)	1 (14.3)	3 (42.9)	0 (0)	0.860
Employed, n (%)	9 (9.7)	15 (16.1)	45 (48.4)	24 (25.8)	0.220
Referral, n (%)					
Antenatal	12 (6.5)	24 (19.7)	58 (47.5)	28 (23.3)	0.893
Postnatal	7 (9.8)	16 (14.8)	62 (57.4)	23 (20.3)	0.893
Pregnancy, mean (SD)	3.5 (2.5)	3.8 (2.4)	3.1 (2.4)	2.9 (1.8)	0.730
Births, mean (SD)	2.1 (1.6)	2.2 (1.4)	1.8 (1.4)	1.8 (1.1)	0.678
Vaizey score, mean (SD)	3.4 (3.1)	5.5 (3.7)			0.001

All women with a history of AI were offered and accepted appointments to a service specialising in bowel control. Overall 71% of symptomatic women (n = 42) attended appointments.

3.4 DISCUSSION

The current data indicates that utilising a bowel-screening tool identified AI in this cohort of women. Symptoms of AI were highly prevalent in antenatal and postnatal women who were primarily referred to the CNS clinic for UI. The presence of the dual complaint of AI and UI are consistent with recent research which indicates there is a relationship between AI and other pelvic floor complaints[26]. Flatus and rectal urgency were often noted as the dual complaints. The identification of these symptoms is imperative as research suggests these symptoms identify pelvic floor dysfunction and are indicative of worsening continence status across the lifespan[27, 28]. Subsequent births and ageing are associated with an increased risk of AI and worsening symptoms, and this is supported by research that identified AI was more prevalent in older women who had two or more deliveries[29]. The communication of a history of AI for subsequent pregnancies is vital for reducing further impact on an already compromised pelvic floor and further supports current research findings of the importance of using a screening tool to identify AI in pregnant women[1, 26].

Our data indicated that an enquiry for AI by specialist health care providers for women who present with other symptoms of pelvic floor dysfunction, identified AI in 26% of women utilising a symptom severity tool. In addition, there is evidence in the literature that direct enquiry of AI symptoms can elicit a response about continence status from sufferers, yet this questioning often does not occur and indicates a screening tool is required[30]. Development and utilisation of a routine screening tool for the identification of AI in reproductive age women will assist clinicians in improving the identification of AI and expediting access to health care services[31, 32].

Women with AI often do not seek help for their condition and conceal its existence for multiple reasons, which include stigma; belief that AI is normal sequelae of childbirth, and an acceptance of learning to live with a chronic condition[20, 22, 23, 31, 33]. Additionally, a study by Tucker and colleagues identified women were determined to maintain their role in society and in-order to cope and remain socially acceptable they often kept AI hidden[17]. Health professionals associated with obstetrics and gynaecology are best placed to enquire about continence status in reproductive aged women. Thus, referrals for women within this study were from a range of health care providers involved in ante and postnatal care. However, there was disparity between the identified concern at initial referral and the identified condition following phone consultation using the St Marks Vaizey score where AI was subsequently identified in 26% of women. The disparity of results may be explained by non-disclosure of symptoms at initial contact, however the data reported that utilising a screening tool identified AI and this raises the question of whether we are adequately screening reproductive aged women for pelvic floor dysfunction.

Attendance at a service which specialised in pelvic floor dysfunction was accepted by all symptomatic women (n = 59) with an overall attendance rate of 71% to specialists services. These findings provide evidence that women will disclose AI when questioned using an appropriate tool and most will accept further services to improve their health outcomes.

3.4.1 Strengths and limitations

Strengths of this retrospective cohort study are that this research identified that the utilisation of the St Marks Vaizey screening tool identified AI in women, which was unidentified at initial referral. This study is unique as it reports the findings from a health service which currently utilises a standardised bowel screening tool for AI in this cohort with pelvic floor dysfunction. A positive acceptance and attendance to appointments provides evidence that routine screening is advantageous for this group of women. Considerable research exists which identifies AI in late pregnancy and the postnatal period , the findings of this research provide information in an area where few studies have examined AI in early gestation and in the early postnatal period of 6 weeks.

The overall small study population limits the potential to establish statistically significant differences between groups, where clinically significant differences may exist. Selection bias may have existed in this cohort as women are not routinely questioned about pelvic floor dysfunction by health care providers and only women who identified with symptoms were referred. Women referred to the CNS had some form of pelvic floor dysfunction and therefore may be at an increased risk of AI. Non-disclosure of symptoms by women may account for disparity in reporting of AI at initial contact with health providers. Original data entry was completed by multiple health professionals which potentially increases the risk of errors in data selection, collection and entry into the database. Additionally the continence status of women within the non-contactable group could not be assessed or compared.

3.5 CONCLUSIONS

Indirect and direct trauma to the pelvic floor structures and nerve pathways following vaginal delivery negatively affects pelvic floor function in reproductive aged women increasing the risk of a lifelong condition of AI. It is evident from this research that routine clinical screening for AI utilising the St Mark's Vaizey score successfully identified AI in antenatal and postnatal women. This indicates the prevalence of this condition is high amongst reproductive aged women with urinary incontinence or other pelvic floor dysfunction. Furthermore, this study indicates it would be advantageous to use a screening tool for AI in all reproductive aged women presenting to health professionals for maternal, obstetric and gynaecological care.

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Chapter 4

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Development and validation of a tool to identify anal incontinence in women of reproductive age: mixed method research

ABSTRACT

Objective: Anal incontinence is associated with direct or indirect mechanical and neuromuscular trauma to the pelvic floor during pregnancy and childbirth. Subsequent pregnancies and childbirth worsen symptoms. Health professionals specializing in the care of pregnant and postnatal women rarely screen all women for anal incontinence and there is no evidence of specific screening tools developed for routine use in this group of women. This mixed method research aimed to design and validate a tool to be utilized in routine clinical practice.

Methods: Test and re-test phase included 45 health professionals and women of reproductive age. The specifically designed bowel screening questionnaire BSQ) was utilized with the St Marks fecal incontinence score (Vaizey score) and the Cleveland score (Wexner score) in 358 prospectively recruited antenatal parous women attending their first antenatal screening. Qualitative interviews reinforced the strengths and limitation of all three screening tools.

Results: The reliability of the bowel-screening questionnaire identified internal consistency at all stages in development with a Cronbach alpha coefficient reported P >0.919 (excellent internal consistency). In the pilot test, 99% of participants recruited completed the BSQ, 33% completed the Vaizey score and 36% completed the Wexner score. Qualitative interviews provided evidence for low completion rates for the latter two tools, which included variable reporting of symptoms, and difficulty in understanding clinical terms. A history of AI was reported in 191 (53%) of the total population utilizing the BSQ. Symptomatic women reported AI in the BSQ (100%) compared to lower reporting with the Vaizey score (62%) and Wexner score (68%). The predominant symptoms identified were rectal urgency (n = 40; 21%) and flatus incontinence (n = 48; 25%).

Conclusion: The newly bowel screening tool is a reliable and valid tool, which identified a high prevalence of anal incontinence in women of reproductive age. Predominant symptoms included the inability to hold on (rectal urgency) and gas or wind. The variability of symptoms not captured in current clinical tools was the main concern for most women.

Keywords: Anal incontinence, pregnant, screening.

4.1 INTRODUCTION

Anal incontinence (AI) is the accidental loss of faeces and gas with associated physical, social and financial implications[1]. A woman's risk of incontinence, is associated with trauma to the pelvic floor during pregnancy and childbirth[2, 3]. Symptoms are variably reported with rates of AI varying from 8% to 65% in late pregnancy and from 3% to 39% in the postpartum period[4-7]. Subsequent pregnancies and childbirth can further compromise the pelvic floor, compounding symptoms for women across their lifespan[8, 9]. The obstetric literature identifies risk factors for pelvic floor dysfunction (PFD), and obstetric anal sphincter injury (OASIS) and its relationship to incontinence following childbirth, but does not suggest or provide evidence to support routine screening for AI in pregnant and postnatal women[3]. Some clinicians do undertake routine screening in the population at risk for AI, particularly when working in clinics specialising in PFD[10-12].

Many tools utilised are developed for the general population and are not specific for pregnant or postnatal women (Table 4.1)[13]. There are similarities between the screening tools in the items measured to assess AI with scoring systems that include incontinence to solid and liquid stool, flatus incontinence, rectal urgency with a frequency scale range of symptoms and the inclusion of quality of life questions[14, 15]. However, clinically derived screening tools are limited with a lack of standardised definitions, and variations in the symptoms assessed[13, 15].

Table 4.1. Comparison of symptom severity scores used in women of reproductive age. Pelvic floor inventory questionnaire (PFIQ-7) (includes colorectal anal impact questionnaire 7 CRADI-7), Pelvic floor distress inventory (PFDI-20) (includes Colorectal Anal distress inventory CRADI-8), Wexner score (Cleveland clinic score), Rapid assessment faecal incontinence score (RAFIS), Modified Miller score (Rothenberg score), St Marks faecal incontinence score (Vaizey score), Manchester Health Questionnaire (MHQ), International consultant on incontinence questionnaire- bowel (ICIQ-B), Faecal incontinence severity index (FISI), FIQoL, Danish anal sphincter rupture questionnaire (ASR), Australian Pelvic floor Questionnaire (FPFQ).

Research instrument	Number of questions	Liquid	Solid	Flatus	Urge	Frequency scale	Other	Timeframe in weeks
APFQ	70 (12 Bowel)	✓	✓	✓	✓	✓	×	Not specified
ASR	33 (12 FI)	✓	✓	✓	✓	×	×	Not specified
FIQoL	29	×	×	×	×	×	QoL	Not specified
FISI	4	✓	✓	✓	×	✓	Mucous	4
ICIQ-B	21	✓	✓	✓	✓	✓	Staining	12
MHQ	31 (12 Bowel)	✓	✓	✓	✓	✓	Passive soiling	Not specified
Vaizey score	8	✓	✓	✓	✓	✓	QoL	4
Modified Miller	4	✓	✓	✓	×	✓	×	Not specified
Parks score	4	✓	✓	✓	×	×	×	Not specified
Pescatori scale	3	✓	✓	✓	×	✓	Mucous	1
RAFIS	6	Not stated	Not stated	Not stated	Not stated	Not stated	Only leakage frequency	4
Wexner score	5	✓	✓	✓	×	✓	QoL	Not specified
PFDI-20	20 (8 Bowel)	✓	✓	✓	✓	✓	×	12
PFIQ-7	21 (7 Bowel)	×	×	×	×	×	QoL	12

The tools preferred by clinicians for assessing AI are often the Cleveland Clinic score described by Wexner and the St Marks score described by Vaizey[16]. Whilst many clinicians favour the Wexner score, it does not measure rectal urgency[5, 14, 17-25]. The Vaizey score unlike the Wexner score is validated and defines AI as including rectal urgency over a four-week timeframe.

Previous research[26] has demonstrated that urgency and incontinence to flatus are predominant symptoms in women of reproductive age and likely to be indicative of damage to the external anal sphincter during vaginal birth and a precursor for worsening function in subsequent births[27-30]. The ability to screenfor these symptoms is therefore important.

There is no doubt that language and clinical terminology in questionnaires, limits the disclosure of this serious affliction[31, 32]. The health literacy of a woman can affect her ability to understand the importance of disclosing AI, further impacting on her ability to access care and can also influence her understanding of written information[32, 33]. Lack of understanding may be further compounded within tertiary birthing centres that care for a high number of multicultural diverse and socially disadvantaged women[34, 35].

This current research has been undertaken in a socially disadvantaged population in the outer northern suburbs of Adelaide, South Australia which has high levels of unemployment (22%), low levels of completion of secondary education (40%), high levels of sole female parenting (22%) and a reliance on public housing (27%)[35]. Negative social determinants of health disadvantage this population, contributing to poor health seeking behaviour and impairing access to services through lack of education and poor health literacy. These factors suggest that the available screening tools may not be effective in screening for AI[32, 36].

This study aimed to develop and validate a bowel-screening tool for women of reproductive age. To the best of the authors' knowledge, there is no validated questionnaire routinely utilised in clinical practice to solely screen for AI within this population of interest.

4.2 MATERIALS AND METHODS

The Human Research Ethics Committees; University of Adelaide Human Research Ethics Committee and the Adelaide Health Service Human Research Ethics Committee (HREC/14/TQEHLMHMH/58) approved this research. The study site was a large tertiary hospital in the northern suburbs of South Australia and the study was performed between December 2014 and May 2017. All questionnaires and qualitative texts were de-identified and information stored on a secure password protected Universal Serial Bus.

4.2.1 Ethical considerations

The informed consent of the women who participated was assured through participant information forms and verbal discussion with the researcher. Anonymity and confidentiality were assured by assigning a code to individual data and then the removal of all information that could link a woman to the information. Information was stored in accordance with university regulations. Participants were aware to contact the research team if they had any concerns or they wanted to withdraw from the research at any point without impact on their care.

4.2.2 Questionnaire development

The development of screening tools or health questionnaires require aspects of validity, reliability and responsiveness to be addressed[37, 38]. Development of the BSQ required a pool of items which focused on symptoms rather than a traditional disease based approach[14]. By undertaking a review of the literature to determine and assess what tools were utilised for bowel screening in women of reproductive age, the commonalities and differences noted within tools addressed aspects of the content validity[14]. The primary researcher (JT) and supervisors (VC, EM), reviewed a pool of items for inclusion in the tool. No timeframe was included in the questionnaire as research identified the variable nature of AI in pregnant and postnatal women[18, 39]. As the aim of the screening tool was to identify AI, no questions on pad use or quality of life (QoL) were included when an initial version of the BSQ was developed. The team were mindful of the demographic area the research was conducted in, and rewording of symptoms for a readability age of 8 to 9 years was undertaken. The wording of items and use of simple language, which identify AI, was an important consideration as previous research reported that the Wexner score as a preferred tool over other screening tools due to its simplicity[14]. Furthermore, incontinence and urgency are frequent terms utilised in screening tools however, they may not be understood by the general population as related research identifies discordance between tools due to lack of comprehension[31, 40]. Revision of items included changing the wording of “stool” to “poo”, “flatus to wind” or “gas”, and “defer”, to “cannot hold on” or “need to rush”. After the test to re-test phase “soiled and/or stained your underwear” were included.

Participants

The BSQ was tested and piloted with women and health professionals. Participants were only included if they had completed a consent form and returned completed questionnaires.

Women of reproductive age, who had a history of AI, were recruited in an outpatient setting by the continence nurse midwives. Initial recruitment was problematic due to disclosure of AI, however, as there were no changes to the BSQ following the first test phase, the research group concluded that 10 women at the re-test phase, and 10 women to pilot-test the BSQ was acceptable.

An email from the researcher invited health professionals including obstetricians and gynaecologists, colorectal surgeons, shared care general practitioners, antenatal, postnatal and domiciliary midwives to participate in the test to re-test phase. The response rate for the health professionals included 25 who completed the BSQ, a further five health professionals were excluded for no response (Fig. 4.1).

The test and re-test phase occurred at two to three week intervals. This process allowed for clarification of the BSQ content, questionnaire wording, relevance, page layout, response categories, consistency, and order of questions and time to complete. Participants completed two additional tools (Vaizey and Wexner scores) to assess convergent validity. There were no further changes at the second test phase. A final pilot-test and re-test occurred at a two to three week interval phase in 10 women of reproductive age, who were symptomatic of AI. No further changes were required and the final version of the BSQ for utilisation in an antenatal population included additional demographic questions and reasons for disclosure and nondisclosure of AI.

4.2.3 Testing the questionnaire - antenatal women

The sample size was derived from the previous year's birth rate of 3333 births at the relevant health service[41]. A power of 80% and alpha value = 0.05, was used to calculate the sample size and this was estimated at 350 women. Three hundred and fifty eight parous women with at least one previous birth, attending their first antenatal booking within a large tertiary hospital, completed the BSQ, Vaizey score and Wexner score. Education about the research tool prior to recruitment phase was given to the triaging midwives in the antenatal clinic.

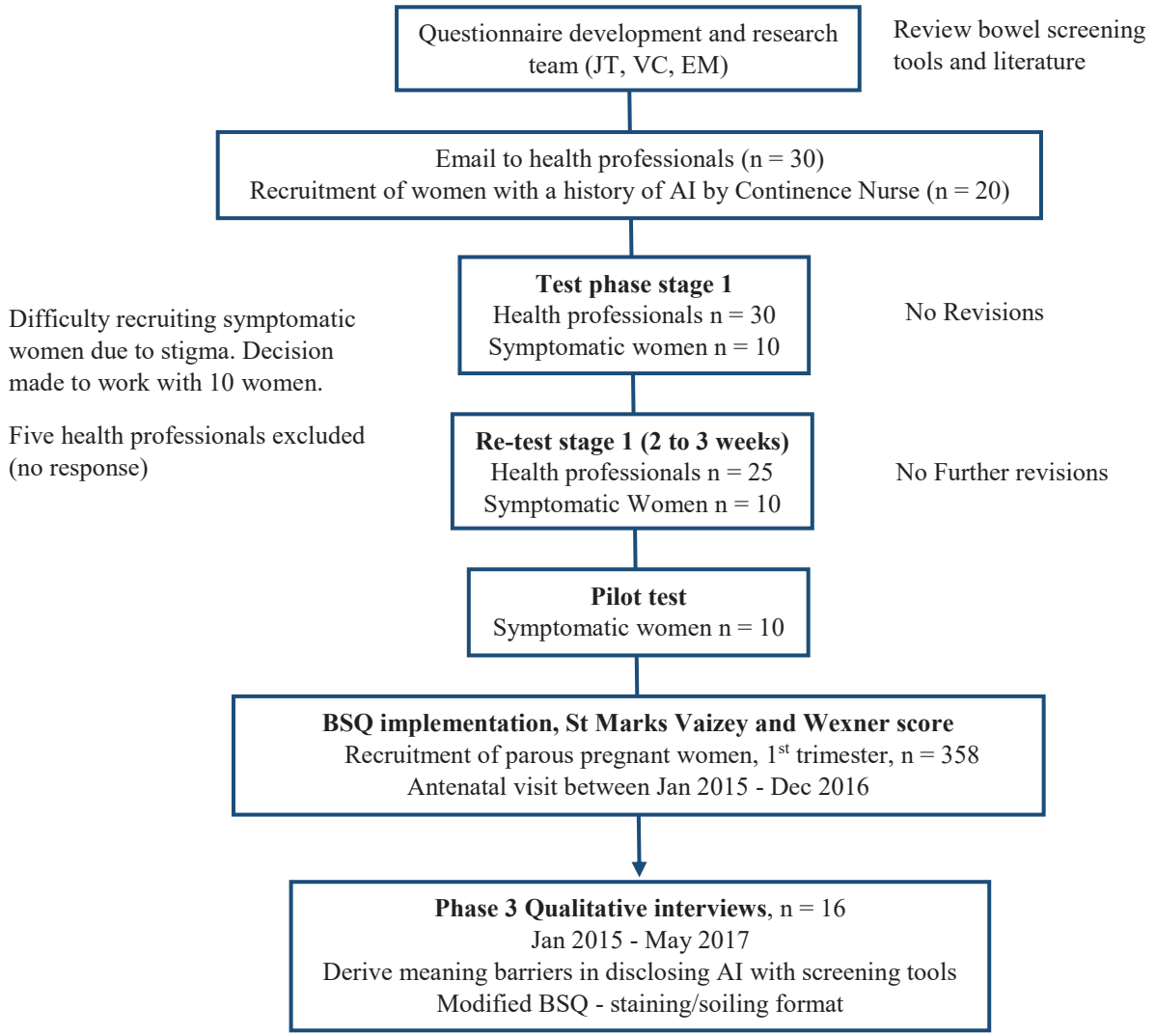

Figure 4.1. Development of screening tool flow chart.

4.2.4 Qualitative interviews

Limited information exists on the disparity in reporting between bowel screening tools in this population of women. Therefore, Interpretive Phenomenology was adopted as a framework for qualitative interviews with guided semi-structured open-ended interviews, verbatim-transcribed text and journaling to explore and develop an understanding of women's experiences of disclosing AI[42-44]. This research has been reported elsewhere[45].

4.3 DATA ANALYSIS

Descriptive statistics were utilised to describe the frequency of AI and its relationship between symptomatic and asymptomatic groups. Comparison of means for continuous data between two groups utilised the independent sample t-test. Statistical analysis was undertaken on quantitative data using SPPS version 24 (Chicago Illinois). Measures of central tendency (mean, median, and mode) and variability (standard deviation ant interquartile range) were presented. Convergent validity of the initial questionnaire (BSQ) compared to the two bowel-screening tools (Vaizey and Wexner scores) used in clinical practice areas. Qualitative data utilised Van Manen thematic analysis[43].

4.4 RESULTS

4.4.1 Questionnaire development

Table 4.2 describes the characteristics of the respondents in the test and re-test phase of the questionnaire development. This included 25 health professionals and 20 women with a history of AI who were predominately Caucasian and non-pregnant, but with a history of OASIS.

Table 4.2. Questionnaire development stage - information from health professionals and women

Health professionals (n = 25)	
Professional group, n (%)	
Midwives	12 (48)
Colorectal	2 (8)
O&G	11 (44)
Senior	24 (96)
Junior	1 (4)
Identify gender, n (%)	
Male	4 (84)
Female	21 (16)

Women (n = 20)	
Ethnicity, n (%)	
Caucasian	14 (70)
Asian	2 (10)
Middle Eastern	4 (20)
Pregnant, n (%)	7 (35)
1st trimester	4 (20)
2nd trimester	3 (15)
History AI, n (%)	20 (100)
Gravida, mean (SD)	2.55 (2.01)
Parity, mean (SD)	1.65 (1.18)
History OASIS, n (%)	
no	5 (25)
3A	5 (25)
3B	1 (5)
3C	7 (35)
4th	2 (10)

4.4.1.1 Validity of the BSQ

The initial review of screening tools at a two to three week interval addressed the content, internal validity and feasibility of the BSQ. There was a consensus from all respondents that all questions were relevant including content, clarity, flow, simplicity and language. Two minor changes were introduced following the first test phase. In the demographic section, changes included altering the wording of "delivery" to "birth". In the symptom section, the additions of soiling and staining resulting in five bowel questions with a yes or no response. At the final phase, no further changes were required and a pilot test was undertaken (Fig. 4.1). There was an acceptable reliability correlation (Cronbach's Alpha = 0.9) between the BSQ and two bowel-screening tools (Vaziey score and Wexner score) in the test, and retest and pilot test phases.

4.4.1.2 Reliability of the BSQ

Cronbach's Alpha and logistic regression assessed the degree of concordance of the BSQ. The reproducibility and reliability of the BSQ conducted at two and three-week intervals identified good internal consistency of the BSQ at all stages in development with an adequate Cronbach alpha coefficient reported P > 0.919. There was not a significant difference in mean BSQ between the test and re-test groups (P value = 0.557).

4.4.2 Testing the questionnaire - antenatal women

Comparison between screening tools and demographic characteristics are presented in Table 4.3 and 4.4. Completion rates for the BSQ (n = 356; 99%) were higher than the Vaizey score (n = 118; 33%) and Wexner score (n = 129; 36%). A history of AI was reported in 191 (53%) of the total population utilising the BSQ. Symptomatic women reported AI within the BSQ (100%) and a lower reporting with the Vaizey score (62%) and Wexner score (68%). There was agreement between the screening tools where AI symptoms compared two instruments at each point of time, examined with a Cohen Kappa's statistic. The Wexner score excluded rectal urgency, unlike the Vaizey score and BSQ.There was agreement for reported symptoms of flatus incontinence and a combination of two or more symptoms between the BSQ and the two screening tools. There was a negative agreement for liquid stool and solid stool between the Vaizey score and Wexner score.

Soiling was reported in a combination of symptoms in the BSQ (n = 3) and the written addition by a participant to the Wexner score (n = 1).

4.4.2.1 Demographic data

The demographic data for the symptomatic population was consistent with the overall population of women accessing the local hospital (Table 4.4). There was a statistically significant association between AI in the symptomatic and non-symptomatic women according to ethnicity and parity.

Using a binary logistic regression model, there was a statistically significant association between reporting of AI and ethnicity (global P value = 0.006). Asian women were less likely to report AI relative to Caucasian women (OR = 0.17, 95%, CI: 0.10, 0.24, P value = 0.0234). The prevalence of AI was higher in women who had had one previous birth to women with two or more births (57% vs 40%) (OR=1.33, CI: 1.21, 1.44, P value = 0.0011) relative to women with two or more previous births (OR =1.20, CI: 1.12, 1.32, P value = 0.034 global P value = 0.0243). There was no statistical differences between the symptomatic and asymptomatic AI groups of women's age (global P = 0.0044). For each year increase in age, the odds of a woman having AI increased 36 % (OR = 1.36, 95% CI: 1.24-1.50).

Ten percent of symptomatic women (n = 20) had previously revealed symptoms to a health care provider (Table 4.5). Reasons for nondisclosure-included variability of symptoms (48%), acceptance as a normal consequence of birth (21%), "too embarrassed" to enquire with a health professional (3%), not stated

(17%) and previously disclosed (11%). Suggestions given to improve assessment of AI included health professional direct enquiry (59%), with a screening tool (12%) that is easy to comprehend by women (5%), better information given at antenatal and postnatal visits (10%) and not stated (14%).

Table 4.3. Anal incontinence identified with screening tools in pregnant women (n = 191).
Symbols: # >2 symptoms ‡BSQ, bowel screening tool; ^Vaizey score - St Marks faecal incontinence score; †Wexner score - Cleveland score (no urgency included).

