Depression and its Association with the Psychosocial Factors of Urinary Incontinence

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF BOXES

LIST OF EQUATIONS

LIST OF ABBREVIATIONS

ABM	Annette Braunack-Mayer
AHM	Alastair Hugh MacLennan
AQoL	Assessment of Quality of Life
AUDADIS-IV	Alcohol Use Disorder and Associated Disabilities Interview Schedule – DSM IV Version
ARMHS	Australian Rural Mental Health Study
ABS	Australian Bureau of Statistics
AWT	Anne Winifred Taylor
b	Black (race)
BABS	Bradburn Affect Balance Scale
BPRS	Brief Psychiatric Rating Scale
BDI	Beck Depression Inventory
BMI	Body Mass Index
CATI	Computer Assisted Telephone Interviewing
CASP	Critical Appraisal Skills Program
CD-RISC	Connor-Davidson Resilience Scale
CES-D	Centre for Epidemiologic Studies Depression Scale
CFA	Continence Foundation of Australia
CIDI-SF, CIDI-A	Composite International Diagnostic Interview Short-Form
CSDD	Cornell Scale for Depression in Dementia
DIS	Diagnostic Interview Schedule
DI	Detrusor Instability
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders, 3rd Edition. American Psychiatric Association.
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th Edition. American Psychiatric Association.
D	Depression
ECT	Electroconvulsive Therapy
EPICONT	*Epidemiology of Incontinence in the County of Nord-Trøndelag*
ES	Effect Size
EpiLUTS	*Epidemiology of Lower Urinary Tract Symptoms Study*
ERP	Estimated Residential Population
FIQL	Faecal Incontinence Quality of Life Scale

FPI	Freiburg Personality Inventory
GDS	Geriatric Depression Scale
GHDS	General Hospital Depression Scale
GHQ-12	General Health Questionnaire 12
GP	General Practitioner
FPI	Freiburg Personality Inventory
HADS	Hospital Anxiety and Depression Scale
HDRS	Hamilton Depression Rating Scale
HIV	Human Immunodeficiency Virus
HRQoL	Health Related Quality of Life
HS	Help-seeking
ICD-10	International Classification of Diseases 10th Edition
ICS	International Continence Society
ICIQ	International Consultation on Incontinence Questionnaire
IIQ	Incontinence Impact Questionnaire
I-QOL	Incontinence Quality of Life Instrument
ISQ	Incontinence Screening Questionnaire
ISSI	Incontinence Symptom Severity Index
JCA	Jodie Christine Avery
LUTS	Lower Urinary Tract Symptoms
MDI	Major Depression Inventory
M	Men
MCS	Mental Component Summary of the SF-36
MHI-5	Mental Health Inventory
MMPI	Minnesota Multiphasic Personality Inventory
MAOIs	Monoamine Oxidase Inhibitors
MUI	Mixed Urinary Incontinence
NAFC	National Association for Continence
NCS-R	National Comorbidity Survey Replication
NEMESIS	*Netherlands Mental Health Survey and Incidence Study*
NHANES	*National Health and Nutrition Examination Survey III*
NESARC	*National Epidemiologic Survey on Alcohol and Related Conditions*
NN	No Depression
NNT	Number Needed to Treat
NS	Nigel Stocks
OAB	Overactive Bladder

OR	Odds Ratio
OMD	Depression diagnosed by PRIME-MD PHQ
OUI	Overflow Urinary Incontinence
PD	Psychological Distress
PMD	Paul Michael Duggan
PCS	Physical Component Summary of the SF-36
PRIME-MD PHQ	Primary Care Evaluation of Mental Disorders Patient Health Questionnaire
PSA	Public Service Announcement
R^2	Coefficient of Determination
RG	Robert Goldney
SAHOS	*South Australian Health Omnibus Survey*
S	Sadness
SF-36	Medical Outcomes Study Short Form 36
SCI	Spinal Cord Injury
SDS	Zung Self-Rating Depression Scale
SSRIs	Selective Serotonin Reuptake Inhibitors
SRD	Self-Reported Depression
SUI	Stress Urinary Incontinence
SS	Statistically Significant
SSH	Statistically Significantly Higher
TACOS	*Transitions in Alcohol Consumption and Smoking*
UI	Urinary Incontinence
UUI	Urge Urinary Incontinence
UDI	Urogenital Distress Inventory
UK	United Kingdom
USA	United States of America
W	Women
w	White (race)
WHA	*Women's Health Australia*