BSQ‡ n (%) (SD)	191 (100) (±0.0)	
Flatus	48 (25)	
Urge	40 (21)	
Solid	0	
Liquid	0	
>2 symptoms # n	103 (54)	
Flatus and urgency	59	
Liquid and solid	0	
Liquid and flatus	30	
Flatus, urgency and soiling	3	
All symptoms	11	
Vaizey Score^ n (%) (SD)	118 (62) (±0.49)	
Flatus	36 (30)	
Urge	3 (3)	
Solid	2 (2)	
Liquid	3 (3)	
Form ticked but no symptoms	37 (31)	
>2 symptoms #	37(31)	
Flatus and urgency	10	
Liquid and solid	1	
Liquid and flatus	15	
Flatus, urgency and soiling	0	
All symptoms	11	
Wexner score† n (%) (SD)	129 (68) (±0.47)	
Flatus	49 (38)	
Urge	0†	
Solid	1 (0.5)	
Liquid	2 (1.5)	
Form ticked but no symptoms	35 (27)	
>2 symptoms #	42 (33)	
Flatus and urgency		
Liquid and solid	0	
Liquid and flatus	18	
Flatus, urgency and soiling	1†	
All symptoms	23†	
	Cohen Kappa's statistic	**95% Confidence Interval (CI)**
BSQ and Vaizey score	0.36	0.30 – 0.43
Flatus	0.35	0.087 – 0.276
Urgency	0.79	0.002 – 0.034
2 or more symptoms	0.31	0.055 – 0.248
BSQ and Wexner score	0.37	0.31 – 0.42
Flatus	0.32	0.139 – 0.363
2 or more symptoms	0.34	0.055 – 0.248
Vaizey and Wexner score	0.77	0.69 – 0.84
Flatus	0.664	0.014 – 0.072
Liquid	-0.004	0.992 – 1.003
Solid	-0.006	0.987 – 1.002
2 or more symptoms	0.565	0.039 – 0.131

Table 4.4. Demographic details of the overall group of women, test questionnaire phase. The comparison of proportions calculator available from https://www.medcal.org/calc/comparison_of_proportions was utilized for the following analyses: Chi-square P value, Fischer's Exact Test P value, Independent T test. Percentages are identified as row percentage. Symbols: *Significant P value; #OASIS (obstetric anal sphincter injury); ^RMLE (Right medio lateral episiotomy).

Number (n 358)	Symptomatic	Not Symptomatic	P value
Anal incontinence, n (%)	191 (54)	167 (46)	0.132
Mean age in years (SD)	29.18 (±5.1)	29.26 (±5.1)	0.874
Marital status, n (%)			0.229
Married/de facto	166 (55)	138 (45)	
Other	25 (46)	29 (54)	
Employed, n (%)	96 (55)	80 (45)	0.656
Ethnicity, n (%)			0.006*
Caucasian	165 (58)	117 (42)	0.008*
Asian	14 (34)	27 (66)	0.194
Middle Eastern	4 (40)	6 (60)	0.490
African	3 (27)	8(73)	0.185
Aboriginal	2 (25)	6 (75)	0.237
Other	3 (50)	3 (50)	1.000
Parity, n (%)			0.243
1 birth	121 (57)	92 (43)	0.011*
2 birth	47 (52)	43 (48)	0.570
>2 births	23 (42)	32 (58)	0.161
Perineal outcome			
Intact	74 (52)	68 (48)	0.368
OASIS#	15 (62)	7 (38)	0.060*
RMLE^	43 (49)	44 (51)	0.853
Small tear	25 (50)	25 (50)	0.625
1st degree tear	25 (52)	23 (48)	0.832
2nd degree tear	24 (48)	26 (52)	0.392
Mode of birth, n			
Normal vaginal	99 (53)	89 (47)	0.782
Instrumental*	28 (53)	32 (47)	0.934
Caesarean section	40 (56)	32 (44)	0.675
Combination all modes	24 (53)	21 (47)	0.998

Table 4.5. Reasons for previous non-disclosure of anal incontinence in pregnant women (n = 191).

Previously Disclosed AI, n (%)	
Yes	20 (10.4)
No	159 (83.3)
Not stated	12 (6.3)
Reason for non-disclosure, n (%)	
Variable symptoms	92 (48)
Acceptance as normal post birth	41 (21)
Embarrassed /waited to be asked by health professional	6 (3)
No reason given	32 (17)
Disclosed previously	20 (11)
What would make disclosure easier?	
Initiated by health professionals	112 (59)
Questionnaire/screening tool	23 (12)
Applicable comprehension	10 (5)
Information given pre/post birth	19(10)
Not stated	20 (14)

4.4.3 Qualitative interviews

Sixteen women participated in qualitative interviews. The findings are reported elsewhere and provide a deeper understanding of inhibitors and enablers to disclose AI when utilising three screening tools[45]. Three key areas were identified to inhibit disclosure: firstly, the social expectations surrounding birth and continence, and the stigma associated with AI; secondly, the need to allow safe disclosure of symptoms; and lastly, the ability to understand questions in relation to screening tools. The latter is vital as the key outcomes suggest that disclosure is inhibited by clinical terminology and the inability of the screening tools to adequately capture variability of symptoms, including rectal urgency and staining.

Women unanimously described the BSQ as the preferred tool, describing the language and tool design easy to understand, promoting completion and disclosure of AI.

4.5 DISCUSSION

4.5.1 Principal findings

The findings suggest that there was a logical, systematic approach to the BSQ development through generation and review of the pool of items by health professionals and women, testing phases, amendments and utilising two standard scoring systems to compare convergent validity. Successful completion of the BSQ in development stages demonstrated the BSQ was easy to complete and understand. Feedback assisted in changes to wording from "delivery" to "birth" and the addition of the symptoms of soiling and staining.

Childbirth increases the risk of PFD and AI however; clinicians involved in the care of women of reproductive age have neglected routine screening. The positive completion and feedback in development of the BSQ from health professionals in these disciplines may signal a change in attitude towards the relationship between AI and childbirth[10, 14].

A key feature of this study was the focus on the development of a screening tool and use of appropriate language. It was apparent that women required simple language to articulate their symptoms. The qualitative findings from this study have been described in detail elsewhere[45]. These findings consistent with those of Bartlett[31] who suggested that simple language and reducing embarrassment would enhance understanding and reduce discordance between screening tools.

4.5.2 Interpretation of results

The variability in completion of the BSQ (99%), Vaizey score (33%) and Wexner score (36%) suggests that higher completion rates of the BSQ may have been a result of improved comprehension of the BSQ. Whilst the kappa statistics utilised to examine agreement showed moderate agreement between all tools, there was substantial agreement between the clinically derived Vaizey score and Wexner score, which reflected similar completion rates in this study. Both tools contained similar wording and scales, and suggests that clinicians developed the tools. Variability within these tools existed with higher reporting of symptoms in the Wexner score than the Vaizey score. This was consistent with the qualitative findings, which provided evidence that the language in the Wexner score was easier to understand and influenced reporting when compared to the Vaizey score[45]. Discordance between clinical screening tools is common with studies such as Bartlett et al.[31] suggesting comprehension was a factor for differences in reporting between clinical derived screening tools.

Conversely, the initial development and refinement of the BSQ with women participants may have enhanced the reporting of symptoms. The active engagement identified roadblocks for disclosing symptoms described as relevant for women. It appeared that health professionals often place greater significance on incontinence to solid stool rather than liquid incontinence, flatus incontinence and

urgency[14, 28, 29, 46]. This undervalues the impact of these symptoms on a person's quality of life and the fact that these symptoms are precursors for worsening function with ageing[14, 28, 29, 46]. Cotterill's[40, 47] research supported the current findings, outlining the importance of developing clinical screening tools with women, in an effort to illuminate areas of concern relevant to the care and management of women, which often is missed or undervalued by clinicians. Interpretation from qualitative interviews provided further clarification that not only the wording but also the omission of symptoms in clinical screening tools (Vaizey score and Wexner score) negatively affected comprehension and were considered roadblocks to disclosing AI[45]. Notably women suggested that the use of screening tools that were easy to understand, and included "not being able to hold on " or "need to rush "(rectal urgency), soiling, along with both historical reporting of AI, and a current history in the past four weeks with a frequency scale, would improve disclosure and allow accurate reporting from screening tools.

This research is unique as it developed and validated a specifically designed screening tool that was able to identify AI in 53% of women in the first trimester of pregnancy. This is unlike previous research, which utilised a range of clinical screening tools, which generally focused on late pregnancy, postpartum and few studies in the first trimester of pregnancy[2, 5, 10, 17-19, 39, 48-60]. These studies have included the Vaizey score, Wexner score and non-validated questionnaires with variable reporting of AI and FI in early pregnancy (26.8% to 40.8%), late pregnancy (1.3% to 40.8%) and the postnatal period (3% to 39%[4-7, 10, 19]. The higher rates of reporting of AI within these studies occurred when rectal urgency was included and with screening tools that utilised non-medicalised terminology, which is consistent with our findings[60]. Van Brummen[60] utilised a specifically designed self-reported defecation distress inventory (DDI) at 12 weeks of pregnancy and attributed the increased reporting of AI compared to other studies, as a result of utilizing a self-reported questionnaire. This is consistent with findings in this study where women self-completed all three tools with similar rates for flatus incontinence compared to the DDI (34.6%). Capturing rectal urgency was problematic for the DDI, the Vaizey score and the Wexner score, which reported much lower rates of urgency compared to the BSQ (21%). Flatus and rectal urgency may be the only reported symptom a woman disclosed, and should not be overlooked as these symptoms suggest pelvic floor trauma and in particular, damage to the anal sphincter muscles[61, 62]. Accurate assessment of symptoms with tools like the BSQ in the first trimester of pregnancy may improve management of this group of women and prevent further compounding injury, and worsening symptoms of AI in the short and long-term.

Passive soiling is variably reported, and may indicate damage to the anal sphincter, particularly the internal anal sphincter with a significant impact on quality of life in women of reproductive age[40, 56, 63]. Neither the Wexner nor the Vaizey score include passive soiling and this may be a limitation in their usefulness in screening in this population. The BSQ reported higher rates of soiling (1.5%) compared to other research which identified soiling (0.5%) in women with no history of PFD, however they did cite "difficulty wiping clean" in 21% of their population[56]. Persson et al.[56] utilised the Danish anal sphincter rupture questionnaire (ASR), and the wording of this tool is easy to comprehend and identified difficulties with cleaning, and hence the risk of soiling. The response rate to the ASR was low and only 51% of questionnaires were analysed which may bias the findings. Passive soiling as a potential precursor for worsening bowel function is important to detect both in research and screening, but also in managing pregnant women and this underlies the need for screening tools like the BSQ, which are easy to use and comprehend.

Whilst the intent of this research study was to develop and validate the BSQ to identify AI in a first trimester population of women, the research identified causal relationships between AI and age, ethnicity, parity, episiotomy (RMLE) and obstetric anal sphincter injury (OASIS) consistent with previous research studies[3, 12, 59, 64].

Importantly, the current findings reported a higher prevalence of AI in women who reported a previously intact perineum, women who had had a previous caesarean section and vaginal birth and in Caucasian women. These results add to the recent body of evidence that pregnancy, labour and birth contributes to weakening the pelvic floor and disruption of nerves in women who birth vaginally or by caesarean

section[3, 4, 7, 53, 64-67]. Compression and traction to pelvic floor muscles and nerves accounting for transient AI has been reported with subsequent injury and ageing[10, 24]. This was consistent in the current findings, which identified for every year of ageing women had a 36% increased risk of AI.

Many studies undertaken in Western societies have reported that Asian ethnicity is linked to increased rates of OASIS, PFD and risk of AI following childbirth due to shorter perineum larger babies and instrumental deliveries[68, 69]. However, the current findings suggested Asian women were less likely to report AI compared to Caucasian women. The relationship of perineal trauma and ethnicity remains unclear and raises concerns about the relevance of findings from studies undertaken in Western societies. These studies may not be representative of Asian cultures and there may be additional factors impacting on perineal trauma other than perineal length[70, 71]. There is evidence that the cultural and social expectations and language barriers may influence the risk of PFD and trauma and also influence disclosure[71-73]. These latter issues are vitally important and therefore needs consideration when screening women for AI.

4.5.3 Strengths and limitations

To the best of the author's knowledge, this is the first bowel-screening tool developed and utilised by pregnant women in the first trimester to identify AI. The strength of the study was the development and validation of a reliable, quick and easy to use tool containing five questions. In addition, comparison of the BSQ and two bowel-screening tools enhanced the validation and strength of this study. During the questionnaire development the sample, population did identify minor changes to the tool enhancing the validity of the BSQ. The BSQ contained no timeframe but reliance on participant's memory may have contributed to recall bias and limitations. Future research could include a sample testing of case notes to compare reporting of symptoms by participants. The pilot test included only a small group of symptomatic women but the reliability of this phase was adequate. The sample size and purposeful recruiting of participants may have been a potential bias and limitation of the findings.

Women suggested the inclusion of a frequency scale for all symptoms and noting both current and historical AI would be useful. These additions would strengthen the current tool in future research. The responsiveness of a questionnaire may alter over time and current findings may alter in the future or with use by a different population. Caution must be considered when taking into account these limitations and when generalising findings or utilising the BSQ in another study population with differing demographic characteristics.

4.6 CONCLUSIONS

This study identified the BSQ as a reliable and valid tool able to identify AI in 53% of parous women attending a first trimester antenatal appointment. Predominant AI symptoms were the inability to "hold on" (rectal urgency) and incontinence of flatus which are known precursors for worsening function. The variable reporting of these symptoms resulted in their omission in previous screening tools and resulted in their inability to screen for both past and present symptoms. The importance in establishing a pre-existing history in the context of current symptoms would assist with improved care and management and further research is required to ascertain if changes in the BSQ format will improve historical and current disclosure of AI in antenatal and community settings.

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Chapter 5

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Understanding what impacts on disclosing anal incontinence for women when comparing bowels screening tools: a phenomenological study

ABSTRACT

Background: There is limited research defining the true prevalence of anal incontinence (AI) in women of childbearing age. Understanding the limitations of the current assessment tools in the identification of AI is paramount for identifying the prevalence of AI and improving the care and management for women of childbearing age. The aim of this research was to explore and develop an understanding of women's experiences in disclosing AI when completing a new bowel-screening questionnaire when compared to two established AI tools.

Methods: A phenomenological qualitative research study was undertaken in a maternity setting in a large tertiary hospital. Parous women in the first trimester of a subsequent pregnancy were recruited to complete a specifically designed screening tool (BSQ), St Marks Faecal incontinence score (Vaizey) and Cleveland (Wexner) score. Qualitative semi-structured interviews were utilised to identify experiences in disclosing AI.

Results: Women (n = 16, 22-42 years) with a history of anal incontinence either following the first birth (n = 12) or the second (n = 4) provided differing responses between the three assessment tools. All women answered the BSQ while the Vaizey and Wexner scores were more difficult to complete due to clinical language and participants level of comprehension. Women identified three major themes that were barriers for disclosing incontinence, which included social expectations, trusted space and confusion.

Conclusion: There are barriers for disclosing AI in the pregnant and post-natal population, which can be improved with the use of an easy assessment tool. The BSQ may facilitate discussion on AI between the patient and health professional leading to earlier identification and improvement in short and long-term health outcomes.

Keywords: anal, incontinence, women, reproductive, screening, tools

5.1 BACKGROUND

Anal incontinence (AI) has a detrimental impact on quality of life. The cause of AI is multifactorial including direct/indirect trauma to muscle and nerves of the pelvic floor following vaginal births[1-4]. Compounding injury to the pelvic floor with subsequent birthing increases the risk of worsening symptoms of AI for women in both the short and long term[2, 5]. Evidence exists to support the use of bowel screening tools in the identification of AI within the pregnant and postnatal population[6-8]. Screening tools are adopted for research but limited in clinical practice as research identifies specialities involved in obstetrics and gynaecology rarely screen women for AI[9]. Importantly, there is no tool, routinely used to screen this at risk group, and the true prevalence of AI in women of reproductive age remains unknown.

Clinically derived bowel screening tools have been utilised in research to report AI in women in the late stages of pregnancy (8%–65%), following birth (16%–49%), gynaecology outpatients (16%–28%), and in the general population (4.4%)[6, 10]. The wide variations in reporting may be a consequence of the definitions utilised to identify AI, the sample size, population studied, selective disclosure, the length and language comprehension of the questionnaire, how the tool was administered[8, 11-14]. Understanding the limitations of the current assessment tools in the identification of AI assists in defining true prevalence and improving the care and management for women of reproductive age.

Minimal research has explored the reasons for discordance between different screening tools from the afflicted person's perspective. Research undertaken by Bartlett et al.[11] identified disagreement between two bowel screening tools, the Self-Administered Faecal Incontinence Questionnaire (SAFIQ) and the

Cleveland Clinic Florida Faecal Incontinence Score (CCF-FI). Bartlett et al.[11] cited terminology and embarrassment were barriers to disclosure and suggested direct enquiry by a health professional utilising an AI questionnaire, in language that was easily understood could improve disclosure. Qualitative research by Tucker et al.[15] identified that women with a history of obstetric anal sphincter injury experienced barriers for disclosing AI and concur with these findings. Concurrent research identified active screening with assessment tools increased reporting of AI[8]. These findings instigated the development of a Bowel Screening Questionnaire (BSQ). The design and pilot testing of the BSQ included qualitative interviews with a group of symptomatic women. The aim of the qualitative research was to explore and develop an understanding of women's experiences in disclosing AI when completing the BSQ and two established bowel assessment tools.

5.2 METHODS

Ethical approval was provided through the University of Adelaide Human Research Ethics Committee and the Human Research Ethics Committee (HREC/14/TQEHLMHMH/58). Research was undertaken between January 2015 and May 2017 and forms part of a larger research project. The research aimed to develop and validate the BSQ to identify AI in antenatal women attending a large tertiary hospital within a low socio-economic demographic area in South Australia. The antenatal triaging midwives invited parous women in their first trimester of a subsequent pregnancy with a previous history of AI to participate in the qualitative research. Nulliparous and asymptomatic women were not included.

Confidentiality was maintained for women who consented to the research. All texts were de-identified and information stored on a secure password protected universal serial bus. Women were aware that if the research caused any distress they could be referred to appropriate services or withdraw from the research without penalty. The main author (JT) undertook interviews. The consolidated criteria for reporting qualitative research (COREQ) guidelines were adhered to for the research.

Interpretive phenomenology was adopted as a framework for this research[16]. A qualitative research method utilising semi-structured open-ended interviews, verbatim-transcribed text and journaling was used to explore and develop an understanding of women's experiences of disclosing AI. Interviews were audio taped which enabled the researcher and women to immerse themselves within the conversations, and to record the realm of emotions and depth of the women's individual experiences. Recruitment continued until no new themes were evident and saturation of data occurred at 16 women.

Research interviews were undertaken at a place and time that was convenient for the woman. Prior to the interview, women completed three bowel assessment tools including BSQ specifically developed by our team for the improved identification of AI. It was compared to the St Mark's faecal incontinence score (Vaizey score) and Cleveland score (Wexner score)[17, 18]. The Vaizey and Wexner scores were included as they are frequently cited in research for this cohort[9, 19].

The Vaizey score is a validated tool and consists of two scoring systems with a five-point scale, which evaluates type and frequency of solid/liquid stool loss, flatus incontinence and impact on quality of life[18]. The Vaizey score is based on the Wexner score (non-validated score), the former including constipation and rectal urgency[19]. The scoring system assesses symptoms over the last month and ranges from 0 (continent) to 24 (total incontinence). Both the Vaizey and Wexner scores are utilised in clinical studies and surgical therapies[19]. The development of the BSQ occurred in consultation with health professionals and women with a history of AI. After review of questions, frequency scales and symptoms from establish tools for AI; the BSQ consisted of a symptom scale similar to the Vaizey and Wexner scores. The BSQ included six items prefaced with the statement "*have you ever lost by accident*?" included additional symptoms of staining, soiling, and request for referral (Table 5.1). A frequency scale measured symptoms and utilised a scale 0 (never) to four (daily) not unlike the Vaizey and Wexner scores. Previous research identified the variable nature of AI impacting on young women's quality of life as such no timeframe was included[15, 20, 21].

Interviews began by asking the woman to describe what it was like living with AI and to share what

Table 5.1. Bowel screening questionnaire (BSQ).

BSQ Qualitative interviews	Never	Rarely	Sometimes	Weekly	Daily
Answer the questions by placing a tick in the column	**0**	**1**	**2**	**3**	**4**
Have you ever lost by accident?					
Solid poo (stool)					
Liquid poo (stool)					
Wind (gas)					
Stained your underwear					
Soiled your underwear					
Do you need to rush to the toilet?					
Total score out of 24 (>0 consider referral)					
Would you like to be referred to a specialist Doctor? (Circle response)	Yes		No		

Table 5.2. Themes, sub-themes and meanings.

Theme	Sub theme	Meaning
Social expectation	Birthing process	Normal consequence, worse in subsequent delivery.
	Keeping it hidden	Self-preservation, avoiding shame, waiting to be asked.
Trusted space	Finding a voice	Safe environment to tell, Being safe, knowing someone understands, listen too, sensitive questions, help me understand the words.
Confusion	Understanding	Embarrassing words, defining words, capture variability.

Table 5.3. Themes, sub-themes and women's statements.

Theme	Sub theme	Example
Social expectation	Birthing process	"That's what happens after a baby… I thought it didn't matter" " It gets worse in your next pregnancy"
	Keeping it hidden	"Health professionals don't ask and I feel horrible that I pass gas all the time" " I would tell if someone asked me" " ask me in words I understand"
Trusted space	Finding a voice	" use words that don't make me feel any more disgusted in myself than I already do" "I need to feel safe to tell…" "How can I tell you I poo myself when I don't know what the word stool is?"
Confusion	Understanding	" Telling a woman is easier… she's been there and birthed" "Health professionals need to be sensitive when asking….I feel dirty and disgusted in myself already" "I don't understand incontinence or urge…. What do they mean?" …what's a plug?" " I don't get symptoms all the time" " If you ask ….I would tell to get help"

factors influenced or inhibited the disclosure of AI when using the three assessment tools. Initially there was uneasiness with the interview process through limited depth to responses and nonverbal body language. The style of the interview encouraged rapport and empathy through a conversational nature, with interviews typically lasting between 30 to 50 minutes. Women were able to seek assistance or clarification from the researcher in the completion of the tools.

5.2.1 Data Analysis

Transcribed verbatim texts, audio recordings and journal entries were analysed utilising Van Manen's thematic analysis[16]. The backwards and forwards process of the hermeneutic circle within the research process assisted in the reflection and uncovering the essence of women's experiences. The repetitious reading and writing of data further developed meaning. Thematic analysis uncovered significant statements and led to the development of three themes and four sub-themes (Tables 5.2 and 5.3).

5.3 RESULTS

Participating women (n = 16) were aged between 22 to 42 years and had a history of AI. All women identified English as first language; and were either Caucasian (n = 13, 81%) or Aboriginal (n = 3, 19%). Participants were predominately (75%) presenting in a second pregnancy, with 25% of women in their third pregnancy. Mode of birth included normal vaginal delivery (n = 13, 81%), forceps (n = 2, 13%) and caesarean section (n = 1, 6%).

Women who were symptomatic of AI following their principal birth accounted for 12 women (75%) with four women (25%) in their second pregnancy. Twelve women (75%) described a history of obstetric anal sphincter injury. Nine (75%) of these women reported the onset of AI following sphincter injury (Table 5.4).

Table 5.4. Demographic details of participants. Abbreviations: OASIS, Obstetric Anal Sphincter Injury; BMI, body mass index; AI, anal incontinence.

Participants, n = 16	
Mean age in years (range) (SD) (St error)	30.8 (22-42) (5.94) (1.49)
Ethnicity, n (%)	
Caucasian	13 (81)
Aboriginal TSI	3 (19)
Parity, n (%)	
2nd	12 (75)
3rd	4 (25)
Gestation weeks, mean (range) (SD)	22 (20-28) (3.5)
English 1st language, n (%)	16 (100)
BMI mean (range) (SD)	29 (21-42) (6.56)
Mode of delivery, n (%)	
Normal vaginal	13 (81%)
Forceps	2 (13%)
Caesarean section	1 (6%)
History OASIS, n (%)	12 (75%)
Onset of AI post OASIS	9 (75%)
AI, n (%)	
Following 1st birth	12(75%)
Following 2nd pregnancy	4(25%)

5.3.1 Initial interpretation of the screening tools

All women who participated in the qualitative interviews completed and provided a detailed account of disclosing AI using the assessment tools, the Vaizey score, Wexner score and BSQ. Women were unaware the BSQ had been newly designed to assess AI. Women identified a disparity in reporting between the three assessments tools, the BSQ easily completed and the Vaizey and Wexner were more difficult to complete due to clinical language and comprehension. The Vaizey and Wexner scores required the assistance of the researcher to understand aspects of the tools.

The Vaizey score was reported to be the most difficult to understand due to the clinical language, including incontinence, stool, plug and defecation. The variability of liquid, solid stool and flatus were assessed by a scoring system from zero to four for each symptom. However, women were critical that the Vaizey score reported symptoms in the last month. Additionally, the absence of a scale to identify the frequency of rectal urgency considered by women to underrepresent the variability of their symptoms.

Whilst the Wexner score included clinical language, women described the wording of this tool easier to understand and the preferred option to the Vaizey score. The Wexner score provided a frequency scale for symptoms with no timeframe. However, women detailed the exclusion of rectal urgency as a major limitation of the Wexner score as it was a predominant symptom for women.

The BSQ was the unanimously preferred tool, with women describing the language and tool design easy to understand when disclosing AI. A statement "have you lost by accident?" prefaced the BSQ and identified solid/liquid stools, flatus, urgency and staining and included a frequency scale 0 (never) to four (daily). Women stated a defined frequency scale for symptoms was preferred. Whilst the strengths and limitations of all tools were identified, women further described important additions in all tools. A frequency scale that identified a past and current history of solid/liquid stool, flatus, rectal urgency and staining was required.

5.3.2 Deeper interpretation in disclosing AI

The disclosure of AI was reported as complex for most women. Understanding what the tool actually intended to ask influenced full disclosure. Women identified three major themes that described how they responded to disclosing AI with the three assessment tools. The themes included social expectations, trusted space and confusion (Tables 5.2 & 5.3).

5.3.2.1 Social expectations

Social expectations were an overarching theme and included two sub themes keeping it hidden and the ***birthing process***. Women within this research identified how this influenced the completion of the bowel assessment tools.

Keeping it hidden

Keeping it hidden detailed how the social stigma surrounding AI limited disclosure. Young women identified the daily struggle of anxiety and despair in an attempt to maintain their dignity in society and coping with the consequences of the need to rush to the toilet and accidental loss of gas. They limited activities of daily living.

"*I feel anxious, the sound and smell is always on your mind, you don't go out…I feel dirty*" (Participant 13).

"*It took a while for me to feel confident to tell someone, I was really embarrassed …..the urgency was bad but I had to tell someone eventually*" (Participant 3).

Birthing process

All women commented on the negative impact of vaginal delivery on pelvic floor function, resulting a weakened pelvic floor and continence issues. There was resignation that the birth process and size of babies would have a negative impact on their pelvic floor, and as such, there was no reason to disclose symptoms. However, the concern for worsening AI was a reality with further birthing. Women stated that symptoms were often variable but worse in pregnancy. They were often not aware as to the clinical significance and under reported symptoms. Women described these concerns with the following statements,

"*Women aren't aware of the importance of AI… it's not seen as a problem because that comes with birthing*" (Participant 1).

"*It happens to all women…doesn't it? So it's not a problem, so why tell anyone*" (Participant 8).

"*I don't get symptoms all the time, sometimes you get worse in pregnancy…. I worry for it (AI) will get worse in next pregnancy and birth. You don't really want to be in nappies!*" (Participant 16).

5.3.2.2 Trusted space

Participants outlined several key factors to improve disclosure. There was the need to be in a safe environment with those who identified with their situation enabling women to feel comfortable in ***finding a voice***. There was a real sense of yearning for health professionals to ask questions related to continence, active screening by the health professional improved disclosure. Women recounted how the bowel assessment tools would help this process but the tool needed to be sensitive and use everyday words.

"*It's never easy to tell…not in a busy place, it needs to be private and I need to trust the health professional. I cannot tell you if I do not understand what you are asking me…the words are confusing. The health professional helped me tell by asking questions differently…I don't understand incontinence*" (Participant 6).

"*Health professionals need to ask especially for those of us who are from different cultural backgrounds…. because I won't tell otherwise*" (Participant 13).

"*I get embarrassed about my symptoms mostly urgency. I think health professionals need to ask about AI. Sometimes it's easier telling a woman, she understands because she's had a baby*" (Participant 14).

5.3.2.3 Confusion

The theme ***confusion*** identified the disparity in reporting symptoms were largely a consequence of not understanding the questions. Women described the difficulty in understanding definitions, clinical language and inability of the tools to capture their symptoms of AI.

The women within this research study described the important role of the health professional in completing the screening tool and disclosing AI. The interpretation of questions by the women often resulted in confusion where women would respond with no symptoms if they did not understand the language or meaning.

"*What does incontinence mean? The words are technical; I do not know what they mean… So even if I do have urgency or staining I say I have no symptoms*" (Participant 8).

"*My symptoms are all over the place especially when I'm pregnant….the tools don't see that? Simple words are needed…. tricky words like continence and defer need changing… who understands that?*" (Participant 1).

"*I need someone to help me understand the words; I don't know incontinence, urgency, and plug. I get staining but is that liquid poo or is that different…I am very confused. I think it's good to sit with the professional and discuss the questions (assessment tools), it's hard otherwise to understand the words*" (Participant 14).

5.4 DISCUSSION

Disclosure of AI when utilising screening tools is reliant on multiple factors. Social expectations, role of the health professional, and how a screening tool is developed is pivotal in enabling or inhibiting disclosure of AI.

Social expectations were the overarching theme, which identified AI as a taboo health and wellbeing issue in many cultural settings. How we are socialised, will influence what illnesses we consider socially acceptable and either inhibit or promote health-seeking behaviour. The inability to conform to societal norms and the mere thought of discussing bodily functions often results in personal disgust and shame affecting disclosure[15, 22-24]. The physical and psychological impact of AI following obstetric anal sphincter injury is detailed by Tucker et al.[15] who identified the self-imposed social isolation, negative health-seeking behaviours and non-disclosure of AI[15]. These findings concur with our research findings, which identified the emotional complexity surrounding AI, stigma, embarrassment and personal disgust limited disclosure to health professionals and full disclosure by clinical screening tools. Embarrassment is reported as another key factor in the underreporting of AI within assessment tools[11].

Health seeking behaviour and disclosure relies on those afflicted with AI to have an understanding or knowledge of the problem[25]. Women within this research identified AI was a normal consequence of birthing and therefore described no reason to seek help or disclose AI. Importantly, whilst it was acknowledged there were concerns about worsening function in subsequent births disclosure was compounded as a result of pending social stigma. Additional research supported these findings, acknowledging nondisclosure was the result of the duality of the consequences of birthing and embarrassment associated with AI[6, 15, 23].

The role of the health professional in the initiation of questioning was pivotal in enabling or inhibiting disclosure of AI. Tucker et al.[15] concur with these findings further citing lack of enquiry by professionals was often viewed by women, as the clinician having limited knowledge or fear of client dissatisfaction in the assessment of continence status. Women from the current research identified with these conclusions noting a safe environment or, a ***trusted space*** and preference for female health professional facilitated the disclosure of AI. The partiality for female health professionals in genital and anal examinations is identified in the literature to facilitate patient centred communication, increased empathy and resultant reduction in embarrassment in reporting symptoms[15, 23, 26]. Whilst there is mixed debate as to the effectiveness of self-reported questionnaires and assessment tools versus clinician assisted discussion, the benefits of sensitive discussion with the latter have been shown to promote disclosure of AI[7, 11, 23]. Whilst this was evident within our findings, women identified a disparity in disclosure between the three assessments tools was a major limitation which focused on the design of the tool, and in particular language and comprehension.

Traditionally bowel screening and assessment tools objectively review type and frequency of AI from a clinicians point of view[19]. The limitations of clinically derived screening tools have been outlined previously[11, 14]. The confusion with terminology and the inability of the screening tools to capture symptoms was evident within our study. This is a concern for women as the underreporting of AI further marginalises them from adequate clinical care and management in current and subsequent pregnancies, potentially worsening quality of life[9, 15].

In order to disclose AI, clinical assessment tools needed to be easy to understand. A higher reading and comprehension level of health tools often results in misunderstanding[27]. Leonard reported there is a need to evaluate whether health literature is at an appropriate level for the intended population[27]. Findings from the current research identified women's confusion with terms such as continence, defecation, stool

and plug in utilising the Vaizey and Wexner scores. This may have been a result of the study population, who were recruited from a tertiary setting within a low socioeconomic demographical area. Confusion often resulted in no symptoms identified in reporting across two of the clinically derived assessment tools the Vaizey and Wexner scores. Preferred terms for incontinence included accidental leakage and is previously supported by Sung et al.[28] who identified AI did not reflect the patients perspective. Additionally research by Cotterill et al.[14] identified the importance of the patient's perspective in the development of clinical tools and identified key areas not previously addressed. Women in the current research study identified the BSQ as the preferred assessment tool; because it did not contain any of the confusing terminology and each statement was prefaced with "*have you ever lost by accident*". The acceptability of the BSQ may be due to the fact it was developed in consultation with women with a history of AI.

The current research identified the disclosure of symptoms often relied on the variability and impact of symptoms on quality of life with less frequent symptoms resulting in underreporting. Research undertaken by Bartlett et al.[11] supported these findings. The inability of the Vaizey and Wexner scores to capture the frequency of rectal urgency was cited as a limitation for this group of women. Previous research identified the shortcomings of assessment tools that do not incorporate the frequency of rectal urgency[19, 29]. Rectal urgency is associated with external anal sphincter injury and precursor of worsening symptoms across the lifespan. The ability of screening tools to identify the frequency of rectal urgency is important in the management of women of reproductive age.

Staining was an additional symptom women in our research identified. The symptom was variable but did result in considerable bother. Sung et al.[28] utilising qualitative research identified mucous loss as a consistent finding that required acknowledgement and inclusion in future frameworks on AI.

Women described the importance of a frequency scale from zero (no symptoms) to four (daily symptoms) to describe the variability of all symptoms. However, they noted limitations of the assessment tools, as they did not effectively identify the variability of symptoms across a longer period, in particular rectal urgency. These findings are consistent with previous research and promote the development of a screening tool which identifies a history of AI and current symptoms over the past 4 weeks[9].

5.4.1 Strengths and Limitations

Qualitative research findings are often limited in generalisability to a larger population. However, findings from this research may be applicable to research which aims to develop tools to identify AI in this population. The research method facilitated open disclosure and increased the richness of women's stories but also allowed potential bias. Research bias was reduced through the invitation for women to take part by triaging antenatal midwives. The nature of the research question and the researcher's role as a health professional may have influenced full disclosure. Despite this, the research methods facilitated open disclosure. The absence of a defined timeframe for the BSQ may be seen as a further limitation if utilised as a standalone tool. However, the aim of the BSQ was to be utilised in clinical practice to screen for AI and promote discussion of symptoms. Findings of the research-identified women wanted both historical and current symptoms identified by assessment tools and provides further information for future tool development.

5.5 CONCLUSIONS

Findings of this research identify factors, which enabled and inhibited disclosure of AI utilising three bowel assessment tools. Women in this research identified the construction and development of screening and assessment tools should consider the appropriate language, comprehension of the tool, account for the variable nature of AI, the frequency of rectal urgency and staining. The BSQ was the preferred screening tools, as it was easy to understand and quick to utilise. However, women described the need for tools to include both historical and current symptom for AI. Whilst the findings are important for the development of screening tools there is an urgent need by clinicians to understand the social stigma surrounding AI and the importance of using sensitive language in a safe environment to facilitate

disclosure. Utilising screening tools like the BSQ in the pregnant and postnatal population will assist with disclosure and the early detection of AI that improves a woman's short and long-term management and health outcomes.

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Chapter 6

Screening women of reproductive age with a newly developed screening tool to identify anal incontinence

Screening women of reproductive age with a newly developed screening tool to identify anal incontinence

6.1 BACKGROUND

Many different bowel-screening tools are utilised in research and in clinical practice areas[1-4]. These clinically derived tools objectively screen for anal incontinence (AI), or for fecal incontinence (FI), excluding rectal urgency[5, 6]. Clinically derived tools were created with little consumer participation in their development and subsequently there is a higher weighting for incontinence to solid stool ccompared to other types of leakage[7-9]. This unfortunately excludes or underrates some symptoms which women rate as important including soiling, urgency and flatus incontinence and thus contributes to under-reporting of symptoms[8, 10]. There is no evidence within these tools of a shared clinical terminology between clinicians and consumers, which may limit the ability of women to understand the questionnaires and disclose clinically relevant incontinence[11, 12].

As part of a larger research project (reported in chapter 4), which included the development and validation of the bowel-screening questionnaire (BSQ) for the routine clinical screening of AI in women of reproductive age, qualitative interviews assessed the reliability and validity of the tool from the consumer perspective[13]. The research identified significant discordance between two frequently used clinical tools utilised in screening women of reproductive age and the BSQ[13]. Women preferred the BSQ as it was easier to understand and included terminology that women understood such as, “poo” (stool), “can’t hold on” (rectal urgency), “wind or gas” (flatus incontinence), “staining and soiling”. To enhance the validity and reliability of the BSQ the suggested changes included having both historical (greater than four weeks) and current reporting (within the past 4 weeks) of AI as no tool currently addressed these concerns. Additionally, screening tools should include a frequency scale for all symptoms and provide equal weighting for symptom bother. The aim of this prospective study was to utilise a revised version of the BSQ to identify the historical and current reporting of AI in two groups of women: 1) pregnant in their first trimester attending an antenatal clinic and 2) non-pregnant reproductive age women attending a community health centre.

6.2 MATERIALS AND METHODS

Two Human Research Ethics Committees (HREC), the University of Adelaide Human Research Ethics Committee and the Adelaide Health Service Human Research Ethics Committee (HREC/14/TQEHLMHMH/58) approved the research. The research was undertaken at two sites. The first site was an antenatal setting in a large tertiary centre in the northern suburbs of Adelaide, South Australia between July 2017 and April 2018. The second site was a community setting in a large general practitioner led health care centre (Adelaide Unicare, University of Adelaide) within the same demographic area between November 2017 and March 2018. A revised format of the bowel-screening questionnaire (BSQ) (Appendix 7) was used within both settings.

Chapter 2 (materials and methods) outlines the methods (2.8; 2.8.1), design (2.8.1), study inclusion and exclusions (2.8.2.1), ethical considerations (2.8.3), data collection (2.8.4.; 2.8.5) for this stage of the research.

6.2.1 Data analysis

Statistical analysis was undertaken on quantitative data using SPPS version 25 (Chicago Illinois) and SAS 9.4 (SAS Institute Inc., Cary, NC, USA). The following descriptive statistics were presented including measures of central tendency (mean, median) and variability (standard deviation (SD), interquartile range (IQR) for continuous variables, and frequencies and percentages for categorical variables). Ordinal logistic generalized estimating equations (GEE) models were performed for historical (greater than four weeks) and current (within the last four weeks) reporting of AI. Presentation of odds ratio (ORs), 95%

confidence intervals (CIs) and P values.

6.3 RESULTS

6.3.1 Antenatal setting

Three hundred and fifty four women in the first trimester of pregnancy completed the BSQ. Rates of completion for historical reporting (100%) were higher than the current history (70%). Caucasian ethnicity was identified as the sole significant difference between antenatal women with and without AI in relation to the demographics and obstetric details described in tables 6.2 to 6.4.

6.3.1.1 Demographic and obstetric details

For women who completed the BSQ, the characteristics of the symptomatic and asymptomatic groups reported were similar including age (mean ± SD: 30 ± 4.96 vs 30± 5.13 yrs.), gravidity (3.3 ± 1.68 vs 3.4 ± 1.69), parity (1.7 ± 1.11 vs 1.7± 1.13) and body mass index (BMI; 27.10 ± 6.94 vs 27.82 ± 6.99; Table 6.2). There was a broader range of BMI in the symptomatic group (15 to 54) when compared with the asymptomatic group (20 to 45). Amongst the total antenatal study population, women were predominantly Caucasian (72.9%, P < 0.001), with a history of a normal vaginal delivery (70.6%) and intact perineum (58.2%).

The prevalence of AI in the 1st trimester of pregnancy was 68% of women (n = 242; Table 6.2). Most of the symptomatic group women were Caucasian (75.2%), then Asian (16.1%), and African (3.7%). Symptomatic women had one previous birth (58%), two previous births (26%), or two or more (16%) births. Mode of birth included normal vaginal delivery (70.7%), instrumental delivery (12.8%), and caesarean section (12.9%) and a combination of all modes (3.6%). Forceps delivery (OR = 1.09, 95% CI: 0.48, 2.46, P value = 0.8402), LSCS (OR = 1.12, 95% CI: 0.56, 2.24, P value = 0.7396) and a combination of LSCS and instrumental deliveries (OR = 1.39, 95% CI: 0.14, 13.35, P value = 0.7750) showed a trend towards increased risk of AI, but without significance.

More symptomatic women were reported as having an intact perineum (56.2%) compared with those who reported having had an episiotomy (RMLE; 25.2 %), a 2nd degree tear (7.4%), or a 1st degree tear (3.7%), and a combination of perineal outcomes (2.5%). Five percent of women were reported to have an OASIS. There was no significant contributing factors to AI within this population, although there was a trend for an increased risk. Predictors which were associated with increased risk of AI including OASIS (OR = 5.79, 95% CI: 0.74, 45.10, P value = 0.0935) or RMLE (OR = 1.06, 95% CI: 0.63, 1.79 P value = 0.839) and second-degree tears (OR = 1.42, 95% CI: 0.55, 3.68, P value = 0.4708; Table 6.3). There was a higher rate of reporting of AI in women who sustained OASIS in the symptomatic (n = 12) group when compared to asymptomatic women (n = 1). Additionally, RMLE rates were higher in women with AI (n = 61) compared to asymptomatic women (n = 27).

A statistically significant association was identified between historical AI and ethnicity (Global P value = 0.0268). Women of African ethnicity (81%) were less likely to have AI when compared to Asian ethnicity (OR = 0.19, 95% CI: 0.07, 0.53, P value = 0.0014). Additionally, African women were less likely to have AI when compared with Caucasian women (OR = 0.23, 95 % CI: 0.10-0.55, P value = 0.0010). Women who identified as Asian and Caucasian reported more AI compared to most other ethnic groups. Asian women (OR = 1.25, 3.00, 95% CI: 0.33, 23.49) were more likely than any other ethnicity to have AI. No statistical association existed between a historical reporting of AI and age, BMI, gravida and parity (Table 6.3). However a yearly increase in age increased the odds of women having AI by 1% (OR = 1.01, 95% CI: 0.96, 1.1.05, P Value = 0.7263), and a reduction in BMI by one unit reduced the risk of AI by 1% (OR = 0.99, 95% CI: 0.96, 1.02, P value = 0.4078).

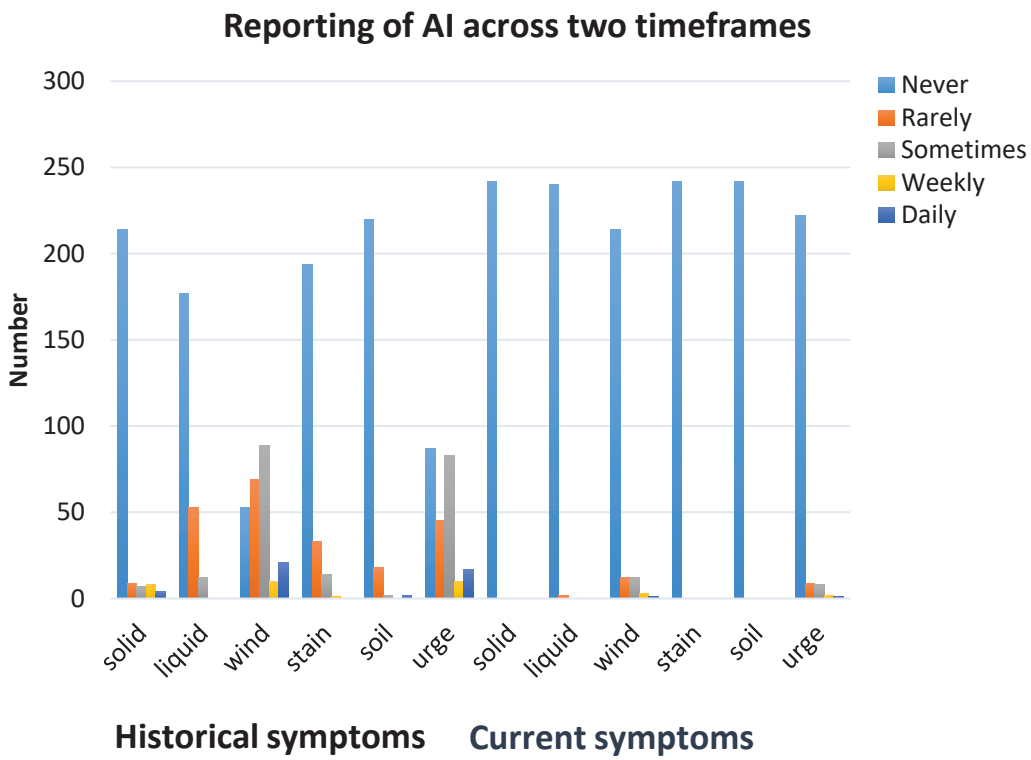

Figure 6.1. Historical and current reporting of AI in antenatal symptomatic women (n = 288). Historical (greater than 4 weeks), current (within the last 4 weeks).

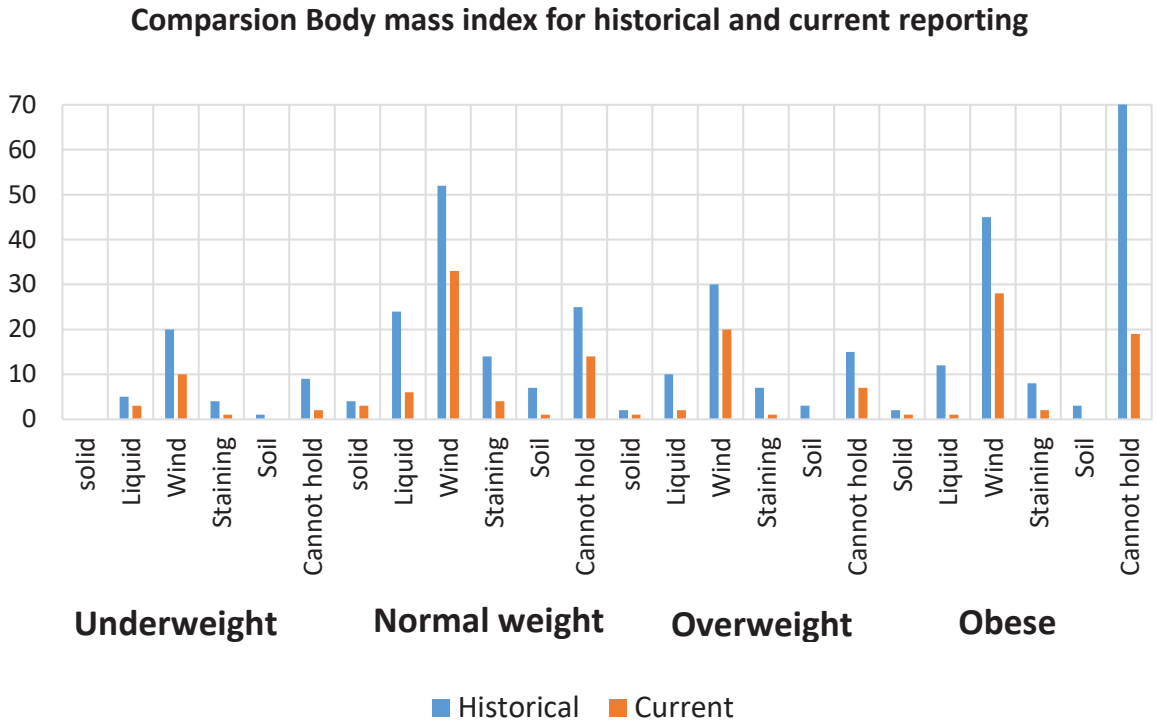

Figure 6.2. Comparison of body mass index between historical and current reporting of AI in community women.

Table 6.1. Screening of AI, first trimester pregnancy. **Percentage, refers to 22 women in sample.

Study	Design	Reporting	AI	Screening tool
Van Brummen et al.[12] (2006)	Prospective Nulliparous (n = 487)	**Antenatal** 12 weeks 36 weeks **Postnatal** 3 months 12 months	**FI – (solid/liquid), (urge)** 3.9%, 34.6% 3.0%, 42.3% 5.7%, 31.9% 3.3%, 30.5%	Defecatory distress inventory (DDI) Self-report
Pares et al.[67] (2015)	Observational Nulliparous (n = 228)	First trimester (25.9%) Last trimester (74.1%)	Faecal urgency (19.7%), FI (40.8%). Symptoms breakdown included solid stool (16.1%), liquid stool (6.4%) and flatus incontinence (77.4).	Wexner score Interview
Brincat et al.[33] (2009)	Prospective Primaparous (n = 228)	**Antenatal** 20 weeks 35 weeks **Post-natal** 6 weeks 6 months 1 year	**FI – (stool only)** 1.3% 1.8% 6.4% 1.8% 5.3%	Questionnaire not stated. Interview
Chaliha et al.[32] (1999)	Prospective Nulliparous (n = 549)	**Prior history** **Antenatal** 34 weeks **Postnatal** 3 months	**FI – 0.4% (solid/liquid), 0.4% (stain), 1.1% (urge), 0.5% (flatus)** 1.1%, 0.5%, 8.7%, 6% 0.9%, 0.9%, 6.2%, 4.9%	Not stated but includes rectal urge, flatus, liquid solid stool and staining. Interview
Solans-Domench et al.[52] (2010)	Prospective UI/FI Nulliparous (n = 1,128) 1st trimester, n = 22 2nd trimester, n = 66 3rd trimester, n = 64 Postnatal, n = 66	**Antenatal** 1st trimester 2nd trimester 3rd trimester **Postnatal** 6 weeks	**FI – (solid/liquid) (flatus)** 45%, 90%** 36%, 100% 34%, 98% 34%, 93%	Wexner score Self-report
Chan et al.[73] (2013)	Prospective Nulliparous (n = 328)	**Antenatal** 9-12 weeks, 26-28 weeks, 35-38 weeks **Postnatal** 8 weeks 6 month 12 month	**FI – (stool) (flatus)** 3.4%, 37.8% 5.2%, 41.8% 3.9% , 40.9% 5.9%, 30.5% 4%, 23.1% 4.3%, 18.3%	Pelvic floor distress inventory (Chinese version). Interview

Table 6.2. Demographic and obstetric details for symptomatic versus asymptomatic antenatal population (n = 354). Compiled using the comparison of proportions calculator available from https://www.medcal.org/calc/comparison_of_proportions. The following analyses were undertaken: Chi-square P value, Fischer's Exact Test P value, Independent T test. Symbols: [+]Missing data in current reporting; [‡]Instrumental (forceps and ventouse birth); [#]OASIS (3rd or 4th degree tear); [^]RMLE (right medio lateral episiotomy); *P value determined by independent student T test.

1st trimester of pregnancy	Symptomatic	Not Symptomatic	P value
Number (%)	242 (68)	112 (32)	<0.001*
Anal incontinence, n (Mean ± SD)	242 (0.68 ± 0.465)	0(0)	
AI last month, n (Mean ± SD)[+]	46 (0.12 ± 0.179)	0(0)	0.0001*
Age (Mean ± SD) (Range)	30±5.13 (20-50)	30 ± 4.96 (20-45)	0.726
BMI,(Mean ± SD) (Range)	27.1 ± 6.99 (15-54)	27.82 ± 6.94 (20-45)	0.409
Gravida (Mean ± SD) (Range)	3.3 (1.69) (2-11)	3.4 (1.68) (2-11)	0.522
Parity (Mean ± SD) (Range)	1.7 (1.13) (1-7)	1.7 (1.1) (1-7)	0.506
Parity, n (%)			
1 birth	140 (58)	56 (50)	0.206
2 births	62 (26)	32 (29)	0.699
>2 births	39 (16)	24 (21)	0.194
Ethnicity, n (%)			<0.010*
Caucasian	182 (75.2)	76 (68)	0.001*
Asian	39 (16.1)	13 (11.6)	0.266
Middle Eastern	2 (0.8)	2 (1.8)	1.000
African	9 (3.7)	16 (14.3)	0.187
Aboriginal	4 (1.7)	2 (1.8)	0.471
Other	6 (2.5)	3 (2.7)	0.362
Mode of birth, n (%)			
Normal vaginal	171 (70.7)	79 (70.5)	0.994
Instrumental[‡]	31 (12.8)	16 (14.3)	0.704
Caesarean section	31 (12.9)	13 (11.6)	0.740
Combination, all modes	9 (3.6)	4 (3.6)	0.555
Perineum, n (%)			
Intact	136 (56.2)	70 (62.5)	0.264
OASIS[#]	12 (5.0)	1 (0.9)	0.059
RMLE[^]	61 (25.2)	27 (24.1)	0.824
1st degree	9 (3.7)	6 (5.3)	0.478
2nd degree	18 (7.4)	6 (5.4)	0.420
Combination (no OASIS)	6 (2.5)	2 (1.8)	0.579

Table 6.3. Demographic predictors and history of AI in antenatal women. Fischer's Exact Test P values as binary logistics model did not converge. Symbols: *Statistically significant P value <0.05; **RMLE (right medio lateral episiotomy); #OASIS (obstetric anal sphincter injury).