ABSTRACT

Urinary Incontinence has been associated with psychological distress, depression and anxiety. However, research exploring these psychological effects has been minimal, mostly concentrating on older people, women or samples of convenience. Only a few studies have examined quality of life, management and coping behaviours, social connectedness, and beliefs and knowledge of the condition, focussing more upon risk factors such as gender, age, cognitive impairment and physical health.

The research question for this thesis is whether the depression experienced by people with urinary incontinence is associated with psychosocial factors related to incontinence. The group of studies that contribute to the project “Depression and its Association with the Psychosocial Factors of Urinary Incontinence” include a population study examining incontinence, depression and quality of life in both men and women; another population study looking at perceptions of seriousness and severity of incontinence in women; a review of the literature; and a qualitative study examining women’s experience of urinary incontinence and depression.

A review of the literature found that incontinence and psychological wellbeing are intertwined. Enquiring about the mental health status of those with incontinence should include an assessment of psychosocial factors to help reduce the burden of incontinence.

I found that depression and incontinence both reduce health related quality of life (HRQoL). When they occur together there appears to be an additive effect which affects both physical and mental health. Clinicians should identify and manage comorbid depression when treating patients who have incontinence to improve their overall HRQoL.

I also found that severity and limitations to lifestyle were predictors of women perceiving that their incontinence was moderate to very serious. Help-seeking for incontinence improves if education and information target women who use continence management aids, have difficulty being involved in activities or who use other management strategies.

Finally, an exploration of how women experience incontinence in relation to their depression status was undertaken. Women who are older and highly resilient experience less depression and can manage their depression better. Women who do not exhibit resilience are more likely to experience depression, and their incontinence has a greater impact on their lives. Age and resilience-focused interventions in women newly diagnosed with incontinence may lessen the impact of depression on these women.

Those who experience incontinence and are affected by depression in their day to day lives experience a reduced quality of life. We can also gauge the impact of incontinence on the lives of women by examining their limitations and perceptions about the seriousness of their condition, and we can target interventions towards those who experience limitations and use management strategies. We can also design targeted interventions for specific age groups that can increase resilience, so that the burden, including depression, is eased and quality of life is increased in women experiencing incontinence.

THESIS DECLARATION

I 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 institution and, to the best of my knowledge and belief, 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 institution without the 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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Jodie Christine Avery

Signed:____ Date: 20th May 2014

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2. Avery J, Braunack-Mayer A, Stocks N, Taylor A, Duggan P. Psychological perspectives in urinary incontinence: a metasynthesis. *OA Women's Health* 2013; **1**(1): 9

3. Avery JC, Stocks N, Taylor AW. Gill TK. Perceptions and prevalence of urinary incontinence in the Australian population. *Australian and New Zealand Continence Journal* Autumn 2014; **20**(1): 7-13.

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4. Avery J, Braunack-Mayer A, Duggan P, Taylor A, Stocks N. “It’s Our Lot”: Resilience and its influence on the experience of depression in women with urinary incontinence. *Health Sociology Review* 2014; X(X)

CONFERENCE PRESENTATIONS ARISING FROM THIS THESIS

2005

Avery JC, Gill TK, Taylor AW, MacLennan AH. (Oral Presentation): *Incontinence Perceptions, Impacts, and Quality of Life*. **36th Public Health Association of Australia Annual Conference** Perth WA. 2005

Avery JC, Wilson I, Braunack-Mayer A, Stocks N, Duggan P (Oral Presentation): *Mental health and its influence on help-seeking behaviour for incontinence.* **HARC Symposium "Multidisciplinary Research in Ageing"** Adelaide SA. 2005