Outcome	Predictor	Comparison	Odds Ratio (95%, CI)**	Comparison P value
AI	**Ethnicity**	Aboriginal vs African	3.56 (0.54, 23.39)	0.1869
		Aboriginal vs Asian	0.67 (0.11, 4.07)	0.6606
		Aboriginal vs Caucasian	0.84 (0.15, 4.66)	0.8372
		Aboriginal vs Middle Eastern	2.00 (0.15, 26.73)	0.6003
		Aboriginal vs Other	1.00 (0.11, 8.95)	1.0000
		African vs Asian	0.19 (0.07, 0.53)	0.0014*
		African vs Caucasian	0.23 (0.10, 0.55)	0.0010*
		African vs Middle Eastern	0.56 (0.07, 4.70)	0.5953
		African vs Other	0.28 (0.06, 1.41)	0.1222
		Asian vs Caucasian	1.25 (0.63, 2.48)	0.5175
		Asian vs Middle Eastern	3.00 (0.38, 23.49)	0.2954
		Asian vs Other	1.50 (0.33, 6.87)	0.6014
		Caucasian vs Middle Eastern	2.39 (0.33, 17.31)	0.3869
		Caucasian vs Other	1.20 (0.29, 4.91)	0.8025
		Middle Eastern vs Other	0.50 (0.05, 5.51)	0.5714
AI	**Age**		1.01 (0.96, 1.05)	0.7263
	BMI		0.99 (0.96, 1.02)	0.4078
	Gravida		0.96 (0.84, 1.09)	0.5216
	Parity		0.87 (0.72, 1.04)	0.1239
	All modes			0.5545
	Combination LSCS/NVD		0.46 (0.09, 2.30)	0.3411
	Combination LSCS/Instrument		1.39 (0.14, 13.55)	0.7750
	LSCS		1.12 (0.56, 2.24)	0.7396
	Ventouse		0.65 (0.24, 1.75)	0.3894
	NVD		1.00 (0.61, 1.64)	0.9994
	Forceps		1.09 (0.48, 2.46)	0.8402
	Perineum			
	Intact		0.77 (0.49, 1.22)	0.2641
	RMLE**		1.06 (0.63, 1.79)	0.8239
	OASIS#		5.79 (0.74, 45.10)	0.0935
	1st degree		0.68 (0.24, 1.97)	0.4791
	2nd degree		1.42 (0.55, 3.68)	0.4708
	Combination RMLE		2.34 (0.27, 20.28)	0.4398
	Combination no RMLE		0.46 (0.03, 7.46)	0.5868

Table 6.4. Comparing individual AI symptoms between the historical (greater than 4 weeks) and current period (within the last 4 weeks) for symptomatic antenatal women (n = 354). Fischer's Exact Test P values as ordinal logistic model did not converge. Symbols: *Significant P value <0.05; †Missing data; **Symptoms are a combination. The table summary is greater than 100% as women identified more than one symptom.

Antenatal women, n = 354	Historical	Current†	P value, Odds Ratio (95% CI)
AI reported, n (%)	242(68)	46(12.9)	
Solid	**28 (8.0)**	**0(0.0)**	0.3927
Never	214 (88.4)	242 (100)	
Rare	9 (3.7)	0(0)	
Sometimes	7 (2.9)	0(0)	
Weekly	8 (3.3)	0(0)	
Daily	4 (1.7)	0(0)	
Liquid	**65(18.3)**	**2(0.6)**	**0.0032*** 8.15 (2.02, 32.82)
Never	177 (73.1)	240(99.2)	
Rare	53 (21.9)	2(0.8)	
Sometimes	12 (5.0)	0(0)	
Weekly	0(0)	0(0)	
Daily	0(0)	0(0)	
Wind or gas	**179 (50.6)**	**28 (7.9)**	**0.0067*** 2.03 (1.22, 3.39)
Never	63 (21.9)	214 (88.4)	
Rare	69 (28.5)	10 (4.1)	
Sometimes	80 (36.8)	13 (5.3)	
Weekly	10 (4.1)	3 (1.2)	
Daily	20 (8.7)	2 (0.8)	
Stain	**48(13.5)**	**0(0.0)**	**0.0034***
Never	194 (80.2)	242 (100)	
Rare	33(13.6)	0(0)	
Sometimes	14(5.8)	0(0)	
Weekly	1(0.4)	0(0)	
Daily	0(0)	0(0)	
Soiling	**22 (6.2)**	**0 (0.0)**	0.2184
Never	220 (90.9)	242 (100)	
Rare	18(7.4)	0(0)	
Sometimes	2(0.8)	0(0)	
Weekly	0(0)	0(0)	
Daily	2(0.8)		
Cannot hold on (urge)	**155(43.7)**	**20(5.9)**	**0.0006*** 2.61 (1.51, 4.51)
Never	87 (36.0)	222 (91.7)	
Rare	45(18.6)	9(3.7)	
Sometimes	83 (34.3)	8(3.3)	
Weekly	10 (4.1)	2(0.8)	
Daily	17(7.0)	1 (0.4)	
Combined symptoms**			<0.0001*13.44 (5.74, 31.48)
1	94(38.8)	39(16.5)	
2	84(34.7)	5(2.1)	
3 or more	66 (26.4)	1(0.4)	

Table 6.5. Demographic and obstetric details for community women (n = 350). Compiled using the comparison of proportions calculator available from https://www.medcal.org/calc/comparison_of_proportions. The following analyses were undertaken: Chi-square P value, Fischer's Exact Test P value, Independent T test, Wilcoxon Rank Sum Test. Symbols: #OASIS (3rd or 4th degree tear); ^RMLE (right mediolateral episiotomy). Combination, all modes, includes vaginal birth, instrumental, and caesarean with subsequent births.

Community women	Symptomatic	Not Symptomatic	P value
Number (%)	179 (51.1)	171 (48.9)	
Anal incontinence, n (Mean ± SD)	179 (0.51 ± 0.50)	171 (0.34 ± 0.47)	0.709
AI last month, n (Mean ± SD)	121 (0.34 ± 0.49)		**0.000***
Age (Mean ± SD) (Range)	33.8 ± 6.73 (20-50)	32.73 ± 6.76 (18-50)	**0.0013***
BMI (Mean ± SD) (Range)	26.05 ± 6.42 (17-47)	25.76±5.94 (18-40)	0.701
Gravida (Mean ± SD) (Range)	2.67 ± 1.37 (1-7)	2.59±1.34 (1-7)	0.230
Parity (Mean ± SD) (Range)	2.28 ± 1.14 (1-7)	2.23±1.16 (1-7)	0.506
1 birth	42 (23.5)	49 (28.7)	0.449
2 births	80 (44.7)	74 (43.3)	0.612
3 births	34 (19.0)	30 (17.5)	0.792
>3 births	23 (12.8)	18 (10.6)	0.408
Ethnicity, n (%)			**0.032***
Caucasian	165 (92.1)	143 (83.7)	0.162
Asian	7 (3.9)	12 (7.0)	0.286
Middle Eastern	1 (0.5)	0 (0.0)	0.327
African	4 (2.3)	10 (5.8)	0.164
Aboriginal	1(0.5)	6 (3.5)	0.150
Other	1 (0.5)	0 (0.0)	0.327
Mode of birth, n (%)			
Normal vaginal delivery	89 (49.7)	101 (59.1)	0.079
Forceps	9 (5.0)	6 (3.5)	0.485
Ventouse	4 (2.2)	4 (2.3)	0.947
Caesarean Section	43 (24.0)	35 (20.4)	0.424
Combination, all modes	34 (19.1)	25 (14.6)	0.613
Perineum, n (%)			
Intact	76 (42.5)	69 (40.3)	0.571
OASIS#	9 (5.0)	4 (2.3)	0.259
RMLE^	38 (21.2)	41 (24.0)	0.539
1st Degree tear	17 (9.5)	23 (13.5)	0.247
2nd Degree tear	6 (3.4)	7 (4.1)	0.714
Combination no RMLE (no OASIS)	7 (3.9)	3 (1.8)	0.226
Combination RMLE (no OASIS)	26 (14.5)	24 (14.0)	0.896

Table 6.6. Binary logistic regression model results of AI (historical) versus various predictors in the community setting. Modelling the probability that AI = Yes. Symbols: †RMLE (right medio lateral episiotomy); ^OASIS (obstetric anal sphincter injury); #Combormle (combination of perineal outcomes but no RMLE); ##Combonorml (combination of perineal outcomes with RMLE); ††LSCS (caesarean section); ×Combo (combination of birth mode in subsequent births); *Statistically significant P value = <0.05.

Outcome	Predictor	Comparison	Odds Ratio (95% CI)	Global P value*
AI	Ethnicity binary	Caucasian vs Other	2.31 (1.17, 4.55)	0.0159*
AI	Forceps	Yes vs No	1.46 (0.51, 4.18)	0.4853
AI	Lscs††	Yes vs No	1.23 (0.74, 2.04)	0.4248
AI	Ventouse	Yes vs No	0.95 (0.23, 3.88)	0.9478
AI	Nvd	Yes vs No	0.69 (0.45, 1.05)	0.0799
AI	Combo×	Yes vs No	1.35 (0.42, 4.34)	0.6133
AI	Allmode	Yes vs No	2.21 (0.67, 7.32)	0.1941
AI	Intact	Yes vs No	1.09 (0.71, 1.67)	0.6892
AI	Rmle†	Yes vs No	0.85 (0.52, 1.41)	0.5390
AI	Oasis^	Yes vs No	2.21 (0.67, 7.32)	0.1941
AI	Second	Yes vs No	0.81 (0.27, 2.47)	0.7143
AI	First	Yes vs No	0.68 (0.35, 1.31)	0.2474
AI	Combormle#	Yes vs No	1.04 (0.57, 1.90)	0.8958
AI	Combonorml##	Yes vs No	2.28 (0.58, 8.96)	0.2383
AI	Age		1.05 (1.02, 1.09)	0.0013*
AI	BMI		1.02 (0.98, 1.05)	0.3534
AI	Gravida		1.10 (0.94, 1.29)	0.2307
AI	Parity		1.08 (0.90, 1.29)	0.4315

6.3.1.2 Main antenatal outcomes

The prevalence of AI was higher in the past (68%) compared to screening that occurred in the four weeks prior to completing the questionnaire (current period) (12.9%) (Table 6.4). The historical reporting of symptoms included solid stool (8%), liquid stool (18.3%), flatus or gas (50.6%), staining (13.5%), soiling (6.2%) and rectal urgency (43.7%). Rates of reported symptoms that were lower in the last four weeks of screening included; liquid stool (0.6%), flatus (7.9%) and rectal urgency (5.9%) and no symptoms reported for solid stool, staining or soiling. Women with a history of AI reported either one symptom (38.8%), combination of two symptoms (34.7%) or reported three or more symptoms (26.4%). Reporting was lower in the last four weeks (current history) with 16.5% of women reporting one symptom, 2.1% two symptoms and three or more symptoms reported in 0.4% of women (Table 6.4 and Fig 6.1).

The difference in the rates of reporting of the symptoms, liquid stool, flatus, staining, and rectal urgency between historical and current periods was statistically significant (Table 6.4). In the first trimester, women were 8.2 times less likely to report liquid stool (OR = 8.15, 95% CI 2.02, 32.82, P value = 0.0003), and 2 times less likely to report incontinence of flatus (OR = 2.03, 95% CI 1.22, 3.39, P value = 0.007). Women were 2.6 times more likely to report a history of rectal urgency in the past (OR = 2.61, 95% CI 1.51, 4.51, P value = 0.0006) compared to current reporting. The historical reporting of a combination of symptoms was greater when compared to current reporting (OR = 13.44, 95% CI 5.74, 31.48, P value = <0.0001).

6.3.2 Women of reproductive age in the community setting

Three hundred and fifty non-pregnant women completed the BSQ for both historical and current reporting of AI. The prevalence of AI was higher historically with 179 (51.1%) of 354 women reporting a history of symptoms compared to 121 of 354 (34.5%) women reporting current symptoms in the last

four weeks. Age and ethnicity were the only demographic factors significantly associated with different rates of reporting with and without AI in relation to the demographics and obstetric details described in tables 6.5 to 6.6.

6.3.2.1. Demographic and obstetric details of community women

Symptomatic women were older (33.8 ± 6.73, P value = 0.0013) and had a higher body mass index (BMI; 26.05 ± 6.42, P = 0.071) compared with asymptomatic women (32.7 years (± 6.76) and BMI 25.76 (± 5.94); Table 6.5). An increase by one unit in BMI increased a woman's risk of AI by 2% (OR = 1.02, 95% CI: 0.98, 1.05, P value = 0.3534). Women reported a range of symptoms across all BMI's and whilst clinically significant this was not statistically significant. Normal BMI was associated with increased reporting of all symptoms whereas, women who were obese reported higher incidence of flatus and rectal urgency (Fig. 6.2).

Regarding ethnicity, 88% of the women in the community group identified as Caucasian, 5.4% as Asian, 4% as African, 2% as Aboriginal, 0.3% as Middle Eastern and 0.3% identified as other ethnicity. Most women reported their previous mode of birth as vaginal (54%), with an intact perineum (41%). More women reported two previous births (44%) than one previous birth (26%), three previous births (18%) or four or more births (11.6%; Table 6.5 & 6.6). No women identified as being currently pregnant.

The associations between AI were analysed in relation to ethnicity, delivery mode, perineal outcome, age, BMI, previous pregnancies and parity (Table 6.6). There were no associations between AI and mode of birth and perineal outcomes. Women with a history of forceps delivery (OR = 1.46, 95% CI: 0.51, 4.18, P value = 0.4853), LSCS (OR = 1.23, 95%CI= 0.74, 2.04, P value = 0.4248), or prior recognised obstetric sphincter injury (OR = 2.21, 95% CI = 0.67, 7.32, P value = 0.1941) did not have significant increased risk of AI (Table 6.6).

A yearly increase in age increased the odds of women having AI by 5% (P = 0.0013, OR = 1.05, 95% CI: 1.02, 1.09, P value = 0.0013). A statistically significant association between AI and ethnicity was identified with Caucasian women being two times more likely to report AI compared with women who identified as non-Caucasian (OR = 2.3, 95% CI: 1.2, 4.6, P value = 0.0159).

6.3.2.2. Main outcomes for women of reproductive age in the community

Women reported a prior history of either one symptom (27.4%), two symptoms (13.7%) or three or more symptoms (10%). When reporting their current symptoms, 26% of women reported only one symptom, compared with 6% with two symptoms and lower rates of 2.5% for three or more symptoms (Table 6.7). There was increased reporting for bowel symptoms between the two reporting times with women having more bowel symptoms in times past relative to the current period.

Predominant symptoms included flatus and rectal urgency. A previous history of symptoms included incontinence to flatus incontinence (41.1%), rectal urgency (21.4%), incontinence to liquid stool (14.9%), staining (8.9%), soiling (4%) and incontinence to solid stool (2.3%) compared to lower reporting of these symptoms within the current period. Current rates of incontinence reported tor flatus reported in 26.8%, rectal urgency in 12.2%, incontinence to liquid stool in 4%, staining in 2.3%, soiling in 0.3% ad incontinence to solid stool in 1.4% (Table 6.7).

In the last four weeks, women were less likely to report soiling compared to a previous history of soiling (OR = 10.10, 95% CI: 1.51, 67.53, P value = 0.0171)). Women were more likely to report incontinence to liquid stool (P value <0.001), incontinence to flatus (P value = 0.0175), staining (P value = 0.0008), rectal urgency (P value <0.0455) and combination of symptoms (P value <0.0001) compared to the past. Solid stool loss was not significantly different across the two reported timeframes (Table 6.7).

6.3.2.3. Comparison of symptomatic women of reproductive age in the antenatal population and community population

There were more symptomatic women in the antenatal population (n = 242) compared with the community population (n = 179). Antenatal women were younger (30 years ± 5.13), had more pregnancies (3.3 ± 1.69) and less births (1.7 ± 1.13) compared with symptomatic women in the community (33.8 years ± 6.73, pregnancies 2.67 ± 1.37 and births 2.28 ± 1.14). BMI was higher (27.1 ± 6.99) with a greater range (15-54) in antenatal women compared with women in the (BMI 26.05 ± 6.42; 17- 47; Table 6.9).

Whilst both groups reported a predominance of Caucasian women with AI, there was a higher number of Caucasian (n = 182) and Asian (n = 39) women in the antenatal group (P value <0.0001). More antenatal women had one previous birth (n = 140) compared with community women who were more likely to report two births (n = 80) or more previous births. Antenatal women with AI reported a higher incidence of NVD (P value <0.0001), forceps delivery (P value = 0.1501), intact perineum (P value = 0.0053), OASIS (P value = 0.9743), second-degree tears (P value = 0.0738) and RMLE (P value = 0.3414) compared with symptomatic community women. There was a significant association between AI and LSCS (P value =0.0030), combination RMLE (P value = 0.0001) and first-degree tears (P value =0.0149) in women within the community (Table 6.8).

There was a higher historical reporting of all symptoms for antenatal women compared with women withim the community (68% vs 51.1%). Antenatal women more likely to report a history of solid stool (P value = 0.013), liquid stool (P value = 0.0003), flatus incontinence (P value =0.0001), rectal urgency (P value = 0.0001), soiling (P value= 0.60) and staining (P value = 0.001) compared with community women (Table 6.9A). Symptoms reported within the last four weeks were higher for community women when compared with antenatal women (34.3% vs 12.9%). The rates of solid stool (P value = 0.0025), liquid stool (P value = 0.004), flatus incontinence (P value =0.0001), rectal urgency (P value = 0.0001), soiling (P value = 0.42) and staining (P value = 0.001) (Table 6.9B). Flatus incontinence and rectal urgency were predominant symptoms across both periods for each subgroup of women (Tables 6.9A & B).

6.3.3 Combined study populations and relationship to anal incontinence

Seven hundred and four women were included in the study. The overall prevalence of AI in the combined study groups was 58.9% (Table 6.10). Current reporting of AI reduced to 23% for the combined antenatal and community group. The obstetric and demographic characteristics between symptomatic and asymptomatic groups were similar for age (mean (SD) = 31.8 ± 6.1 vs 31.5 ± 6.1; P value = 0.069), gravida (3.0 ± 1.6 vs 3.1 ± 1.6; P value = 0.139), parity (2.0 ± 1.2 vs 2.0 ± 1.2; P value = 0.174) and BMI (26.7 ± 6.8 vs 26.6 ± 6.5; P value = 0.56; Table 6.10).

Women reporting AI were more likely to be Caucasian (82.4% vs 80.3%; P value = 0.0995) or Asian (10.9% vs 10.0%; P value = 0.366), with one previous birth (43.2% vs 40.9 %; P value = 0.120) compared with the overall population. No associations were observed in relation to mode of birth. The mode of birth varied and included vaginal delivery (62% vs 62.4%; P value = 0.60), LSCS (17.6% vs 17.3; P value = 0.821) and forceps delivery (7.1% vs 6.4%; P value = 0.333). The perineal outcomes were similar between groups with symptomatic women reporting a predominance of intact perineum (50.3% vs 51.1%; P value = 0.74), RMLE (23.5% vs 23.7%; P value = 0.875) and a combination of perineal outcomes with RMLE (7.4% vs 8.0%; P value = 0.488). Women with AI identified as having a first-degree perineal tear (6.2% vs 7.8%; P value = 0.0507) and second-degree tear (5.7% vs 5.3%; P value = 0.519), OASIS (5.0% vs 3.6%; P value = 0.033) and a combination of perineal outcomes with no RMLE and OASIS (1.9% vs 1.7%; P value = 0.623).

Women who reported a history of AI were more likely to report having sustained an OASIS (OR= 0.34, 95% CI: 0.13, 0.92, P value = 0.0334) or second-degree tear (OR = 0.80, 95% CI: 0.40, 1.59, P value = 0.5194)) compared with no OASIS or second-degree tear. Women had a 2% increased risk of having AI

with each yearly increase in age (OR = 1.02, 95% CI: 1.00, 1.05, P value = 0.0690). Women were more likely to report AI if they had one previous birth (OR = 0.78, 95% CI: 0.58, 1.07, P value = 0.1205), and were Caucasian (OR = 0.73, 95% CI: 0.50, 1.06, P value = 0.0995) or Asian (OR = 0.79, 95% CI: 0.47, 1.32, P value = 0.3669). None of these associations reached significance however sustaining a forceps delivery (OR = 0.73, 95% CI: 0.39, 1.38, P value = 0.333), or LSCS (OR = 0.96, 95 % CI: 0.64, 1.42, P value = 0.8213) also increased the risk of AI but was not significantly.

Table 6.7. Comparison of historical and current AI in community women (n = 350). Fischer's Exact Test P values as ordinal logistic model did not converge. Symbols: *Significant P value <0.05; †Missing data; **Symptoms are a combination. Table summary is greater than 100% as women identified more than one symptom. Percentage is calculated out of a total of n = 350.

Community women, n = 350	**Historical**	**Current**	***P value, Odds Ratio (95% CI)***
AI reported, n (%)	179 (51.1)	121 (34.3)	
Solid	**8 (2.3)**	**5 (1.4)**	0.7957, 1.08 (0.62, 1.87)
Never	171 (95.5)	174 (97.2)	
Rare	8 (4.5)	5 (1.4)	
Sometimes	0(0)	0(0)	
Weekly	0(0)	0(0)	
Daily	0(0)	0(0)	
Liquid	**52(14.9)**	**14(4.0)**	**<.0001*,** 3.37 (2.02, 5.63)
Never	127 (71.0)	165 (92.2)	
Rare	52 (29.1)	14 (4.0)	
Sometimes	0(0)	0(0)	
Weekly	0(0)	0(0)	
Daily	0(0)	0(0)	
Wind or gas	**114(41.1)**	**94(26.8)**	**0.0175*,** 1.56 (1.08, 2.25)
Never	35 (19.6)	85 (48.0)	
Rare	144 (80.5)	94 (52.0)	
Sometimes	0(0)	0(0)	
Weekly	0(0)	0(0)	
Daily	0(0)	0(0)	
Stain	**31(8.9)**	**8(2.3)**	**0.0008*,** 2.93 (1.56, 5.52)
Never	194 (80.2)	171 (95.5)	
Rare	31 (13.6)	8 (4.5)	
Sometimes	0(0)	0(0)	
Weekly	0(0)	0(0)	
Daily	0 (0)	0(0)	
Soiling	**14 (4.0)**	**1 (0.3)**	**0.0171*,** 10.10 (1.51, 67.53)
Never	165 (92.2)	178 (99.4)	
Rare	14 (47.8)	1 (0.6)	
Sometimes	0(0)	0(0)	
Weekly	0(0)	0(0)	
Daily	0(0)	0(0)	
Cannot hold on (urge)	**75 (21.4)**	**43 (12.2)**	**0.0455*,** 1.34 (1.01, 1.78)
Never	104 (58.1)	136 (76.0)	
Rare	75 (41.9)	43 (24.0)	
Sometimes	0 (0)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily	0 (0)	0 (0)	
Combined symptoms**			**<.0001*,** 3.11(2.12, 4.57)
1	96 (27.4)	91 (26.0)	
2	48 (13.7)	21 (6.0)	
3 or more	35 (10)	9 (2.5)	

Table 6.8. Comparison of symptomatic community (n = 179) and antenatal women (n = 242). The following analyses were undertaken: Chi-square, Fisher's Exact Test, Independent t-test, Wilcoxon Rank Sum Test. *Significant P value 0.05.

Women reproductive age	Community group, n = 179	Antenatal group, n = 242	P value
Age (Mean ± SD)(Range)	33.8 ± 6.73 (20-50)	30 ± 5.13 (20-50)	**<0.0001***
BMI,(Mean ± SD)(Range)	26.05 ± 6.42 (17-47)	27.1 ± 6.99 (15-54)	**0.0011***
Gravida (Mean ± SD) (Range)	2.67 ± 1.37 (1-7)	3.3 (1.69) (2-11)	**<0.0001***
Parity (Mean ± SD) (Range)	2.28 ± 1.14 (1-7)	1.7 (1.13) (1-7)	**<0.0001***
Parity, n%			**<0.0001***
1 Birth	42 (23.5)	140 (58.1)	
2 Births	80 (44.7)	62 (25.7)	
3 Births	34 (19.0)	21 (8.7)	
>3 Births	23 (12.9)	18 (7.5)	
Ethnicity, n (%)			**0.0001***
Caucasian	165 (92.2)	182 (75.2)	
Asian	7 (3.9)	39 (16.1)	
African	4 (2.2)	9 (3.7)	
Aboriginal	1 (0.6)	4 (1.7)	
Middle Eastern	1 (0.6)	2 (0.8)	
Other	1 (0.6)	6 (2.5)	
Mode of birth, n (%)			**<0.0001***
NVD	89 (49.7)	171 (70.5)	**<0.0001***
Forceps	9 (5.0)	21 (8.7)	0.1501
LSCS	43 (24.0)	31 (12.9)	**0.0030***
Ventouse	4 (2.2)	10 (4.1)	0.4111
Combination LSCS	7 (3.9)	3 (1.2)	0.1050
Combination all modes	9 (5.0)	3 (1.2)	**0.0341***
Perineum, n %			**<0.0001***
Intact	76 (42.5)	136 (56.1)	**0.0053***
RMLE	38 (21.2)	61 (25.2)	0.3414
Combination RMLE	26 (14.5)	5 (2.1)	**<0.0001***
OASIS	9 (5.0)	12 (5.0)	0.9743
Second degree tear	6 (3.5)	18 (7.4)	0.0738
First degree tear	17 (9.0)	9 (3.7)	**0.0149***
Combination no RMLE or OASIS	7 (3.9)	1 (0.4)	0.121

6.4. DISCUSSION

6.4.1 Principal findings

AI is very common in women of reproductive age affecting 58.9% of women in this study. A main strength of this study was the identification of both a history and current symptoms of AI at one point in screening in women attending either an antenatal clinic or community health centre. The variable reporting of AI symptoms was evident with higher reporting in the historical period within all subgroups of the study compared to the current reporting.