Avery JC**,** Taylor AT, MacLennan AH. (Oral Presentation): *A population perspective of urinary and anal incontinence in South Australia.* **14th National Conference on Incontinence,** Melbourne VIC. 2005

Avery JC**,** Wilson I, Braunack-Mayer, AJ (Poster Presentation): *Beliefs and Barriers about Seeking Help for Incontinence.* **14th National Conference on Incontinence,** Melbourne VIC. 2005

2006

Avery JC, Stocks N, Braunack-Mayer A, Duggan P, Wilson I. (Oral Presentation): *Mental health and its influence on help-seeking behaviour for incontinence.* **diamond Consortium Colloquium for Research Higher Degree Students** University of Melbourne VIC. 2006

Avery JC, Stocks N, Braunack-Mayer A, Duggan P, Wilson I, (Invited Speaker): *Depression and Association with the Psychosocial Factors of Urinary Incontinence*. **South Australian Urological Nurses Society Study Day**. Adelaide SA. 2006

2011

Avery J, Braunack-Mayer A, Stocks N. (Poster Presentation): *A Metasynthesis of Psychological Perspectives of Urinary Incontinence.* **Faculty of Health Science Post Graduate Conference**, University of Adelaide. Adelaide SA. 2011.

**NB Winner of School of Population Health and Clinical Practice: Best Poster Award

2012

Avery JC, Braunack-Mayer A, Stocks N. (Oral Presentation): *Psychological Perspectives of Urinary Incontinence: A Metasynthesis* **PHCRIS**: Canberra ACT. 2012

2013

Avery JC, (Invited Speaker): "*Am I likely to laugh today?" Depression and its Association with Urinary Incontinence* **Adelaide West Rotary Club**. Adelaide SA. 2013

Avery JC, Braunack-Mayer A, Duggan P, Taylor A, Stocks N, (Poster Presentation): "It's our lot": the influence of depression on the experiences of incontinence **41st Public Health Association of Australia Annual Conference** Melbourne VIC. 2013

2014

Avery JC, Stocks N, Braunack-Mayer A, Duggan P, Taylor A. (Abstract Submitted, Poster presentation accepted): Depression and its Association with the Psychosocial Factors of Urinary Incontinence): **23rd National Conference on Incontinence,** Cairns QLD. 2014

Abstracts for the above presentations are available in Appendix 2 at the end of the thesis.

MEDIA COVERAGE OF FINDINGS FROM THIS THESIS

2013

Media Release:

Incontinence takes mental toll on younger women, Friday 14 June 2013 (See Appendix 2)

http://www.adelaide.edu.au/news/news62021.html?utm_source=hootsuite&utm_medium=uniofadelaide&utm_campaign=socialmedia

Reported in many news services around the world

News story:

Channel 10 Friday 14 June 2013

http://youtu.be/K9xy6LhFMgw

Radio Program:

Evenings with Peter Goers ABC891 Radio: Monday 24 June 2013 interview.

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1 PREAMBLE

1.1 INTRODUCTION

1.1.1 BACKGROUND

As our community ages, the prevalence of chronic conditions increases[1]. The public health benefits of attending to some conditions in their early stages include lessening the impact on the individual, their carers and the health system[2]. In 2002, the National Research Priority Ageing well, ageing productively, looked at "developing better social, medical and population health strategies to improve the mental and physical capacities of ageing people"[3]. In the 2010-12 Strategic Plan[4], the National Health and Medical Research Council (NHMRC) identified ageing and health as a key area of focus, stating that: "maintaining health as we age is an important social and economic objective. Other government reports highlighting this include the Prime Minister's Science, Engineering and Innovation Council report entitled "Promoting Healthy Ageing in Australia"[5], the Australian Government's "Framework for an Australian Ageing Research Agenda"[6], and more recently, the Productivity Commission's report on "Caring for Older Australians"[7]. In its 2013-2015 Strategic Plan[8], ageing was not emphasised, instead the most pressing health issue became "Improving care of patients with multiple and complex chronic disease", however mental health (with a focus on depression), remained a National Health Priority Areas. In order for the population to maintain life quality, we must address some chronic conditions in their initial stages. It is paramount in these instances to identify and overcome barriers associated with obtaining diagnosis and treatment.