Flatus and rectal urgency are important precursor for worsening incontinence and were commonly reported symptoms both at the time of screening and in the past. Women of reproductive age are at risk of worsening symptoms because of subsequent pregnancies, births and ageing[14-16]. The ability to identify both a previous history of symptoms and current symptoms early in pregnancy assists in the improved management and prevention of worsening pelvic floor dysfunction and incontinence in subsequent births and across the lifespan. The BSQ is the first questionnaire to capture both historical and current AI symptoms and opens the way for a more accurate way of identifying women with incontinence symptoms.

Table 6.9A. Reporting of historical AI symptoms (greater than 4 weeks) in community women (n = 179) and antenatal women (n = 242). The following analyses were undertaken: Chi-Square, Fisher's Exact Test P value, Wilcoxon Rank Sum Test. *Significant P value <0.05.

Historical reporting AI	Antenatal	Community	P value, Odds Ratio (95% CI)
AI reported, n (%)	242 (68)	179 (51.1)	
Solid	**28 (8.0)**	**8 (2.3)**	**0.0025***
Never	214 (88.4)	171 (95.5)	
Rare	9 (3.7)	8 (4.5)	
Sometimes	7 (2.9)	0 (0)	
Weekly	8 (3.3)	0 (0)	
Daily	4 (1.7)	0 (0)	
Liquid	**65 (18.3)**	**52 (14.9)**	**0.0040***
Never	177 (73.1)	127 (71.0)	
Rare	53 (21.9)	52 (29.1)	
Sometimes	12 (5.0)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily	0 (0)	0 (0)	
Wind or gas	**179 (50.6)**	**114 (41.1)**	**<0.0001***
Never	63 (21.9)	35 (19.6)	
Rare	69 (28.5)	144 (80.5)	
Sometimes	80 (36.8)	0 (0)	
Weekly	10 (4.1)	0 (0)	
Daily	20 (8.7)	0 (0)	
Stain	**48 (13.5)**	**31 (8.9)**	**0.0010***
Never	194 (80.2)	194 (80.2)	
Rare	33 (13.6)	31(13.6)	
Sometimes	14 (5.8)	0 (0)	
Weekly	1 (0.4)	0 (0)	
Daily	0 (0)	0 (0)	
Soiling	**22 (6.2)**	**14 (4.0)**	0.6058
Never	220 (90.9)	165 (92.2)	
Rare	18 (7.4)	14 (47.8)	
Sometimes	2 (0.8)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily	2 (0.8)	0 (0)	
Cannot hold on (urge)	**155 (43.7)**	**75 (21.4)**	**<0.0001***
Never	87 (36.0)	104 (58.1)	
Rare	45 (18.6)	75 (41.9)	
Sometimes	83 (34.3)	0 (0)	
Weekly	10 (4.1)	0 (0)	
Daily	17 (7.0)	0 (0)	
Combined symptoms			<0.0052
1	94 (38.8)	96 (27.4)	
2	84 (34.7)	48 (13.7)	
3 or more	66 (26.4)	35 (10)	

The reporting of AI within the literature ranges between 2% and 50% of the population, a result of variations in how incontinence was defined, the type of study, study size, population studied and disclosure by participants[1, 17-25]. The higher rates of reporting of AI within these studies occurred when rectal urgency and flatus incontinence were included, which was consistent with our research outcomes[18, 20, 26-29]. Pares et al.[27] cross sectional study of 228 nulliparous women utilised the Wexner score and identified 40.8% of women in early and late pregnancy having at least one episode of AI. Additionally, screening tools that utilise language, which is easy to understand, or that use non- medicalised terminology, not unlike the BSQ, also reported higher rates of AI[26, 29, 30]. Brown et al.[31] concurred with these findings and suggested disclosure is enhanced through the type of screening tool (self-report versus clinician) and the

Table 6.9B. Reporting AI symptoms in the current period (within last 4 weeks) in symptomatic community women (n = 121) and antenatal women (n = 46). The following analyses were undertaken: Chi-Square, Fisher's Exact Test P value. *Significant P value <0.05; †Missing data.

History of AI	Antenatal† N = 242	Community N = 179	P value, Odds Ratio (95% CI)
Current AI reported, n (%)	46 (12.9)	121 (34.3)	
Solid	**0 (0.0)**	**5 (1.4)**	
Never	242 (100)	174 (97.2)	
Rare	0 (0)	4 (1.4)	
Sometimes	0 (0)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily	0 (0)	0 (0)	
Liquid	**2(0.6)**	**14 (4.0)**	**0.0003***
Never	240 (99.2)	165 (92.2)	
Rare	2 (0.6)	14 (4.0)	
Sometimes	0 (0)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily	0 (0)	0 (0)	
Wind or gas	**28 (7.9)**	**94 (26.8)**	**<0.0001***
Never	214 (88.4)	85 (48.0)	
Rare	10 (4.1)	94 (52.0)	
Sometimes	13 (5.3)	0 (0)	
Weekly	3 (1.2)	0 (0)	
Daily	2 (0.8)	0 (0)	
Stain	**0(0.0)**	**8 (2.3)**	**0.0010***
Never	242 (100)	171 (95.5)	
Rare	0 (0)	8 (4.5)	
Sometimes	0 (0)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily	0 (0)	0 (0)	
Soiling	**0 (0.0)**	**1 (0.3)**	0.4252
Never	242 (100)	178 (99.4)	
Rare	0 (0)	1 (0.6)	
Sometimes	0 (0)	0 (0)	
Weekly	0 (0)	0 (0)	
Daily		0 (0)	
Cannot hold on (urge)	**20(5.9)**	**43 (12.2)**	**<0.0001***
Never	222 (91.7)	136 (76.0)	
Rare	9 (3.7)	43 (24.0)	
Sometimes	8 (3.3)	0 (0)	
Weekly	2 (0.8)	0 (0)	
Daily	1 (0.4)	0 (0)	
Combined symptoms**			**<0.0001***
1	39 (16.5)	91 (26.0)	
2	5 (2.1)	21 (6.0)	
3 or more	1 (0.4)	9 (2.5)	

use of terminology. This study involved 5817 women over the age of 45 years in the United States, and included an online questionnaire adapted from a validated bowel screening tools the Faecal Incontinence Severity Index (FISI) and the Wexner score. Whilst the self-reporting format of the questionnaire enhanced reporting with 97% of women noting a history of AI in the last 12 months, there were issues surrounding terminology with 31% of women never having heard the term faecal incontinence[31]. The strength of the BSQ was in the design and development of the questionnaire, which included consumer participation, where it was apparent women preferred non-clinical terminology, which included "poo", "gas or wind", "cannot hold", and "staining". This enhanced disclosure and described symptoms women associated with anal incontinence[13]. This was consistent with other studies, which have shown women

Table 6.10. Total research population of women of reproductive age (n = 704). Binary logistic regression, anal incontinence versus predictor. *Significant P value <0.05.

Women of reproductive age	Total group, n = 704	Anal incontinence group, n = 421	P value	Odds Ratio (95% CI)
Age (Mean ± SD) (Range)	31.5 ± 6.1 (18 to 50)	31.8 ± 6.1 (20–50)	0.0690	1.02 (1.00, 1.05)
BMI (Mean ± SD) (Range)	26.6 ± 6.5 (15 to 54)	26.7 ± 6.8 (15–54)	0.5622	1.01 (0.98,1.03)
Gravida (Mean ± SD) (Range)	3.0 ± 1.6 (1,11)	3.1 ± 1.6 (1,11)	0.1329	1.08 (0.98,1.19)
Parity (Mean ± SD) (Range)	2.0 ± 1.2(1,7)	2.0 ± 1.2 (1,7)	0.1742	0.92 (0.81,1.04)
Parity, n%				
1Birth	288 (40.9)	182 (43.2)	0.1205	0.78 (0.58,1.07)
2 Births	247 (35.0)	142 (33.7)	0.3699	1.15 (0.84,1.58)
3 Births	94 (13.4)	55 (13.0)	0.7934	1.06 (0.68, 1.65)
>3 Births	74 (10.5)	41 (0.23)	0.4216	1.22 (0.75,1.98)
Ethnicity, n (%)				
Caucasian	566 (80.3)	347 (82.4)	0.0995	0.73 (0.50,1.06)
Asian	71 (10.0)	46 (10.9)	0.3669	0.79 (0.47,1.32)
African	39 (5.5)	13 (3.1)	0.0009*	3.18 (1.60,6.29)
Aboriginal	13 (1.8)	5 (1.2)	0.1245	2.42 (0.78,7.48)
Middle Eastern	5 (0.7)	3 (0.71)	0.9927	0.99 (0.16,5.97)
Other	10 (1.4)	7 (1.7)	0.5112	0.63 (0.16,2.47)
Mode of birth, n (%)				
NVD	439 (62.4)	260 (62.0)	0.6029	1.09 (0.80,1.48)
Forceps	45 (6.4)	30 (7.1)	0.3333	0.73 (0.39,1.38)
LSCS	122 (17.3)	74 (17.6)	0.8213	0.96 (0.64,1.42)
Ventouse	25 (3.5)	14 (3.3)	0.6933	1.18 (0.53,2.63)
Combination LSCS	18 (2.6)	10 (2.4)	0.7101	1.20 (0.47,3.07)
Combination all modes	54 (7.6)	32 (7.6)	0.2190	0.49 (0.16,1.53)
Perineum, n %				
Intact	360 (51.1)	212 (50.3)	0.7470	0.95 (0.70, 1.29)
RMLE	167 (23.7)	99 (23.5)	0.8754	1.03 (0.72, 1.47)
Combination RMLE	56 (8.0)	31 (7.4)	0.4801	1.22 (0.70, 2.11)
OASIS	26 (3.6)	21 (5.0)	**0.0334***	0.34 (0.13,0.92)
Second degree tear	37 (5.3)	24 (5.7)	0.5194	0.80 (0.40,1.59)
First degree tear	55 (7.8)	26 (6.2)	0.0507	1.73 (1.00,3.01)
Combination no RMLE or OASIS	12 (1.7)	8 (1.9)	0.6231	0.74 (0.22,2.48)

preferred health literature appropriate to the literacy level for the intended population, and including terms, which were easy to understand and enhanced reporting of symptoms[30-33].

Rectal urgency, the inability to defer defecation longer than 15 minutes, and flatus incontinence, were common symptoms reported in women of reproductive age and this is consistent with other research[20, 26-28, 34]. Passive soiling and staining are indicative of damage to the anal sphincter complex, particularly the internal anal sphincter. These symptoms have a significant impact on quality of life in women of reproductive age, yet few studies have assessed soiling and staining[1, 20, 23, 26, 27, 35-37]. Other studies however, which included soiling, reported similar rates to findings from this current study[38, 39].

Screening women of reproductive age for AI is difficult due to the transient nature of symptoms. The BSQ identified the varied reporting of symptoms both in the past and at the current time of screening. Symptoms were reported less frequent in the current period; in particular, for the antenatal group of women suggesting early pregnancy may influence or alter the incidence of AI. It is known that pregnancy hormones increase the risk of constipation in the first and second trimester and reduce the risk of AI during this timeframe and may account for the differences observed in the study outcomes[40,

[41]. Additionally, 29.9% of BSQ were not completed or partially completed for this timeframe; as a result, the lower response rates may have influenced the validity of the findings for the antenatal group. Prospective studies have identified the varied reporting of AI across different points of time with bowel screening tools, which were consistent with our study findings[21, 24, 26-28, 35]. The inability of these tools to identify a pre-existing history of AI in addition to current symptoms limits their use as a quick and easy screening tool and may prevent early intervention in care and management, which would reduce the risk of worsening symptoms. Birth pathway planning generally begins in the first trimester of pregnancy and requires assessment of pre-existing and current history of incontinence symptoms. However, the transient nature of AI and inability of current clinical tools to screen effectively increases the risk for compounding injury and worsening incontinence. The BSQ is therefore a superior tool, which will assist in the early assessment of women of reproductive age. It will detect incontinence symptoms and enable women and clinicians caring for them to make decisions, which can help, preserve their continence over time and provide women with prions for care to improve their quality of life[42-44].

6.4.2. Obstetric predictors and relationship to AI

Overall findings for the 704 women in our study suggested OASIS was the only significant risk factor for AI. Previous studies have confirmed our findings and identified the risk associated between AI and OASIS, with many women continuing to experience symptoms 12 months following birth[45-47]. Increasing age is associated with an increased risk of AI and whilst the findings in our study were not significant , it was identified the risk of AI increased by 1% to 5% with every year of ageing and adds to the current literature[1, 48]. The overall risk of AI in the study was associated with older age, increased BMI, ethnicity, forceps, first birth, LSCS, OASIS, second-degree tear and intact perineum's and has been demonstrated in other studies[35, 49-52].

There was a higher reporting of historical symptoms by antenatal women compared to women in the community. The differences may be a result of the compounding effects of risk factors including BMI, first birth, ethnicity, forceps delivery, normal vaginal delivery, RMLE, OASIS, second degree tear, intact perineum. Several studies have shown associations between increased BMI and AI and this was consistent with the antenatal findings in our study[35, 50, 52]. Macarthur et al.[35] reported predominant symptoms of faecal incontinence (7.1%) and flatus incontinence (24%) in overweight women, and these are comparable to our findings. My study was undertaken in a socially disadvantaged population, which increased the likelihood of obesity[53-56]. Over half women, surveyed (53%) were overweight (BMI ≥ 25) with 32% of women with a BMI of 30 or more (obese). Obese women are more likely to have obstetric complications including the risk of high blood pressure, gestational diabetes, larger babies, risk of instrumental delivery, perineal trauma and in particular, OASIS, which are all known risk factors for AI[53, 57, 58].

Asian ethnicity increased the risk of AI in the overall group of women and sub group of antenatal women. The shortened perineal length, body type and less pelvic organ mobility in labour for Asian women are described in studies as risk factors for perineal trauma and AI[28, 35, 49, 59-61]. Additional findings identified Caucasian women, were likely to have, AI compared to other ethnic groups excluding Asian women. The overall study population was predominately Caucasian and therefore the predominance of an ethnic group within a study may have influenced my findings and consistent with findings from other studies[62] .

Studies have continually shown the relationship of forceps delivery, RMLE and OASIS and provided support for the findings within our study[63-65]. Interventional modes of delivery increase the risk of perineal trauma where women with instrumental deliveries are more likely to sustain trauma and potential AI. My findings however suggested uncomplicated vaginal birth was associated with AI. This may be a consequence of a longer second stage increasing the risk of underlying indirect trauma or neuropathy[66-69]. Studies identified the risk of perineal trauma increased with every hour in the second stage of labour and the risk increased further with the intervention of instrumental delivery[67]. The relationship of AI to an intact perineum and previous LSCS were identified in the study and are consistent with our previous

research (chapter 4). Pregnancy, labour and birth are known risks, which contribute to weakening the pelvic floor and disruption of nerves in women who birth vaginally or by caesarean section and these findings are similar to other studies[23, 25, 66, 70-74]. Our current study did not assess length of second stage or differentiate between elective LSCS or emergency LSCS, which would influence reporting of AI.

Second-degree tears were associated with AI in the antenatal group of women and these findings are consistent with the current literature which identified an increased trend where AI was doubled in women who sustained second degree tears (22.8%)[52]. Further studies suggested in the absence of known OASIS, the cause of incontinence can be a result of undetected OASIS, or pudendal neuropathy and subclinical damage in the first birth may play a role for the development of AI[46, 52, 72]. This concurred with the study findings where more women had only one previous birth and higher numbers of first and second-degree tears.

6.4.3 Strengths and limitations

This study is unique as it reported the findings of a specifically designed bowel-screening tool, which assessed both historical, and current reporting of anal incontinence at one time point. There is currently no other screening tool which achieves this outcome. This was a major strength of the BSQ and an important aspect of risk assessment for women of reproductive age when presenting in a subsequent first trimester of pregnancy. Women may not present with symptoms due to the variable nature of AI and influence of pregnancy hormones on bowel function. The ability of the BSQ to assess the variable reporting and the prevalence of flatus incontinence, and rectal urgency, commonly reported symptoms and precursors for worsening function with age, was a further strength of the findings. Importantly the BSQ identified an additional precursor for worsening function; soiling a symptom not routinely included in assessing women of reproductive age.

The prevalence of AI within the overall groups were high and comparable to studies, which utilised screening tools developed with consumer participation. The importance of consumer participation in symptom selection and use of common terms that were easily understood enhanced the reporting of symptoms within the BSQ. Although women who were health seeking or wanting to assist the research may have influenced the findings through the provision of affirmative answers and this may have been a limitation to the overall reporting.

A further limitation may have resulted due to selection bias. A consequence of attending health professionals who may have encouraged recruitment of symptomatic women, which would have influenced a higher reporting of AI. The accuracy of prevalence rates further influenced through response bias where the BSQ was utilised as a mixed mode questionnaire. Women could self-report but also seek assistance when required. Completion of the questionnaire in the presence of a health professional may have caused embarrassment and non-disclosure for antenatal women, and influenced the current reporting period, with 29.9% of BSQ not completed and limited the accuracy of the findings. The variability of symptoms have been shown to influence reporting where higher inaccuracies were associated with the severity of health concern and longer periods between reporting. The current study relied on women to recall their birth history and continence symptoms and the period between births or variability of symptoms may have influenced reporting. Additionally, women in the community self-assessed their weight and height and the provision of socially desirable responses in particular underreporting BMI may have influenced the accuracy and reliability of the findings. The study did address the issue of recall bias for antenatal women with the extraction of fifteen percent of data from the antenatal case-notes and a significant interrater agreement was identified.

Whilst clinically significant differences and associations between known risk factors for AI including parity, BMI, Asian ethnicity, forceps delivery, RMLE were established there were no statistical significance. This may be a result of multiple predictors being responsible for causation of AI as 58.9% of women in the study had more than one previous birth and differing birth mode. The findings of the study reported a relationship between AI and LSCS, NVD, intact perineum's, second-degree tears;

factors not identified as common predictors within the literature. The higher reporting of AI in women who reported LSCS provided evidence that multiple factors influence AI. Although the findings did not differentiate between women who had an emergency LSCS and elective LSCS, it could be concurred the impact of labour on the pelvic floor might have further influenced outcomes. The compounding effect of predicators, including family history and collagen weakness outlined in other studies influence pelvic floor function and risk of AI. The aim of this study was not to assess the relationship between AI and predictors but identify the prevalence of AI in women of reproductive age. However, assessment of a pre-existing history in the context of current reporting of symptoms not only improves detection but also allows for further investigation for causation.

6.5 CONCLUSIONS

In conclusion, the findings of this this study suggests there is a high prevalence of anal incontinence in women of reproductive age and the reporting of incontinence symptoms is variable. The identification of symptoms, inparticular flatus incontinence, rectal urgency and soiling, precursors for worsening function has in the past been problematic a result of the transient nature and lack of routine screening with an appropriate tool that captured both past and current history of AI. Results from this study have shown the BSQ a specifically designed screening tool developed as part of the overall thesis is the first bowel-screening tool to identify a pre-existing history and or a current reporting of incontinence symptoms at one point of screening. The findings of this study demonstrate lower reporting of symptoms in women with a history of anal incontinence in their first trimester of pregnancy. The ability of the BSQ to detect past symptoms from current reporting makes it superior to other clinical tools as it therefore reports the true prevalence of anal incontinence. The correct identification of symptoms translates to earlier referrals and access to clinical care, which can ultimately improve the quality of life for women in both the short and long-term.

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CHAPTER 7

Final discussion and recommendations

Final discussion and recommendations

OVERVIEW

The preceding chapters of this thesis have addressed the following research questions:

1. What factors influence the disclosure of anal incontinence (AI) in women of reproductive age?

2. Would the identification of these issues assist in the development and validation of a bowel-screening tool to identify AI in this group of women?

Three research aims answered the research questions utilising a mixed methodological approach. The quantitative research (chapters 3, 4 and 6) addressed the development and validation of the bowel screening tool (BSQ). The qualitative interviews (chapter 5) assisted in the development of the BSQ by deriving a deeper understanding on the inhibitors and enablers associated with disclosing anal incontinence (AI).

Research aims:

The overarching aim of this study was to develop and validate an easy-to-use tool to identify AI in women of reproductive age. This stage was informed by two further research aims;

1. To determine whether routine screening was already undertaken in the pregnant and postnatal population to identify AI, and;

2. To analyse the factors that affect the disclosure of symptoms of AI to health care providers. This would further inform the development and validation of a screening tool for AI.

The outcomes of the study have demonstrated that the newly developed bowel-screening tool is a valid and reliable tool for the identification of AI. Importantly, the research has shown that AI was evident in the first trimester of pregnancy with flatus incontinence, rectal urgency and soiling identified as predominant symptoms. These symptoms are suggestive of damage to the anal sphincter muscles and are known precursors for worsening symptoms with age[1]. The research findings show the variable reporting of AI across different times. The strengths of the BSQ was that it recognised both historical and current reporting of incontinence (within the last four weeks), and that it captured the transient nature of AI, which was not identified with the clinical tools used in current practice. The thesis findings demonstrate a need to screen all women of reproductive age regardless of a history of birth trauma because there is a clear link between risk factors such as parity, Asian ethnicity, forceps delivery, episiotomy and obstetric anal sphincter injury (OASIS). Other factors such as age, body mass index (BMI), vaginal delivery and caesarean sections are also associated with AI.

Research to date has largely focused on the causes of AI, and has identified multiple risk factors for pelvic floor dysfunction and resultant AI[2-6]. At present, routine screening does not appear to be undertaken during the first trimester of pregnancy when initial planning and management of care is implemented. There is also a lack of evidence to suggest that specific screening tools have already been developed by and for pregnant or postnatal women[2, 7-15]. The Wexner and Vaizey scores are two tools currently used by clinicians to identify incontinence. This thesis highlights that such clinical tools are limited in busy clinical settings because they contain jargon that is too difficult for women to understand, there is no standard definition of AI, and they use inconsistent frequency scales and scoring systems[16]. The inability of these tools to capture a previous history of AI during current screening of women presenting in pregnancy therefore under reports the true prevalence of AI and negatively impacts on the women's wellbeing. The findings from this thesis demonstrated that the new BSQ, developed in partnership with women, identified a high prevalence of AI, captured the variability of reporting across different times,

and identified soiling as a symptom for inclusion.

7.1 INHIBITORS FOR DISCLOSING ANAL INCONTINENCE

This thesis aimed to identify factors that affected disclosure of AI to health care providers. The findings from the first stage of the study showed that 89.6% of women had not disclosed AI to another person. These findings are consistent with other studies that report rates of disclosure between 10% and 20%[17, 18]. These studies reported that women rarely sought care and were more likely disclose to a friend (51%) than a doctor (10% to 30%)[17, 19, 20]. Health-seeking was identified as being complex and involved a person's understanding that AI was a problem, and not a normal consequence of birthing[21, 22]. Additionally, the motivation to ask for help was influenced by social beliefs, frequency of symptoms, and the receptiveness of health professionals[21, 22]. This was consistent with the findings from the prospective and qualitative stages (chapters 4 and 5), which demonstrated that women often did not recognise AI was a problem, but considered it to be a normal consequence of pregnancy and childbirth. The increased frequency of symptoms was a main factor that promoted health-seeking[23-25].

The inability to conform to societal norms and maintain continence status, or personal disgust and shame associated with discussing bodily functions, were identified in other studies as roadblocks to disclosure[24-27]. Such findings are consistent with those from this thesis (chapters 4 and 5). The qualitative findings from this thesis demonstrated that the role of the health professional in screening for AI was pivotal; however, disclosure was complex for both the clinician and person afflicted because of the stigma surrounding incontinence. This is consistent with other qualitative research where lack of enquiry because of stigma or the undervaluing symptoms from the patients perspective influenced non-disclosure[24].

The thesis findings demonstrated a gap within the care of pregnant and postnatal women; it is now evident that a screening tool has not yet been specifically developed for this group of women, and routine screening is rarely undertaken[28]. Screening tools are utilised in speciality areas or research settings. These tools are often borrowed from other disciplines and are developed for the general population with no consumer participation[16, 29]. The retrospective findings of this thesis demonstrated a disparity in the reporting of AI at primary referral, and following screening by the speciality service (chapter 3). This raises questions as to how health providers undertook screening at the initial point of contact.

Importantly, this thesis has shown that clinical terminology and the inability of tools to capture the variability of symptoms, including rectal urgency and staining, inhibits disclosure with the current clinical screening tools. These findings are similar to to those from research undertaken by Bartlett[30] who stated that disclosure is enhanced when the screening tools capture the variability of all symptoms and included a public vocabulary. Brown[31] reported that the use of clinical terminology in the screening tool, such as the word "incontinence", was shown to negatively impact the reporting of AI. The qualitative findings from this thesis identified that women were less likely to provide affirmative responses if they did not understand the question or the wording used in the clinical tools.

7.2 THE WEAKNESS WITHIN CURRENT SCREENING TOOLS UTILISED FOR WOMEN OF REPRODUCTIVE AGE

The development of the BSQ required a review of the screening tools presently used to assess bowel incontinence in women of reproductive age. This review identified that the current tools are limited as the questions are not standardised. Whilst the tools all describe the type of incontinence, they also differ in their ability to capture the frequency and severity of all of symptoms that are relevant to women of reproductive age[7, 28, 32]. The use of clinical language and the omission of symptoms that are important to women, also limited disclosure[16, 29, 30]. These findings are consistent with the outcomes from this thesis.

The development and validation of the BSQ included a comparison of findings between the Vaizey and Wexner scores, which are the preferred tools currently used by clinicians. This thesis demonstrated a that

there is disparity in reporting AI when utilising the current tools due to the omission of flatus incontinence, rectal urgency and soiling. The lack of a frequency scale for rectal urgency, and a timeframe for reporting, compounded by difficult terminology within current tools, further limited disclosure (chapters 4 and 5).

Clinical tools that have had no consumer participation in their development often assign a higher weighting of solid stool severity and frequency compared with other types of leakage, and thus symptoms are often under-reported from the women's' perspective[20, 33, 34]. The findings from this thesis have shown a higher reporting and frequency of rectal urgency when using the BSQ, compared with the Vaizey and Wexner scores. Rectal urgency is a known precursor for worsening function in subsequent births. It is indicative of damage to the external anal sphincter and the inability of the current tools to effectively screen this symptom limits their usefulness in screening[23, 24, 26, 35]. Passive soiling, or faecal seepage, was identified by the BSQ, and is strongly associated with obstetric anal sphincter injury. Whilst the exact prevalence remains unknown, it is a common symptom within the general community (reported between 7% and 23%)[36]. Neither the Wexner nor Vaizey score included passive soiling from mucous or faeces in symptom selection, further limiting their purpose as a quick and easy tool to screen AI in this group of women[37, 38].

This thesis has highlighted the importance of identifying both past and present symptoms of incontinence by women (chapters 5 and 6). The Wexner score and the initial version of the BSQ contained no timeframes, and only captured the historical perspective for reporting AI. This limited their usefulness in the identification of AI in the first trimester of pregnancy. The hormonal influences of pregnancy during this period slows gut transit and increases the risk of constipation, which often keeps AI hidden[39, 40]. Using the Vaizey score was also limited, as it only assessed the last four weeks, excluding the occurrence of symptoms outside this timeframe. Whilst no current clinical tools report symptoms over both timeframes, prospective cohort studies have provided evidence of the variable reporting of AI at different points in pregnancy and the postnatal period, reinforcing the importance of identifying a previous and current history[41, 42]. The ability to assess a history prior to pregnancy is advantageous not only in the identification and planning of care, but also in the identification of causation[40]. The revision of the BSQ to include a history greater than four weeks as well as current reporting (within the last four weeks) improved reporting of AI over both periods (chapter 6).

The qualitative findings from this thesis (chapter 5) have shown that the language used within the clinical screening tools (Wexner and Vaizey scores) is a main inhibitor to disclosing AI. Lower completion rates of the questionnaires using these tools was often a result of poor comprehension of terms such as "plug", "incontinence", and "urgency". This finding is consistent with studies that have identified clinical terminology within bowel screening tools to be a potential barrier to a person's health literacy, which further influenced their disclosure[30, 43-45]. The benefits of including the perspective of those afflicted establishes a shared vocabulary and the identification of symptoms that are important to consumers but often missed by health professionals[29, 33, 37]. Studies identified that 60% to 70 % of women do not understand clinical terms such as incontinence, which has resulted in under-reporting of AI[21, 30, 44].

7.3 DEVELOPMENT OF THE BSQ

7.3.1 Strengths

This thesis implemented a logical and systematic process to develop a new BSQ to identify common symptoms currently utilised in clinical screening tools. The test to re-test phases and qualitative interviews improved the content and clarity of the initial questionnaire items with the inclusion of frequency scales for all symptoms, the symptom of soiling, and the timeframes of reporting.

The mixed method research design adopted in the development of the BSQ utilised consumer participation from the early development phase. This enhanced the validity of the tool through changes to the language at each test phase and further refinement following qualitative interviews (chapter 5). The benefits of the research design allowed the qualitative research findings to inform and complement

quantitative research findings. This process identified omissions or a misunderstanding of terms, and assisted in evaluating the findings, which is consistent with the literature[46, 47].

Rectal urgency was a predominant symptom reported by women within this thesis. It was under-reported by other tools as a result of its omission as a symptom, or the lack of a frequency scale. The qualitative findings from this thesis have shown that the variable nature of rectal urgency has a significant impact on a woman's quality of life, and this is often difficult to capture. These findings assisted with further development of the BSQ, which included a frequency scale to assess these symptoms (chapter 6).

The qualitative findings of this thesis identified soiling to be a common symptom identified by women, and therefore it should be included within the BSQ. Soiling had a negative impact on quality of life and was identified as a precursor for worsening function with future births and age. This finding is consistent with studies that have linked high reporting to multiparous women who had instrumental deliveries, and thereby had an increased risk of anal sphincter damage[48]. There was limited evidence of this symptom being measured by current tools.

The development of new questionnaires requires consideration of whether the new questionnaire actually measures what it intends and if it assesses ways in which bias can be reduced. The validation and strength of a tool is further enhanced by its comparison with a 'gold standard measurement'[49-52]. This thesis employed this method of validation by comparing the BSQ with the Wexner and Vaizey scores. The latter two tools, while not labelled as 'gold standard measurements' for bowel incontinence, are the current preferred tools by clinicians, which justified their use in this study. The thesis findings demonstrated agreement between all tools, and that the BSQ was a reliable, valid and effective assessment of AI in the clinical and community settings.

This study was undertaken at a tertiary birthing centre in a community with an increasing number of multicultural and socially disadvantaged women, where access to health care services and low literacy levels can negatively affect the disclosure of AI[53, 54]. The thesis findings demonstrated that consumer participation was pivotal in the development of the BSQ, which was strongly reliant on the health literature being at an appropriate level for the intended population. Revisions included symptoms identified as relevant by women, using a shared vocabulary[55]. The successful completion of the BSQ at each research stage demonstrated the reliability of the BSQ in reporting AI. The enhanced reporting was similar to studies that have included consumer participation in their development, an evaluation as to whether the new questionnaire was appropriate, and whether it contained words which were intelligible and questions that were unambiguous[49, 52, 56].

There is limited evidence within that health literature to suggest that current screening tools report both a past and current history of symptoms. An exception is with mental health, which utilises two tools in conjunction with one another. The Antenatal Risk Questionnaire (ANRQ) and the Edinburgh postnatal depression scale (EPDS) screen women for a past and current history of depression[57]. Screening with both tools at one point in time enhances clinical assessment, providing the clinician with a good indication of when a referral or subsequent review is required[57]. The Beck Depression Inventory Primary Care scoring system (BDI-PC) measures symptoms within the past two weeks, including symptoms reported on the day of screening[58-61]. This allows for the identification of depression when used in different stages of care, where there is variable reporting across the different trimesters of pregnancy (2.2% to 16.7%), and in the postnatal period (6% to 25%)[62]. The ability to assess pre-existing and current symptoms is paramount for conditions such as depression and incontinence where symptoms are often variable and easily missed or underreported as a result of stigma[40]. The thesis findings demonstrated this to be a major strength of the BSQ as it is an important aspect of risk assessment for all women of reproductive age presenting in the first trimester of a subsequent pregnancy. The early identification of AI improves the care and management of women during their successive pregnancies, births and with ageing, thereby improving a woman's quality of life[63]. Furthermore, the ability to assess both a history and current reporting of incontinence assists in identifying causation and improves care through modification of potential risk factors[40].

7.3.2 Limitations

This thesis implemented the BSQ was within a low socio-economic population. The social determinants of health reflected high levels of unemployment, low levels of completion of secondary education, high levels of sole female parenting, and a reliance on public housing[35]. Negative social determinants of health disadvantage this population, contributing to poor health-seeking behaviour and poor health literacy. The thesis findings may therefore not be applicable in different populations where the social and or cultural influences may affect participant reporting. Further research is therefore required to assess the responsiveness of the questionnaire in other populations. The findings from this thesis are similar to other studies that suggest that the translation of tools into other languages, and/or display cultural references, will improve accuracy of reporting[64-67]. Furthermore, the literature also highlights the need to assess whether the tool truly communicated information at the right level of understanding for the study population as lower literacy levels may influence understanding and inability to follow instructions leading to inaccuracies in reporting[67].

The BSQ was implemented as a mixed mode questionnaire. There remains debate within the literature as to the benefits and limitation of self-report questionnaires and questionnaires implemented by clinicians[45, 49]. Self-report questionnaires are limited by social desirability, where conditions like AI with undesirable outcomes negatively influence reporting[49]. Conversely, questionnaires implemented by clinicians can increase investigator bias[49]. These factors may have inadvertently influenced the development of the BSQ.

The initial BSQ did not contain a frequency scale for all symptoms; however, the intention of this stage was to identify AI (chapter 4). The findings from this thesis have shown that the omission of frequency scales especially for rectal urgency in clinical tools contributed to the underreporting, and undervaluing of symptoms from the perspective of women. These findings are consistent with other studies that used qualitative interviews to evaluate items in quality of life tools[7, 26, 37]. Cotterill's[37] qualitative findings of interviews identified additional items that were previously excluded by health professionals, but identified by patients as having a significant impact on their quality of life. Following the qualitative interviews, a frequency scale for all symptoms was therefore included in the revised BSQ (chapter 6).

7.4 IMPORTANT FINDINGS OF THE BSQ

The overall prevalence of AI reported within this thesis is high relative to other studies that have also included the symptom of rectal urgency[6, 42, 48, 68]. The findings varied to other studies, which reported lower rates, because of the different clinical screening tools used, study sample and size, and how incontinence was defined as either as AI or FI[40, 69, 70].

The preceding chapters of this thesis have demonstrated the benefits of consumer participation in the development of the BSQ through the identification of symptoms important to women and the transient nature of AI that were not previously included in screening tools. Importantly, the findings identify the BSQ to be superior to current tools because of its ability to identify the pre-existing history and current history of AI together, at one point of screening. Current rates of reporting of AI were lower in all groups compared to historical rates but were of particular interest in pregnant women in their first trimester of pregnancy and consistent with previous research, which assessed AI across different stages of pregnancy[14, 42, 68, 71]. The capability of the BSQ to establish a pre-existing history in the current context of symptom screening assists in determining the cause of AI, as there is a growing consensus that the cause of AI, and worsening AI symptoms, are a result of multiple predictors[2, 4, 72, 73]. This is consistent with other studies of nulliparous women presenting with a history of AI in pregnancy where symptoms worsened postnatally[6, 14, 42, 68, 69]. These studies identified that women who were experiencing one symptom during pregnancy, often suffered with the same symptom following birth, and that this symptom worsened with age[69].

The findings from this thesis have shown a higher reporting of historical symptoms by antenatal women

compared with the women within the community. This difference may be a result of the compounding effects of multiple risk factors reported within the literature such as parity[74-76], instrumental birth[2, 77], episiotomy[78-81], maternal age[48, 82], ethnicity[65, 83], foetal macrosomia[77, 84, 85], and prolonged second stage for > 1 hour[86-88]. The findings have also demonstrated a link between factors that are not normally deemed to be risk factors such as caesarean section (LSCS), second-degree perineal tears, and intact perineum (chapters 3, 4 and 6). These findings are similar to those reported in previous studies that recognised the influence of additional pre-pregnancy factors, rather than linking causation solely to the consequences of labour and birth[89-91]. Ageing and increased BMI were predominant factors associated with worsening AI in all stages within the thesis and adds to the existing literature[92, 93]. Several studies have shown associations between increased BMI and AI and this was consistent with the thesis findings[2, 94, 95]. Symptomatic women with a normal BMI experienced a range of all symptoms; flatus incontinence and rectal urgency were reported by obese women. Similarities existed between the thesis findings and Macarthur et al.[2] who reported predominant symptoms of faecal incontinence (7.1%) and flatus incontinence (24%) in overweight women. This thesis has shown that over half the women surveyed (53%) were overweight, with 32% of women with a BMI of 30 or more (obese). Obese women are more likely to have obstetric complications including the risk of high blood pressure, gestational diabetes, larger babies, risk of instrumental delivery, perineal trauma and in particular OASIS, which are known risk factors for AI[96-98].

7.5 HEALTH LITERACY IN TOOL DEVELOPMENT

The health literacy of a woman can affect her ability to understand the importance of disclosing AI, accessing care, and it influences her ability to understand written information[43, 99]. Health literacy in the development of screening tools needs to be sensitive to a specific health group and utilisation of common terminology for bowel problems would be advantageous in improving the disclosure of symptoms in the screening and the identification of anal incontinence[30, 100, 101]. As previously outlined, the findings from this thesis have demonstrated that there is a lack of mutually agreed definitions, complex language and terms ascribed to AI, and is consistent with other studies[30, 100, 101]. Terms used in screening tools, which included incontinence, plug, and urgency were difficult to comprehend with many women opting to say no to symptoms, as they did not understand the questions. This contributed to the disparity between reporting with the BSQ and clinical tools in the quantitative research findings (chapter 4). The lower completion of clinical tools as a result of a lack of mutually shared language between health professionals and consumers was consistent with other studies where participants did not understand the term "faecal incontinence" although when the phrase "accidental bowel leakage" was used, reporting of AI increased[44, 102]. Importantly, the previous study showed that consumer participation in tool development enhanced reporting of AI. This was consistent with the findings from this thesis, where a higher completion rate and reporting of rectal urgency and lower reporting of solid and liquid stool was seen with the BSQ when compared with the Wexner and Vaizey scores[44].

7.6 IMPLICATIONS OF THE EARLY IDENTIFICATION OF AI FOR WOMEN

Health settings commonly undertake screening tests to detect specific conditions or disease in groups at risk, often when no symptoms exist thus improving treatment and management[103]. Timely intervention reduces the worsening physical aspects of a condition, and the psychological, social and financial burden of conditions like AI[103, 104]. The thesis findings demonstrated there was a high prevalence of AI in women of reproductive age, however, there was a lack of routine screening by health professionals within this at risk population (chapters 1, 3, 4, 5 and 6).

Whilst pregnancy and childbirth pose the greatest risk for PFD and AI, women with a history of incontinence prior to conception and birth are at risk of worsening bowel function 5 to 10 years following their first birth[40,41,105]. Women who are symptomatic of AI at 12 weeks of pregnancy or late in pregnancy are at increased risk of worsening function postnatally[6, 14, 18, 105, 106]. Unlike other screening tools, the BSQ presented in this thesis has the ability to screen for both past and current symptoms of AI. In a

subsequent pregnancy, the early identification of AI assists in planning and management of a pregnancy and birth to reduce further damage to a compromised pelvic floor and anal sphincters[89, 90]; however, the gastrointestinal influences on gut motility in early pregnancy increases the risk of constipation and therefore the accuracy in reporting AI. The BSQ in this thesis identified a lower reporting of flatus incontinence, rectal urgency, soiling and staining in the current period compared with the historical period. The ability of the BSQ to capture both current and past symptoms is vitally important in women who may present with no symptoms in their first trimester of pregnancy.

7.7 LIMITATIONS OF THE RESEARCH

The findings of this thesis have shown that health-seeking is complex. It requires that a person has understanding that AI is a problem, and it is influenced by their social beliefs and ability to self-motivate to seek help. Poor health-seeking is often associated with infrequent episodes of AI, or the belief that AI is a normal consequence of birth. Likewise, worsening symptoms that are often associated with a worsening state of depression, are a strong motivator for health-seeking. This difference in heath-seeking may account for variable reporting observed in each of the research stages of this thesis[20, 21, 27, 107, 108]. Additionally, Shrank et al.[109] described the healthy user effect as contributing to research bias. The findings of this thesis may have been influenced by these factors during the recruitment phases of the research; women receiving positive engagement about AI may have been motivated to participate in the research process[109]. Conversely, the stigma associated with AI may have negatively influenced the accuracy in reporting and have attributed to social desirability bias[110].

Recall bias is common in studies that require participants to recall past events and often results in inaccurate reporting[110]. The research literature extensively reports the effects of recall bias with most research undertaken in studies examining dietary intake, pain management and asthma, with few in obstetric care[110-117]. This type of bias is often influenced by the length of time in recall period, characteristics of the disease, severity of the disease, the patient, and study design[110, 118]. The findings from this thesis may have been influenced by recall bias where disclosure was influenced by stigma and the severity of symptoms, which is reported by other studies[19, 107]. These findings are similar to previous research, which investigated the level of agreement in reporting foetal loss, estimated date of last delivery and gestational age when compared with hospital records. Higher inaccuracies were associated with the severity of the health concern and longer periods between reporting[115-117].

This thesis identified that past obstetric history, BMI, a history of AI symptoms, and results may have all been influenced by recall bias; however, the design of the research attempted to reduce recall bias. The thesis findings demonstrated good interrater reliability by cross-checking obstetric data in hospital records in 10% to 15% of the research (chapters 3 and 4).

The research presented in this thesis assessed women from a low socio-economic areas, which may be considered a further limitation. Low socio-economic status has been linked to inaccuracies in reporting due to poorer health literacy. Further research should assess if the BSQ is valid in other socio-economic settings[115, 118].

The thesis findings have shown that there is a link between AI, obstetric risk factors and demographic characteristics. The thesis findings were clinically significant, however, the research showed few statistical associations, excluding OASIS. Whilst the overall study and sample size was powered to 80% in relation to the previous year's birth rate within the hospital, the thesis findings are similar to those from other studies, which suggests that more than one risk factor influences the risk of AI[14, 69, 119, 120]. Importantly, there is growing recognition that pre-existing factors contribute to the development AI in the postnatal period[14, 42, 69, 120]. Previous studies identified that a collagen deficiency or other presenting genetic factors may increase the risk of birth trauma and pregnancy or sub-clinical injury to the levator ani or chronic pudendal neuropathy following birth[4, 69, 121, 122]. Many women may not be symptomatic in the short term, but weakened muscle tone increases risk with subsequent injury[121, 122]. Therefore, the ability to assess pre-existing symptoms of AI and compare those with the current reporting of symptoms,

with a tool such as the BSQ, improves identification and management, and reduces risk for all women of reproductive age.

7.8 FUTURE DIRECTIONS

The findings of this thesis have identified that whilst disclosure relies on multiple factors, enquiry by a health professional either inhibits or enables disclosure, which is consistent with other studies[16, 23, 30, 107]. Previous research is limited in that is does not derive a deeper understanding of the factors that influence screening from a health professional focus. Further research is therefore required in this area.

The BSQ is the first screening tool to report AI at initial screening for both a history of symptoms and current reporting of symptoms. Future prospective research should consider screening with the BSQ at different times to assess the reproducibility of both the historical and current reporting of AI. The known influence of pregnancy hormones at different stages of pregnancy identifies a need for further research with implementation of the BSQ pre-pregnancy, in each trimester of pregnancy and during the postnatal period. This would provide a comparison of reporting at different stages.

This thesis has demonstrated that the BSQ was responsive in the study populations (chapters 4, 5 and 6) although further testing in different socio-economic populations is required to establish the responsiveness of the BSQ in other health settings in different demographic areas.

Both existing research literature and the findings from this thesis have identified a relationship between AI and obstetric and demographic risk factors, many of which can coexist at birth[76]. Our study did not differentiate between emergency or elective LSCS, nor the length of the second stage, which would have affected the findings. Therefore, further research is required to identify the associations between elective compared to emergency LSCS and AI.

The research in this thesis has identified a relationship between AI, second-degree tears and intact perineum. These findings are consistent with studies that identified women who sustained no perineal injury were symptomatic of AI[123, 124]. The advent of endo anal ultrasound in screening for OASIS has increased the reporting from 20% to 41% of women who were previously undiagnosed[79]. Therefore, routine screening for AI should occur for all women of reproductive age to ascertain the reliability of the BSQ in identification of AI. Future research may consider the identification of injury to anal sphincter muscles and relationship to AI through screening with the BSQ and endo anal ultrasound assessment in women with no perineal trauma[40].

7.9 CLINICAL IMPLICATIONS AND CONCLUSION

There is a growing awareness of the high prevalence of anal incontinence and poor reporting across the lifespan for women[70]. Primary prevention strategies play an important part in early screening and risk reduction[125, 126]. The ability to identify a previous history of incontinence is advantageous in reducing further demise of the pelvic floor and assists in understanding factors that precipitate worsening incontinence such as pre-pregnancy issues, pregnancy or birth related trauma[40, 89]. The thesis findings demonstrate that the BSQ is a valid and simple tool that effectively identifies the variable reporting of AI in women of reproductive age in a tertiary setting and within the community. The ability of the BSQ to report both a history of AI and current symptoms, together at the one point of screening, highlights that it is an important tool for use in everyday clinical practice, and in particular, within the obstetric setting. The variable nature of symptoms such as flatus incontinence, staining and soling are typically not captured by current clinical tools, however, they are addressed by this new BSQ. This has resulted in improved assessment, and is likely to influence the management and care of women by minimising risk and worsening symptoms[20].

The findings from this thesis have shown that the BSQ contained questions that could be easily understood by women in the community. Its simplicity allowed for higher completion rates, which is paramount

in increasingly busy clinical settings within the community and acute care settings[118]. The use of non-clinical terminology in the study improved engagement with women, allowed for earlier assessment of symptoms, and further discussion through engagement. This was consistent with other studies that recognised that positive engagement by health professionals led to improved rates of disclosure, implementing early referral to speciality clinics or review of obstetric care in particular discussion on the mode of birth[27].

In conclusion, the BSQ has proved itself to be is a reliable and validated tool in the reporting of AI across two timeframes for women of reproductive age. It has filled a gap within healthcare where no previous tool existed. Consideration of a woman's health literacy in the development of the BSQ resulted in enhanced reporting of AI in women of reproductive age, especially in the first trimester of pregnancy. The transient nature of AI negatively influences reporting in the first trimester of pregnancy where there is the initiation of management and birth planning for women. It is paramount that tools such as the BSQ are utilised in this at-risk population where pelvic floor dysfunction may further compromise pelvic floor function and worsen AI across the lifespan.

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Appendicies

Materials & Methods (Chapter 2)

Appendix 1. Extraction table for data.

Does routine screening identify anal incontinence - coding definitions	
1 Primary referral - what's written only	**17 Martial status**
Urinary incontinence	**Sections 18 to 20 yes/no response**
Urinary incontinence- new/history	**18 Employed**
Stress incontinence- new/history	**19 Antenatal**
Urge Urine -new/history	**20 Postnatal**
Anal incontinence (AI)	**Section 21 to 22 add number to box**
Anal incontinence (AI)- new/history	**21 Gravida**
Rectal urgency	Parity
Other symptoms PFD	**22 Gestation in weeks /40**
Incorrect referral	**23 Delivery outcomes**
Questions 2 to 10 answers as follows	**Insert number for delivery type and 99 for no history**
YES	Normal vaginal delivery
NO	Forceps
Not stated	Ventouse
Not contactable	Emergency caesarean section (LSCS)
Not applicable	Elective LSCS
2 Vaizey score documented - case notes	m/c
3 Vaizey score documented - database	Top
4 Previous disclosure AI to health provider	Not applicable
5 Vaizey score>0	**Perineal outcomes**
6 Has literature been sent	**Insert number for outcome and 99 for no history**
7 Referral offered to CNS	Intact
8 Acceptance to referral	Episiotomy
9 Attendance to CNS booking	Small tear not sutured
10 Attendance to endo anal ultrasound	1degree tear
11 Timeframe AI	2nd degree tear
12 Pregnant	3rd degree tear 3A
13 Obstetric review	3rd degree tear 3b
14 Birth plan post obstetric review	3rd degree tear 3c
Elective lower segment caesarean section	4th degree tear
Vaginal delivery	**25 Onset of AI following type of delivery**
Not applicable	Sections 26 and 27 add response to box
15 AGE (write age)	YES
16 Ethnicity	No
Caucasian	not applicable
Aboriginal	not stated
Asian	**26 AI identified in consult**
Other	**27 Rectal urge identified in consult**
	28 Vaizey score 0-24 (score in box or not stated)
	29 Cleveland score 0-36 (score in box or not stated)
	30 Referral source

Appendix 1A. Participant Information Sheet and Consent Form.

Government of South Australia
SA Health

PARTICIPANT INFORMATION SHEET 1A

Title: Development of a screening tool to identify anal incontinence in women of reproductive age.

INVITATION TO PARTICIPATE

We invite you to participate in a research project which we believe is of importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand

why we are doing the research and
what it would involve if you agree to participate.

We are therefore providing you with the following information.
Please read the following information carefully and be sure to ask any questions you have. The nurse researcher conducting the research will be happy to discuss this information with you and answer any questions that you may have.
You are also free to discuss the information with others if you wish. (E.g. family, friends, your local Doctor)
You do not have to make an immediate decision.

PARTICIPATION IS VOLUNTARY

Participation in the research study is voluntary. If you do not wish to take part, you are not obliged to. Should you agree to take part in the research study, you may change your mind and withdraw at any stage. Your decision to take part, not to take part or to withdraw will not affect your routine treatment or your relationship with those treating you.

BACKGROUND TO THE STUDY

What is the research about?

We are investigating how many women who have had a baby or are currently pregnant experience accidential loss of bowel control sometimes known as anal incontinence. Accidential loss of bowel control (anal incontinence) means not being able to hold on to a gas or poo/stool from the backpassage(anus).

This research study will develop and use a screening tool to identify accidential loss of bowel control (anal incontinence) in women who have had a baby or are currently pregnant.

In order to develop a bowel control screening tool we will need to identify women who experience accidential loss of bowel control. This will be done through an initial questionaire. We will then interview these women to help develop the bowel screening tool. The bowel

control screening tool will be trialed at the Lyell Mc Ewin hospital antenatal clinic and the GP super clinics.

Why is the research being done?
Accidental loss of bowel control (anal incontinence) affects 1.3 million Australians. Anal incontinence can worsen over a person's life and has a negative impact on their quality of life. Women are affected more than men, due to birthing and delivery. There are no recognised tools which screen anal incontinence in pregnant and postnatal women. The research aims to develop a tool which can screen and identify women who have anal incontinence. Early assessment may improve quality of life in pregnancy and across the lifespan.

Who is sponsoring this research?

The research project is under the governance of the University of Adelaide, Robinson Institute, Lyell McEwin Hospital**.**

How and why have I been chosen as a possible participant in the research?

Group 1
You have been asked to participate in the research if you have had at least one previous delivery and are pregnant attending the Lyell McEwin Hospital for your first antenatal appointment (ANEW). We are trying to find out if you have experienced accidental loss of control (anal incontinence).

Group 2
You have been invited to participate if you have had at least one previous delivery and are attending a GP Super Clinic. We are trying to find out if you have experienced accidental loss of control (anal incontinence).

Group 3
You have been asked to participate if you have had a previous delivery and have a history of accidental loss of bowel control (anal incontinence) and are attending the continence clinic at the Lyell McEwin Hospital. You are invited to participate in the pre-testing, re-testing and to provide feedback of the *questionnaire assessment of bowel control* and *bowel control screening tool.*

How many other people have been asked to consider participating?

The research has 5 stages and we are recruiting 1100 women throughout the research. Women will be recruited from ANEW bookings at the Lyell Mc Ewin Outpatient department, the Continence Nursing Service at the Lyell Mc Ewin Hospital and GP Super clinics.

PROCEDURES AND TREATMENT

Will I have to come back to the clinic more often or remain in hospital for longer than would normally be the case?
Listed below is more information for each group.

Group1

Bowel control questionnaire
The research questionnaire will occur at your first antenatal booking, the ANEW. The questionnaire will take no longer than 5 minutes to complete.

Individual interview
However If you wish to take part in an individual interview we will need to set a time convenient for you to attend the Lyell Mc Ewin Hospital. At this interview we would also like you to complete a questionnaire. The questionnaire asks questions about how accidental loss of bowel control (anal incontinence) affects your quality of life. The interview and questionnaire will take approximately 60 minutes.

Group 2
Bowel control screening tool
Pilot testing of the bowel screening tool will occur during a routine visit to your health provider, either at the Lyell McEwin Hospital antenatal clinic or the GP Super clinic. The bowel control screening tool asks questions about bowel control and will take less than 5 minutes for the health provider to complete.

Group 3
Questionnaire assessment of bowel control and bowel control screening tool
The pre-test, re-test and providing feedback on the *questionnaire assessment of bowel control* and the *bowel control screening* tool will require an individual interview. This will take approximately 10-15 minutes for each session. A time will be set which is convenient for you to attend the Lyell Mc Ewin Hospital.

What will I be asked to do?
This depends on what you have consented for in the research. Listed below is more information for each group.

Group 1
1. The *questionnaire assessment of bowel control*
   The questionnaire will be undertaken at your ANEW booking and will take less than 5 minutes to complete

2. **Individual interview**
   If you consent to take part in an individual interview, this may take approximately 60 minutes. We would like you to tell us what makes it easier and harder to tell others about accidental loss of bowel control (anal incontinence). We also would like you to complete a questionnaire on how your accidental loss of bowel control (anal incontinence) affects your quality of life. The quality of life questionnaire will take 10 minutes to complete.

Group 2
1. **Bowel screening tool**
   The bowel screening tool will be undertaken in a routine antenatal visit (ANEW) At the Lyell McEwin Hospital. The antenatal Midwife will ask several questions about your bowel control. This will take no longer than 5 minutes.
   If you are attending the GP Super Clinic your doctor will ask several questions about your bowel control. This will take no longer than 5 minutes.

Group 3
1.***Questionnaire assessment of bowel control and bowel control screening tool***

You will be asked to pre-test, re-test and provide written and or verbal feedback of the bowel control questionnaire and bowel control screening tool.

How long will my participation in the study last?

Group 1

1. The initial questionnaire at ANEW booking will last 5 minutes.
2. The individual interview will be arranged to take place at the Lyell McEwin Robinson Institute, at a time convenient to you, lasting approximately 60 minutes.

Group2

1. The bowel screening tool will be included in a routine visit to the ANEW appointment at the Lyell McEwin Hospital or the GP Super clinic. The screening tool will take 5 minutes.

Group 3

You will be asked to test, re-test and provide written and or verbal feedback for the *questionnaire assessment of bowel control* and *bowel screening tool.*

What procedures will I be asked to submit to and what are the likely effects?

Procedures are outlined above.

If I decide not to take part what other treatments are available to me?

Your decision to take part, not to take part or withdraw from the research study will not affect your routine treatment.

Are there any factors which would exclude me from participating?

Women who have not had a baby are ineligible to participate. We thank you for your interest.

PARTICIPANT MANAGEMENT
DISCOMFORTS, RISKS AND SIDE EFFECTS

Are there likely to be side effects from the research procedures, and if so what are they?

Disclosing personal information may cause you emotional concern. If this arises please inform the researcher or Midwife at your antenatal booking. You will be referred to appropriate counselling support within the Lyell McEwin Hospital.

Who should I contact if I am worried about any effects that I experience?

You can discuss your concerns with the researcher. Details can be found at the end of this information sheet.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED?

How will my confidentiality be protected? How will information and results be de identified?

Your confidentiality is ensured. Your information will be de-identified and linked with a study number. All information is password protected and is cross linked to the hospital medical record number. Contact information can only be accessed by the primary researcher. Participation is voluntary and you can withdraw from the study at any point in time with no penalties.

Will I be informed about the results of the study?

Data a collected will be published in research journals. If you would like a copy of the research findings, you will need to contact the primary researcher

How long will information be stored for?

Research information is kept for 5 years and then destroyed. This is keeping with the South Australian Heath Policy and the NMHRC code for Responsible Conduct of research.

WHAT ARE MY RIGHTS?

If you become injured during this study, and your injury is a direct result of the effects of study procedures, The Lyell McEwin Hospital will provide reasonable medical treatment. Your participation in this study shall not affect any other right to compensation you may have under common law.

How can I obtain more information?
Julie Tucker
Primary Researcher
Or
Associate Professor Vicki Clifton
Robinson Institute, Lyell Mc Ewin Hospital
Phone 81332133

PAYMENT FOR PARTICIPATION

Will I be paid for my participation?
Participation is voluntary.

BENEFITS OF THE RESEARCH

Is there any chance that the proposed research will be of benefit to me personally, or to future patients with the same condition?

Whilst your direct involvement may not benefit you, your contribution to this research is valuable in developing a bowel control screening tool to assist other women.

If you are identified to have anal incontinence you will be offered referral to a specialist service which deals with accidental loss of bowel control.

The research aims to develop a bowel control screening tool to identify anal incontinence in women of childbearing age, early identification may lead to improved quality of life in pregnancy, birthing and across the lifespan.

WHAT IF I HAVE A QUESTION ABOUT THE STUDY?

If you have any questions about this study, please contact one of the researchers:
Julie Tucker
Primary researcher
University of Adelaide
Robinson Institute, Lyell Mc Ewin Hospital
Or
Associate Professor Vicki Clifton
Robinson Institute
Lyell McEwin Hospital
Ph 81332133

The Human Research Ethics Committee (TQEH/LMH/MH) has approved this study.

Should you wish to speak to a person not directly involved in the study in relation to:

- matters concerning policies,
- information about the conduct of the study
- your rights as a participant, or
- Should you wish to make a confidential complaint

You may contact The Executive Officer of this Committee, on (08) 8222 6841.

Government of South Australia
SA Health

CONSENT FORM

Title: Development of a screening tool to identify anal incontinence in women of reproductive age

Protocol Number:

I, the undersigned.....

hereby consent to my involvement in the research project explained above.
Which is to participate in the **(Circle those applicable**)

1. Pre-test, re-test and provide feedback of the research questionnaire: *assessment of bowel control for women of reproductive age*
2. **The questionnaire: *assessment of bowel control for women of reproductive age***
3. **Individual interview and quality of life questionnaire**.
4. Pre-test, re-test and provide feedback of *bowel control screening tool*.
5. Bowel control screening tool at a ANEW antenatal booking LMH
6. Bowel control screening tool at GP Super clinic

- I have read the information sheet, and I understand the reasons for this study. The research worker has explained the ways in which it will affect me. My questions have been answered to my satisfaction. My consent is given voluntarily.

- I understand that the purpose of this research project is to improve the quality of medical care, but my involvement may not be of benefit to me.

- The details of the research project have been explained to me, including:
  - The expected time it will take
  - The nature of procedures being performed, and number of times they will be performed
  - Any discomfort which I may experience

- I have been given the opportunity to have an interpreter or member of family or a friend present while the project was explained to me.
- My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.
- My involvement in the study will not affect my relationship with my medical advisers. I understand that I am able to withdraw from the study at any stage without having to give a reason, and that by withdrawing it will not affect my treatment at this hospital in the future.

PATIENT SIGNATURE……..... DATE …./……./…….

WITNESS……..... DATE …./……./…….

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

INVESTIGATOR:.....DATE …/…../……..

Appendix 1B. Participant Information Sheet and Consent Form.

Government of South Australia
SA Health

PARTICIPANT INFORMATION SHEET 1B

Title: Development of a screening tool to identify anal incontinence in women of reproductive age.

INVITATION TO PARTICIPATE

We invite you to participate in a research project which we believe is of importance. However, before you decide whether or not you wish to participate, we need to be sure that you understand

why we are doing it, and
what it would involve if you agreed.

We are therefore providing you with the following information.
Please read the following information carefully and be sure to ask any questions you have. The nurse researcher conducting the research will be happy to discuss this information with you and answer any questions that you may have.
You are also free to discuss it with others if you wish. (E.g. family, friends your local Doctor)
You do not have to make an immediate decision.

PARTICIPATION IS VOLUNTARY

Participation in the research project is voluntary. If you do not wish to take part, you are not obliged to. Should you agree to take part in the research study, you may change your mind and withdraw at any stage.

BACKGROUND TO THE STUDY

What is the research about?

We are investigating how many women who have had a baby or are currently pregnant experience accidential loss of bowel control sometimes known as anal incontinence. Accidential loss of bowel control (anal incontinence) means not being able to hold on to a gas or poo/stool from the backpassage(anus).

This study will develop and use a screening tool to identify accidential loss of bowel control (anal incontinence) for women who have had a baby or are currently pregnant.

In order to develop a bowel control screening tool, we will need to identify women who experience accidential loss of bowel control. This will be done through an initial questionaire. We will then interview these women to help develop the bowel screening tool. The bowel control screening tool will be trialed at the Lyell Mc Ewin hospital antenatal clinic and the GP Super clinics.

Why is the research being done?

Accidental loss of bowel control (anal incontinence) affects 1.3 million Australians. Anal incontinence can worsen over a person's life and has a negative impact on their quality of life. Women are affected more than men, due to birthing and delivery.
There are no recognised tools which screen anal incontinence in pregnant and postnatal women. The research aims to develop a tool which can screen and identify women who have anal incontinence. Early assessment may improve quality of life in pregnancy and across the lifespan.

Who is sponsoring this research?
The research project is under the governance of the University of Adelaide, Robinson Institute, and Lyell McEwin Hospital**.**

How and why have I been chosen as a possible participant in the research?

You have been invited to participate as a health professional involved in the care of women of reproductive age.

How many other people have been asked to consider participating?

The research has 5 stages and we are recruiting 1100 women throughout the research. Women will be recruited from ANEW bookings at the Lyell Mc Ewin Outpatient department, the Continence Nursing Service at the Lyell Mc Ewin Hospital and GP Super clinics.
Health professionals are invited to participate in the pre-test and re-test of the questionnaire *assessment of bowel control for women of reproductive age* and *bowel screening tool.* It is anticipated 30 health professional are required for each stage of the research.

PROCEDURES AND TREATMENT

Will I have to participate more than the specified participation?

No.
The researcher will make a time convenient with you, the health professionals to pre-test, re-test and gain feedback from the *questionnaire assessment of bowel control* and the *bowel control screening tool.*

What will I be asked to do?
This depends on what you consent for in the research. You will be asked to pre-test and re-test the *questionnaire assessment of bowel control* and provide feedback. This should take approximately 10 minutes.

You will be asked to pre-test and re-test the *bowel control screening tool* and provide written and or verbal feedback. This will take approximately 10 minutes

How long will my participation in the study last?

The pre-test and re-test of the *questionnaire assessment of bowel control* and *bowel control screening tool* will take approximately 10 minutes for each session.
What procedures will I be asked to submit to and what are the likely effects?

Procedures are outlined above.

What if I decide not to take part?

The findings from this research study will be disseminated through educational sessions, research articles and journals.
.

PARTICIPANTMANAGEMENT
DISCOMFORTS, RISKS AND SIDE EFFECTS

Are there likely to be side effects from the research procedures, and if so what are they?

No there are no potential risks or side effects associated with the research.

Who should I contact if I am worried about any effects that I experience?

You can discuss your concerns with the researcher. Details can be found at the end of this information sheet.

WHAT WILL HAPPEN TO THE INFORMATION COLLECTED?

How will my confidentiality be protected – will information and results be de identified?

Your confidentiality is ensured. Your information will be de-identified and linked with a study number. All information is password protected. Contact information can only be accessed by the primary researcher. Participation is voluntary and you can withdraw from the study at any point in time with no penalties.

Will I be informed about the results of the study?

Data a collected will be published in research journals. If you wish you can contact the chief researchers and we can send you a copy of the results.

How long will information be stored for?

Research information is kept for 5 years and then destroyed. This is keeping with the South Australian Heath Policy and the NHMRC code for Responsible Conduct of research.

WHAT ARE MY RIGHTS?

If you become injured during this study, and your injury is a direct result of the effects of study procedures, The Lyell McEwin Hospital will provide reasonable medical treatment. Your participation in this study shall not affect any other right to compensation you may have under common law.

How can I obtain more information?
Julie Tucker
Primary Researcher
Or
Associate Professor Vicki Clifton
Robinson Institute, Lyell Mc Ewin Hospital Phone 81332133

PAYMENT FOR PARTICIPATION

Will I be paid for my participation?
Participation is voluntary.

BENEFITS OF THE RESEARCH

Is there any chance that the proposed research will be of benefit to me personally, or to future patients with anal incontinence?

Whilst your direct involvement may not benefit you, your contribution to this research is valuable in developing a bowel control screening tool to assist women of reproductive age.

The research aims to develop a bowel control screening tool to identify anal incontinence in women of childbearing age, early identification may lead to improved quality of life in pregnancy, birthing and across the lifespan.

WHAT IF I HAVE A QUESTION ABOUT THE STUDY?

If you have any questions about this study, please contact one of the researchers:

Julie Tucker
Primary researcher
University of Adelaide
Robinson Institute, Lyell Mc Ewin Hospital
Or
Associate Professor Vicki Clifton
Robinson Institute
Lyell McEwin Hospital
Ph 81332133

The Human Research Ethics Committee (TQEH/LMH/MH) has approved this study.

Should you wish to speak to a person not directly involved in the study in relation to:

- matters concerning policies,
- information about the conduct of the study
- your rights as a participant, or
- Should you wish to make a confidential complaint

You may contact The Executive Officer of this Committee, on (08) 8222 6841.

Government of South Australia
SA Health

CONSENT FORM

Title: Development of a screening tool to identify anal incontinence in women of reproductive age

Protocol Number:

I, the undersigned .....

hereby consent to my involvement in the research project explained above.
Which is to participate in the **(Circle those applicable**)

1. Pre-test, re-test and provide written and or verbal feedback of the research questionnaire: *assessment of bowel control for women of reproductive age*

2. Pre-test, re-test and provide written and or verbal feedback of *bowel control screening tool*.

- I have read the information sheet, and I understand the reasons for this study. The research worker has explained the ways in which it will affect me. My questions have been answered to my satisfaction. My consent is given voluntarily.

- I understand that the purpose of this research project is to improve the quality of medical care, but my involvement may not be of benefit to me.

- The details of the research project have been explained to me, including:
  - The expected time it will take
  - The nature of procedures being performed, and number of times they will be performed
  - Any discomfort which I may experience

- I have been given the opportunity to have an interpreter or member of family or a friend present while the project was explained to me.
- My identity will be kept confidential, and nothing will be published which could possibly reveal my identity.
- My involvement in the study will not affect my relationship with my medical advisers. I understand that I am able to withdraw from the study at any stage without having to give a reason, and that by withdrawing it will not affect my treatment at this hospital in the future.

PARTICIPANT SIGNATURE…….... DATE …./……./…….

WITNESS…….... DATE …./……./…….

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation

INVESTIGATOR:.....**DATE** …./……./…….

Appendix 2. Recruitment Pamphlet.

The University of Adelaide Research

Bowel control in pregnant women and women who have had a baby

This research is approved by The University of Adelaide Human Research Ethics Committee (HREC) and The Human Research Ethics Committee (TQEH/LMH/MH).

Have you recently had a baby and are you currently Pregnant?

Do you experience accidental loss of bowel control?

Would you like to be involved in our research study.?

Government of South Australia
SA Health

THE UNIVERSITY of ADELAIDE

Appendix2: Recruitment pamphlet. Title: Development of a screening tool to identify anal incontinence in women of reproductive age. Version 2 Date 22.5.14

What is accidental loss of bowel control?

Accidental loss of bowel control is where you have accidentally lost control of wind/gas, liquid poo/ stool or solid poo/stool from the back passage[1].

Accidental loss of bowel control is also known as anal incontinence.
Incontinence occurs when the pelvic floor muscles; which are like a big trampoline holding your bladder, bowel and uterus become weakened.

Is accidental loss of bowel control common?

Accidental loss of bowel control occurs in 6–17 % of the general community[1].
That's about 1 in every 20 people in the community

More women than men are affected by accidental loss of bowel control .

Accidental loss of bowel control becomes more common as we get older[2].

What are the causes of accidental loss of bowel control?

There are lots of reasons why accidental loss of bowel control occurs.

Hormonal changes in pregnancy and weakened pelvic floor muscles from childbirth are two reasons accidental loss of bowel control may occur[2].

Why is this research important?

The research aims to develop a screening tool which asks questions about accidental loss of bowel control for women who are pregnant or have had babies

It is important to screen for accidental loss of bowel control because if you have it, you can be referred to a service which specialises in accidental loss of bowel control.

The screening tool will be used by your Doctor or Midwife at your antenatal visits.

What's involved in the research?

There are five stages to the research.

Your participation is welcomed in the early stages of the research where we need to understand who has accidental loss of bowel control.

So ,if you are interested we would like you to complete a quick questionnaire that takes about 5 minutes to complete.

Your identity will remain anonymous. All information you provide will be kept strictly confidential .

So what do I do if I want further information?

Ask the midwife at your antenatal visit today,

or contact the researcher:

Julie Tucker

The University of Adelaide

Robinson Institute,

Lyell McEwin Hospital

Ph. 81332133

References

1. Continence Foundation of Australia, Deloitte Access Economics. The economic impact of incontinence in Australia. ACT: 2011.
2. Continence Foundation of Australia. Poor Bowel control 2010. Available from: http://www.bladderbowel.gov.au/all/bowelproblems.htm

Appendix 3A. Professional letter of introduction.

Invitation to participate

Dear Colleague

As a health care professional who provides care to women of reproductive age, you are invited to participate in the current research, which aims to develop a screening tool, which identifies anal incontinence in women of reproductive age. Anal incontinence is often underreported and has a debilitating impact on a woman's quality of life. Birthing women are at risk of pelvic floor injury resulting in a negative impact on pelvic floor functional reserve. Importantly minor injury following childbirth may be clinically significant with further vaginal delivery and ageing. The development of a screening tool will assist in the early identification, referral to appropriate health services and may improve quality of life for women in pregnancy and across the lifespan. We appreciate and acknowledge your time is valuable.

This research is part of a PHD programme with the University of Adelaide department of Obstetrics and Gynaecology, School of Paediatrics and Reproductive Health. The title of the research is Development of a screening tool to identify *anal incontinence in women of reproductive age*. Ethics has been approved through two human research ethics committees

If you agree to participate, you are invited to participate and provide written and/ or verbal feedback to the primary researcher in the development of

1. *The questionnaire assessment for bowel control for women of reproductive age.*
2. *Bowel control screening tool for women of reproductive age*.

All research information is confidential, de-identified and accessed only by the primary researcher. Research findings will inform current health practice and be reported through relevant peer reviewed journals, conferences and education sessions.

Thank you for taking the time to read this information. If you have any queries regarding the research or wish to participate in the research please contact the primary researcher Julie Tucker (details below)

Investigators:

1. Primary Researcher: Julie Tucker , RN, RM, BN, MN, MNSc
   PhD candidate Univeristy of Adelaide, Robinson Institute, School of Paediatrics and Reproductive Health, Elizabeth Vale, S.A *julie.tucker@adelaide.edu .au*. Ph. 81332133.
2. Supervisor: Associate Professor Vicki clifton.Univeristy of Adelaide, Robinson Institute, School of Paediatrics and Reproductive Health Elizabeth Vale, S.A.Ph. 81332133.
3. Supervisor: Dr Elizabeth Murphy. Colorectal consultant. Department of Surgery Lyell McEwin Hospital , Elizabeth Vale, S.A. Ph. 81829000.
4. External advisor: Associate Professor Anne Wilson. School of Medicine, Flinders University, Bedford Park, SA.

Appendix 3B. Pre-test questionnaire.

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Dear Participant

You have been invited to participate in this research, which aims to develop a tool for health professionals (Doctors/Nurses) to screen and identify accidental loss of bowel control (anal incontinence) in women of reproductive age.

This research is part of a PHD programme with the University of Adelaide department of Obstetrics and Gynaecology, School of Paediatrics and Reproductive Health.

The title of the study is *Development of a screening tool to identify anal incontinence in women of reproductive age*.

Ethics has been approved through two human research ethics committees; Human Research Ethics Committee (TQEH/ LMH/ MH) Ethics number AU/15/0687119 and the University of Adelaide Human Research Ethics Committee.

The development of a screening tool which identifies accidental loss of bowel control will assist in the early identification of this condition and referral to appropriate health services may improve the quality of life for women of reproductive age. Accidental loss of bowel control (anal incontinence) is often underreported and has a negative impact on a woman's life. Childbirth increases the risk of accidental bowel loss. Further vaginal childbirth and ageing may worsen symptoms of accidental loss of bowel control (anal incontinence).

The research process includes five stages. You have been invited to participate in part of stage 1, the pre-test and re-test of the questionnaire *assessment for bowel control for women of reproductive age and two bowel screening forms.* You are requested to complete the questionnaire and screening forms and provide feedback on the sheet provided. Each session should take approximately 5-10 minutes.

Your participation is voluntary. All research information is de-identified, stored on a USB which is password protected and accessed only by the primary researcher. Findings will be disseminated through relevant peer reviewed journals, conferences and education sessions to relevant health professionals.

Your participation and time is valued. If you require further information regarding this research please contact Associate Professor Vicki Clifton Robinson Institute Ph. 81332133

Or

Julie Tucker

RN, RM, BN, MN, MNSc

Principal researcher Julie Tucker Robinson Institute ph. 81332133.

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Feedback sheet

The questionnaire *assessment of bowel control for women of reproductive age* and two bowel-screening forms aim to

1. Identify women who are pregnant and have accidental loss of bowel control (anal incontinence).
2. The questionnaire aims to identify women who would like to participate in an interview about disclosing accidental bowel loss (anal incontinence).

To indicate your response please place a circle around (Yes) or (No.) A comments section is provided if you require more space to provide written feedback.

3. Before you begin, please note the time.

1. Did you find the questionnaire easy to follow?

Please circle one of the following Yes No

Comment _____

_____

_____

_____

_____

_____

2. Did you find the questionnaire easy to understand?

Please circle one of the following Yes No

Comment _____

_____

_____

_____

_____

_____

3. Did you find the language was appropriate?

Please circle one of the following Yes No

Comment _____

_____

_____

_____

_____

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

4. In your opinion were there any questions that should not have been asked?

Please circle one of the following Yes No

Comment _____

5. In your opinion were there any other questions which should be asked?

Please circle one of the following Yes No

Comment _____

6. Do you think the questionnaire helps to identify accidental loss of bowel control in pregnant women?

Please circle one of the following Yes No

Comment _____

7. Do you think the questionnaire helps to identify women who may want to participate in an interview?

Please circle one of the following Yes No

Comment _____

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

8. Do you have any other comments or suggestions?

Please circle one of the following Yes No

Comment _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

9. How long did the questionnaire take to complete? minutes

Thank you for your time in completing the feedback form. Please return the questionnaire and feedback form in the addressed envelope provided to the researcher.

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

The two bowel screening forms; the St Mark's incontinence score "Vaizey" and the Wexner score are provided at the end of the questionnaire section.

To indicate your response please place a circle around **Yes** or No. A comments section is provided if you require more space to provide written feedback.

Before you begin, please note the time.

1. Did you find the Vaizey and Wexner scores easy to follow?

Please circle one of the following Yes No

Comment _____

2. Did you find the Vaizey and Wexner scores easy to understand?

Please circle one of the following Yes No

Comment _____

3. Did you find the language was appropriate?

Please circle one of the following Yes No

Comment _____

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

4. In your opinion were there any questions that should not have been asked?

Please circle one of the following Yes No

Comment _____

5. In your opinion were there any other questions which should be asked?

Please circle one of the following Yes No

Comment _____

6. Do you think the screening forms help to identify accidental loss of bowel control in pregnant women?

Please circle one of the following Yes No

Comment _____

Please explain which screening form you prefer and why? _____

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

7. Do you have any other comments or suggestions?

Please circle one of the following Yes No

Comment _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

8. How long did the questionnaire take to complete? minutes

Thank you for your time in completing the feedback form. Please return the questionnaire and feedback form in the addressed envelope provided to the researcher.

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

ID number [ ] Ethics ID [ ]

Questionnaire assessment of bowel control for Women of Reproductive Age

This questionnaire is part of a research study being undertaken through the University of Adelaide and asks about control of your bowel. We are interested in identifying how many women of reproductive age experience accidental loss of bowel control, known as anal incontinence. Anal incontinence is loss of a liquid stool/poo; solid stool/poo or gas/wind by accident. Early identification of bowel problems may improve quality of life for pregnant women and women across the lifespan

We invite you to participate in this questionnaire. Your participation is voluntary and nonparticipation will not affect your antenatal care. **The questionnaire should take approximately 5 minutes to complete.**

All information is treated with the strictest confidence. **If you have any questions or concerns about the questions please speak to the researcher who has given you the questionnaire**.

Please place the completed questionnaires in the envelope provided and return it to the **Red box at the booking desk** .Thank you for participating in this questionnaire. We appreciate your time.

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Please respond to the questions by placing a tick☑ in a box and/ or writing in the spaces provided.

Section A: Background Information
About you the person completing the questionnaire

1. Please tell me your age? _____

2. Are you?

☐	Never married	☐	Married/defacto
☐	Single	☐	Divorced
☐	Widowed	☐	Separated

3. What is the usual postcode where you live? _____

4. How would you describe your employment situation?

☐	Fulltime	☐	Unemployed	☐	
☐	Part-time	☐	Student	☐	
☐	Casual	☐	Home duties	☐	
☐	Other				

5. What is your ethnicity?

Caucasian		Asian	
Aboriginal		African	
Torres Strait Islander		Middle Eastern	
Other			

6. For each of your deliveries could you indicate whether you delivered vaginally or by caesarean section?

Please tick ☑either vaginal delivery or caesarean section in box 1 for your first delivery, box 2 for second delivery and following boxes for subsequent deliveries.

Baby	1	2	3	4	5	6
Vaginal						
Caesarean						

7. For each of your deliveries please tick in a box ☑whether you had a normal delivery, forceps or Ventouse delivery

Delivery	1	2	3	4	5	6
Normal						
Forceps						
Ventouse						

8. For each of your deliveries could you tick in a box☑ if you had an episiotomy (a cut between the vagina and back passage) or tear following vaginal delivery or deliveries?

Delivery	1	2	3	4	5	6
Intact (no tears)						
Episiotomy						
Small tear						
3rd/4th degree tear /Large tear						

Appendix 3B:Pre-test questionnaire Assessment of bowel control for women of reproductive age
HREC/14/TQEHLMH/58/AMO1
Title: Development of a screening tool to identify anal incontinence in women of reproductive age
Version 2 Date 22.5.14

THE UNIVERSITY of ADELAIDE

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Section B: Bowel control.

Could you provide information about your bowel control?

Please respond to each of the following questions by a placing a tick ☑ or a cross ☒ in a box and writing in the spaces provided.

9. Have you ever had a solid poo (solid stool) slip out by accident?

Yes ☐
No ☐

10. Have you ever had a liquid poo (liquid stool) slip out by accident?

Yes ☐
No ☐

11. Have you ever had wind or gas slip out by accident?

Yes ☐
No ☐

12. Do you have to rush to the toilet to do a poo or pass wind or gas?

Yes ☐
No ☐

If you answered **NO to all questions 9 to 12** you have completed the questionnaire.

Please place the questionnaire in the envelope provided and place in the **RED Box** on the booking desk in Family clinic.

Thank you for your participation.

If you answered YES to any of the questions 9 -12 please continue with the questionnaire.

Section C: Information seeking.

The following questions ask you about who you have told of your accidental loss of bowel control (anal incontinence).

Please respond to the questions by placing a tick ☑ or a ☒ in a box and writing in the spaces provided

13. Have you discussed your accidental loss of bowel with a health professional (e.g. nurse, doctor, and/ or specialist?)

Yes ☐ Please go to question 14
No ☐ Please go to question 16

14. Which health professional did you discuss your concerns with?

Family doctor	☐	Colorectal (Bowel) doctor	☐
Obstetrician	☐	Continence Nurse	☐
Midwife	☐	General Practitioner (GP)	☐
Gynaecologist	☐	Physiotherapist	☐
Other	☐	Please Specify	

_____

_____

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

15. Why did you choose to talk to your health professional?

She/he asked me about it	☐
Felt comfortable to talk	☐
I have been worried for sometime	☐
I know other women with the problem	☐
	☐
Other (please specify)	☐

Please go to question 18.

16. Why did you choose ***not*** to talk to your health professional?

I don't lose control often	☐
Didn't think it was a problem	☐
Embarrassed	☐
Health professional didn't ask	☐
I hoped it would go away	☐
Health professional disinterested	☐
Other (please specify)	☐

17. If you were to seek assistance or talk to someone about your accidental bowel loss, who would you choose?

Family doctor	☐	Colorectal (Bowel) doctor	☐
Obstetrician	☐	Continence Nurse	☐
Physiotherapist	☐	Gynaecologist	☐
Midwife	☐	General Practitioner (GP)	☐
Don't Know	☐		
Other	☐	Please Specify	

18. In your opinion what would make it easier to tell someone about your accidental loss of bowel control?

Directly asked by health professional at health visit	☐
Questionnaire/ survey	☐
Information provided to you before birth	☐
Information provided to you after birth	☐
Using common everyday words	☐
Other (please specify)	☐

Section D: Research information

The information you have provided will assist in continuing research seeking to improve healthcare for women with accidental loss of bowel control.

Please respond to a question by placing a tick☑ or ☒ in a box provided…

19. Would you like more information about a clinic that specialises in accidental loss of bowel control (anal incontinence)?

Yes	☐	Please ask the Midwife at your appointment today or provide your name and contact number in the space below
No	☐	

Name

Phone number

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

20. Would you like to be referred to a clinic which specialises in accidental loss of bowel control?

Yes ☐ Please ask the Midwife at your appointment today or provide your name and contact number in the space below

No ☐

Name

_____

Phone number

_____

21. Would you like to participate in an interview to talk about how accidental loss of bowel control affects your life?

Yes ☐ Please provide your name and phone number so the researcher can contact you

No ☐

Name

_____

Phone number

_____

Thank you for taking the time to complete the questionnaire. Your information is important for our research and improving healthcare for women with accidental loss of bowel control.

Please place your completed questionnaire in the envelope provided and return to the RED BOX located on the booking desk in Family clinic

Appendix 4. Questionnaire: assessment of bowel control for women of reproductive age.

THE UNIVERSITY of ADELAIDE

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Ethics number

HERC/14/TQEHLMH/58/AMO1

ID number

Questionnaire assessment of bowel control for Women of Reproductive Age

This questionnaire is part of a research study being undertaken through the University of Adelaide and asks about control of your bowel. We are interested in identifying how many women of reproductive age experience accidental loss of bowel control, known as anal incontinence. Anal incontinence is loss of a liquid stool/poo; solid stool/poo or gas/wind by accident. Early identification of bowel problems may improve quality of life for pregnant women and women across the lifespan.

We invite you to participate in this questionnaire. Your participation is voluntary and nonparticipation will not impact on your antenatal care. **The questionnaire should take approximately 5 minutes to complete.**

All information is treated with the strictest confidence. **If you have any questions or concerns about the questions please speak to the Midwife or researcher who has given you the questionnaire**.

Please place the completed questionnaires in the envelope provided and return it to the **Red box at the booking desk** .Thank you for participating in this questionnaire. We appreciate your time.

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Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Please respond to the questions by placing a tick☑ in a box and/ or writing in the spaces provided.

Section A: Background Information

About you the person completing the questionnaire

1. Please tell me your age? _____

2. Are you?

Never Married	☐	Separated	☐
Single	☐	Divorced	☐
Married/Defacto	☐	Widowed	☐

3. What is the usual postcode where you live?

_____

4. How would you describe your employment situation?

Full-time	☐	Student	☐
Part-time	☐	Unemployed	☐
Casual	☐	Home duties	☐
Other	☐		
(Please explain)			

5. What is your ethnicity?

Caucasian	☐	African	☐
Aboriginal	☐	Asian	☐
Torres Strait Islander	☐	Middle Eastern	☐
Other	☐		

6. For each of your births could you indicate whether you delivered vaginally or by caesarean section? Please tick ☑either vaginal birth or caesarean section in box 1 for your first birth, box 2 for second birth and following boxes for subsequent births.

Baby	1	2	3	4	5	6
Vaginal birth						
Caesarean section						

7. For each of your vaginal births please tick☑ in a box whether you had a vaginal birth, forceps or Ventouse (vacuum cup).

Birth	1	2	3	4	5	6
Vaginal						
Forceps						
Ventouse						

Appendix 4: Questionnaire Assessment of bowel control for women of reproductive age
HREC/14/TQEHLMH/58/AMO1.Title: Development of a screening tool to identify anal incontinence in women of reproductive age Version 1 Date 21.10.14

THE UNIVERSITY of ADELAIDE

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

8. For each of your births could you tick in a box☑ if you had an episiotomy (a cut between the vagina and back passage) or tear following the birth?

Delivery	1	2	3	4	5	6
Intact (no tears)						
Episiotomy						
Small tear (no stitches)						
1st degree tear						
2nd degree tear						
3rd/4th degree tear						

Section B: Bowel control.

Could you provide information about your bowel control?

Please respond to each of the following questions by a placing a tick ✓ in a box and writing in the spaces provided.

9. Have you ever had a solid poo (solid stool) slip out by accident?

Yes ☐
No ☐

10. Have you ever had a liquid poo (liquid stool) slip out by accident?

Yes ☐
No ☐

11. Have you ever had wind or gas slip out by accident?

Yes ☐
No ☐

12. Have you ever needed to rush to the toilet to do a poo, pass wind or gas?

Yes ☐
No ☐

13. Have you ever soiled or stained your underwear with poo?

Yes ☐
No ☐

If you have answered **NO to all questions 9 to 13** you have completed the questionnaire.

Please place the questionnaire in the envelope provided and place in the **RED Box** on the booking desk in Family Clinic.

If you answered **YES to any of the questions 9-13 please continue** with the questionnaire.

Appendix 4: Questionnaire Assessment of bowel control for women of reproductive age HREC/14/TQEHLMH/58/AMO1.Title: Development of a screening tool to identify anal incontinence in women of reproductive age Version 1 Date 21.10.14

THE UNIVERSITY of ADELAIDE

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

Section C: Information seeking

The following questions ask you about who you have told of your accidental loss of bowel control (anal incontinence).

Please respond to the questions by placing a tick ✓ in a box and writing in the spaces provided.

14. Have you discussed your accidental loss of bowel control with a health professional? (e.g. nurse, doctor, and/or specialist?)

Yes	☐	**Please go to question 15.**
No	☐	**Please go to question 17.**

15. Which health professional did you discuss your concerns with?(tick all that apply)

Family doctor	☐	Colorectal doctor	☐
Obstetrician	☐	Continence Nurse	☐
Midwife	☐	General Practitioner	☐
Gynaecologist	☐	Physiotherapy	☐
Other	☐		
(please explain)			

16. Why did you choose to talk to your health professional? (tick all that apply)

She/he asked me about it	☐
Felt comfortable to talk	☐
I have been worried for sometime	☐
I know other women with the problem	☐
Other	☐
(please explain)	

Please go to question19

17. Why did you choose ***not*** to talk to your health professional? (tick all that apply)

I don't lose control often	☐
Didn't think it was a problem	☐
Embarrassed	☐
Health professional didn't ask	☐
I hoped it would go away	☐
Health professional disinterested	☐
Other	☐
(please explain)	

18. If you were to seek assistance or talk to someone about your accidental loss of bowel control, who would you choose? (tick all that apply)

Family doctor	☐	Colorectal doctor	☐
Obstetrician	☐	Continence nurse	☐
Physiotherapist	☐	Gynaecologist	☐
Midwife	☐	General Practitioner	☐
Don't know	☐		
Other	☐		
(please explain)			

THE UNIVERSITY of ADELAIDE

Government of South Australia
SA Health

Questionnaire
Assessment of bowel control for women of reproductive age

19. In your opinion what would make it easier to tell someone about your accidental loss of bowel control? (tick all that apply)

Directly asked by health professional at health visit.	☐
Questionnaire/ survey	☐
Information provided to you before birth	☐
Information provided to you after birth	☐
Using common everyday words	☐
Other (please explain)	☐

Section: Research information

The information you have provided will assist in continuing research seeking to improve healthcare for women with accidental loss of bowel control.

Please respond to a question by placing a Tick ✓in a box provided…

20. Would you like more information about a clinic that specialises in accidental loss of bowel control (anal incontinence)?

Name _____

Phone number _____

21. Would you like to be referred to a clinic, which specialises in accidental loss of bowel control?

Yes ☐ Please ask the Midwife at your appointment today and/ or provide your name and contact number in the spaces below

No ☐

Name _____

Phone number _____

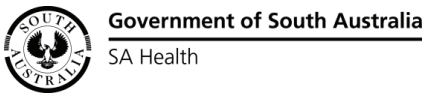
22. Would you like to participate in an interview to talk about how accidental loss of bowel control affects your life?

Yes ☐ Please provide your name and phone number so the

No ☐ Researcher can contact you

Name _____

Phone number _____



Questionnaire
Assessment of bowel control for women of reproductive age

Thank you for taking the time to complete the questionnaire. Your information is important for our research and improving healthcare for women with accidental loss of bowel control.

Please place your completed questionnaire in the envelope provided.

Then place the envelope in the RED BOX located on the booking desk at Family Clinic.

Appendix 4: Questionnaire Assessment of bowel control for women of reproductive age HREC/14/TQEHLMH/58/AMO1.Title: Development of a screening tool to identify anal incontinence in women of reproductive age Version 1 Date 21.10.14

Appendix 5. Semi-formal interview guide.

THE UNIVERSITY of ADELAIDE

Government of South Australia
SA Health

Semi- formal interview guide

Semi-formal interview guide for women with accidental loss of bowel control (anal incontinence)

Objective 1: To identify what impacts on disclosing anal incontinence to a health professional

Problem statement: Some people express concerns about talking to their doctor or nurse about accidental loss of bowel control- how do you feel about this?

Question 1: Can you tell me more about what it is like to live with anal incontinence?

Question 2: Can you tell me who you have discussed your accidental loss of bowel control with?

Question 3: Tell me more about what made that easier?

Question 3: Can you tell me more about what made telling others more difficult?

Question 4: Can you describe to me what factors you think would help women to tell others about accidental loss of bowel control?

Appendix 5A. Participant Information Sheet/Consent Form.

Participant Information Sheet/Consent Form

Non-Interventional Study - *Adult providing own consent*

The University Of Adelaide

Title	Development of a screening tool to identify anal incontinence in women of reproductive. age.
Short Title	Development of a screening tool to identify anal incontinence
Protocol Number	HREC/14/TQEHLMH/58
Coordinating Principal Investigator/ Principal Investigator	Ms Julie Tucker PhD candidate University of Adelaide
Associate Investigator(s)	Principal Supervisor Dr Vicki Clifton Dr Elizabeth Murphy Associate Professor Anne Wilson
Location	Family Clinic Lyell Mc Ewin Hospital Unihealth Playford and Highbury FPU Clinics Highbury and Elizabeth

Part 1 What does my participation involve?

1 Introduction

You have been invited to take part in this research project, "Development of a screening tool to identify anal incontinence in women of reproductive age". This is because you have had a baby or are currently pregnant. Accidental loss of bowel control (anal incontinence) is associated with pregnancy and childbirth and is often underreported. Further vaginal childbirth and ageing may worsen symptoms of accidental loss of bowel control. The research project is aiming to develop a tool for health professionals (Doctors/Nurses) to screen and identify accidental loss of bowel control (anal incontinence) in women of reproductive age.

This Participant Information Sheet/Consent Form tells you about the research project. It explains what this research involves. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:
• Understand what you have read
• Consent to take part in the research project
• Consent to the completing a bowel screening tool
• Consent to the use of your personal and health information as described.

2 What is the purpose of this research?

This research aims to develop a bowel-screening tool to identify accidental loss of bowel control (sometimes known as anal incontinence) in women who have had a baby or are pregnant. Anal incontinence affects 1.3 million Australians and affects more women than men due to birthing and delivery. Early identification of anal incontinence in women who are pregnant or had babies, may improve quality of life in pregnancy and the postnatal period. Currently there is no recognised screening tool that is used to screen for anal incontinence for women who are pregnant or had babies.
In order to develop a bowel-screening tool we need to recruit women who have had a baby.
The results of this research will be used by the study researcher, Julie Tucker to obtain a Doctor of Philosophy (PhD) Medicine degree.

3 What does participation in this research involve?

If you consent to take part in the research study a consent form will be signed prior to any study assessments being performed.

Who is included in the research study?

• You may only participate in the research study if you are aged between 15 and 44 years and have had a baby.
• Women who are pregnant and attending the Family clinic at the Lyell McEwin Hospital for a first antenatal appointment will be invited to take part in the research study.
• Women attending Unihealth Playford and Highbury FPU clinics (Highbury and Elizabeth) who have had a baby will be invited to take part in the research study.

What do I need to do?

• You will be asked to complete a few questions about your bowel control. The questions will be included in a routine visit to the Lyell Mc Ewin antenatal clinic or Unihealth Playford and Highbury FPU clinic. Your health care professional (Doctor or Nurse) will ask you several questions about your bowel control and the questions will take less than 5 minutes to complete.
• You will need to complete this on one occasion.

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study doctors or participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid.

4 Other relevant information about the research project

The research study will include approximately 350 women from the Lyell McEwin Hospital antenatal clinic and 350 women from the Unihealth Playford and Highbury FPU clinics.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with the Lyell Mc Ewin Hospital and Unihealth Playford and Highbury FPU clinics.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the development of a screening tool to identify anal incontinence in other women. If you are identified with anal incontinence, you will be offered referral to a specialist service, which deals with accidental loss of bowel control.

7 What are the possible risks and disadvantages of taking part?

While this research does not involve any treatment. Disclosing personnel information may cause emotional concerns. If this happens, you will be offered counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. This counselling will be provided free of charge. If you are worried about any effects from participation in this research, you can talk with your study researcher.

8 What if new information arises during this research project?

If new information becomes available that a similar study has been done, we may need to stop the study.

9 Can I have other treatments during this research project?

Whilst you are participating in this research project, you may take all of the medications or treatments you have been taking for your condition or for other reasons.

10 What if I withdraw from this research project?

If you decide to withdraw from this research project, please notify a member of the research team before you withdraw. Your decision to not participate in the research study will not affect your routine care or treatment by your health care professional.

If you do withdraw your consent during the research project, the study doctor and relevant study staff will not collect additional personal information from you, although information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected by the investigator up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form, you consent to the study doctor and relevant research staff collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will be stored in a de-identified form (that is no identity details are attached and given a study number). All information is linked to a study number to identify details on a separate sheet and stored separately, securely and only accessible by the investigator. All information is password protected and only accessible by the investigator. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. Research information will be kept for 5 years and then destroyed.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, you will not be able to be identified.

12 Complaints and compensation

If you have any concerns because of this research project, you should contact the study team as soon as possible and you will be assisted with your concerns. Participants requiring counselling services will be assisted with counselling arrangements.

13 Who is organising and funding the research?

This research project is being conducted under the governance of the University of Adelaide, Robinson Research Institute, Lyell Mc Ewin Hospital.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of The Queen Elizabeth Hospital, Lyell Mc Ewin Hospital, Modbury Hospital (TQEH/LMH/MH).
This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies. The research will be undertaken in the Family clinic at the Lyell Mc Ewin Hospital and Unihealth Playford and Highbury FPU clinic (Highbury and Elizabeth)

15 Further information and who to contact

The person you may need to contact will depend on the nature of your query.
If you want any further information concerning this project, you can contact the principal study researcher on 81332133

Clinical and Complaints contact person

Name	Julie Tucker
Position	Study Researcher
Telephone	81332133
Email	Julie.tucker@adelaide.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Heather O'Dea
HREC Executive Officer	HREC Executive officer TQEH
Telephone	0882224139 or 82226841
Email	Healther.Odea@sa.gov.au

Local HREC Office contact (Single Site -Research Governance Officer)

Name	Alison Barr
Position	Research Governance Officer
Telephone	0881829346
Email	Alison.barr@sa.gov.au

Consent Form - *Adult providing own consent*

Title	Development of a screening tool to identify anal incontinence in women of reproductive age
Short Title	Development of a screening tool to identify anal incontinence
Protocol Number	HREC/14/TQEHLMH/58
Coordinating Principal Investigator/ Principal Investigator	Julie Tucker
Associate Investigator(s)	Professor Vicki Clifton, Dr Elizabeth Murphy, Associate Professor Anne Wilson
Location	Family clinic Lyell Mc Ewin Hospital and Unihealth Playford and Highbury FPU clinic

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____

Signature _____ Date _____

Name of Witness* to Participant's Signature (please print) _____

Signature _____ Date _____

* Witness is not to be the investigator, a member of the study team or their delegate. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. Witness must be 18 years or older.

Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher† (please print) _____

Signature _____ Date _____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

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Form for Withdrawal of Participation - *Adult providing own consent*

Title	Development of a screening tool to identify anal incontinence in women
Short Title	Development of a screening tool to identify anal incontinence
Protocol Number	HREC/14/TQEHLMH/58
Coordinating Principal Investigator/ Principal Investigator	Julie Tucker
Associate Investigator(s)	Professor Vicki Clifton, Dr Elizabeth Murphy, Associate Professor Anne Wilson
Location	Family clinic Lyell Mc Ewin Hospital and GP Super clinic

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with the Lyell Mc Ewin Hospital or Unihealth Playford and Highbury FPU clinics.

Name of Participant (please print) _____

Signature _____ Date _____

Declaration by Study Doctor/Senior Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Study Doctor/
Senior Researcher† (please print) _____

Signature _____ Date _____

† A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

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Appendix 6. Excerpt from researcher's journal for qualitative interviews.

Interview 3 field notes

Kelly (pseudonym) is 26 years old; she is not pregnant but recounts her last birth and resultant 3rd degree tear. She actively engaged in the interview, her body relaxed and using hand gestures to emphasise her point.

The researcher noticed Kelly using the bowel screening tools as a divide between the researcher and herself. She holds them upright as she described what it is like living with anal incontinence (AI).

Kelly had been symptomatic of wind incontinence and urge since delivery. Her voice was quiet during the exchange in dialogue, there were long pauses and her body language changed as if she wanted to be smaller or hide. The researcher provided verbal acknowledgement of her concerns but recognised a sense of grief and sadness through Kelly's recount. Holding the paper as a barrier was this a sign of difficulty to disclose? Or was it due to disgust?

The researcher facilitated the discussion further to find deeper meaning asking Kelly what makes it easier to disclose AI.

There was almost a sigh of relief from Kelly, the paper barrier softened and she lifted her gaze and moved her hand slowly; "It's being asked". Tears filled her eyes but she pushed on describing the embarrassment surrounding AI. As a young mother, she was saddened that she should not have to deal with this. She stated, "I feel dirty and I cannot tell anyone". She articulated that she was scared of the future, her voice became louder and hands moved chaotically articulating her concerns. The softly spoken response of the researcher acknowledged her frustration and there was a need to facilitate discussion around disclosure.

There was a sense of despair in her voice as she described wanting the health professional to ask questions. Her voice became angry as she described the lack of professional enquiry was a result as she believed health professionals assume it is not something that happens to young women. The researcher questioned was this a plea in her voice for professionals to take time to wait for an answer, as it was not easy to disclose?

Her voice softened and she lifted her eyes to clarify that it was easier telling a female, as they understood as they have had babies. Kelly's comments challenged the researcher's role as a health professional; the researcher acknowledged this discomfort and further discussion helped to clarify Kelly's anger.

Kelly's hand gently picked up the bowel screening tools, pointing to each as she described these tools would make it easier to disclose. Her voice was engaging, her body language now relaxed facing the researcher she described what she thinks about each tool.

The change in her body language and vocal tone was amazing, as it has been 30 minutes in the interview before she actively engaged. What did this tell the researcher? Does she feel heard and was that why she wanted to engage?

The screening tools now flat on the table, Kelly picked up a pen scribbling over the tools are described what would inhibit or enable disclosure. Circling several times words like incontinence and plug, (Vaziey score). Her pen tapping on these words as she laughed and stated what does it mean? If I do not know the meaning then I will put no, even if I have symptoms.

Kelly's voice softened again when she talked about the variability of her symptoms; as she looked up she uses the screening tools to emphasis her frustration in disclosing AI. She puts a very large arrow across the page of the Wexner score and stated… *see no question about not holding on.* The same forceful marking on the Vaizey score where she asked *what does urge mean?* In addition, she stated it does not even give her options it is just a yes or no. She smiled briefly and pointed to the BSQ stating this is her kind of language but there is no scale (she raised her eyebrows and smiled).

Appendix 6 (cont.). Excerpt from researcher's journal for qualitative interviews.

At the end of the interview, Kelly looked tired but relieved. She smiled at the researcher and thanked her for the opportunity to tell her stories. Kelly stated that she felt better being able to share her thoughts.

Commonalities across all sixteen field notes included the social disgust surrounding AI, the lack of enquiry by health professionals and confusion in understanding questions when asked. The availability of the screening tools within the interviews provided women with a medium to describe their feelings and experience. The journaling undertaken in the research process added depth to the transcribed text and audio tape providing clarity and understanding of the phenomenon at hand, where text alone would have not reflected the depth of information.

The interviews challenged the researcher's preconceived beliefs of the role of the health professional. Acknowledging the comments by women, the researcher brought to the foreground their prior beliefs, challenged by current interview findings and reformulated a deeper understanding in disclosing AI.

Appendix 7. Bowel control screening tool.

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Government of South Australia
SA Health

HERC/14/TQEHLMH/58/AMO1

ID number

Bowel control screening tool

Questionnaire assessment of bowel control for Women of Reproductive Age

This questionnaire is part of a research study being undertaken through the University of Adelaide and asks about control of your bowel. We are interested in identifying how many women of reproductive age experience accidental loss of bowel control, known as anal incontinence. Anal incontinence is loss of a liquid stool/poo; solid stool/poo or gas/wind by accident. Early identification of bowel problems may improve quality of life for pregnant women and women across the lifespan.

We invite you to participate in this questionnaire. Your participation is voluntary and nonparticipation will not impact on your antenatal care. **The questionnaire should take approximately 5 minutes to complete.**

All information is treated with the strictest confidence. **If you have any questions or concerns about the questions please speak to the Midwife or researcher who has given you the questionnaire**.

Please place the completed questionnaires in the envelope provided and return it to the Midwife or **researcher at the clinic desk** .Thank you for participating in this questionnaire. We appreciate your time.

Appendix 7: Bowel control screening tool for women of reproductive age - antenatal and community setting
Title: Development of a screening tool to identify anal incontinence in women of reproductive age
Version 1.2 Date12/05/2017

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Government of South Australia
SA Health

Please place information or a tick ☑ in the YES or NO box for the woman's response to the questions.

Age		
BMI		
Ethnicity		
Pregnant	Yes	No
Gravida		
Parity		
Delivery history		
Vaginal	Yes	No
Caesarean	Yes	No
Forceps	Yes	No
Ventouse	Yes	No
Perineal history		
Anal sphincter injury	Yes	No
Episiotomy	Yes	no
Other state		

Answer the questions by placing a tick☑ in the column.	Never	Rarely	Sometimes	Weekly	Daily
Have you ever lost by accident?	0	1	2	3	4
Solid poo (Stool)					
Liquid poo (Stool)					
Wind (gas)					
Stained your underwear					
Soiled your underwear					
Do you need to rush to the toilet					
Total score >0 consider referral Past history = (/24)					
Answer the questions by placing a circle in the column if in the last 4 weeks, have you had an accident? Current Score = (/24)					
Would you like to be referred to a specialist bowel Doctor? (Circle response)	Yes		No		

Appendix 7: Bowel control screening tool for women of reproductive age - antenatal and community setting
Title: Development of a screening tool to identify anal incontinence in women of reproductive age
Version 1.2 Date12/05/2017