Incontinence is one condition where treatment or management of symptoms can make a significant difference to the impact on individual quality of life, carers, and the health system[9-11]. It has been found that urinary incontinence affects approximately 1,840,000 women[11] and costs each Australian the equivalent of $710.44 per annum, with additional other indirect costs. More recent figures suggest the total cost of incontinence in Australia could be as much as $1.6 billion per annum[12]. In 1998, an estimated 245,000 community dwelling South Australians had urinary incontinence[13]. Prevention of incontinence before symptoms appear in pregnant women can be effective[14], but there are also other factors that may contribute towards the psychosocial impact of incontinence that are potentially modifiable, such as the mental health of those with incontinence.

The thesis primarily focuses on urinary incontinence and depression, but also extends to other urinary symptoms and mental health problems.

1.1.2 RATIONALE FOR RESEARCH

Incontinence has been associated with psychological distress, depression and anxiety[15]. However, research exploring these psychological effects of incontinence has been minimal, mostly concentrating on older people, women or samples of convenience[16-18]. Few recent investigations have concentrated on the impact of mental health upon psychosocial issues relating to incontinence such as quality of life, management and coping behaviours, social connectedness, and beliefs and knowledge of the condition, focussing more upon risk factors such as gender, age, cognitive impairment and physical health[15,19,20].

Depression may adversely influence the psychosocial factors that are associated with incontinence. People with incontinence experiencing depression may be less likely to seek help for their condition, may have a lower quality of life, may be more socially isolated, may perceive that they have more severe symptoms and may use health services less than individuals with incontinence who are not depressed. Associations between incontinence, mental health and psychosocial outcomes such as quality of life, may provide an opportunity to address health problems in an alternative way. As depression may be more amenable to treatment than incontinence, an ideal opportunity to alleviate the burden of incontinence may be presented for the 30% of those with incontinence who also suffer from depression[21-24].

Evidence suggests there are barriers to help-seeking by people with incontinence, such as mental health, but further investigation into the reasons for the existence of these barriers may be needed to overcome them[25]. Help-seeking may be related to the subjective perceptions of those experiencing incontinence, with regard to their condition. Additionally, mental disorders such as depression, in association with other psychosocial factors, could play a role in the patient's subjective assessment of the severity of urinary incontinence and may also have an effect on help-seeking[24]. Positive psychosocial factors include the enhancement of quality of life, decreased symptom severity, psychological distress and service barriers[26]. Further exploration into the implications of the connection of mental health and the psychosocial factors of incontinence is necessary[16,27-30].

Many people with incontinence suffer from depression. However, the relationship between incontinence and depression, and other psychosocial factors remains unclear. This thesis will examine the hypothesis that depression is associated with psychosocial factors such as quality of life, help-seeking and resilience in people with incontinence, and will identify the consequences of incontinence and depression for individual social psychological factors, identities, and social relationships.

1.2 OUTLINE

This thesis is a combination of written text (Chapters 1-3, and Chapters 6,7,9,11) and peer-reviewed journal papers that have either been published (Chapters 4 - 5, and Chapter 8) or have been submitted for publication (Chapter 10). The thesis is also divided into two sections, where Section 1 concerns the quantitative population studies undertaken for this thesis, and Section 2 relates to the qualitative studies undertaken including a metasynthesis and an in-depth interview study.

Section 1 of this thesis introduces the primary hypotheses which are then discussed in Chapter 1: *The Preamble*. It provides the background to the topic including the definition of key terms and concepts, and a review of the current literature surrounding incontinence, mental health and some initial psychosocial outcomes for Chapter 2: *Population Studies concerning Incontinence, Depression and Psychosocial Factors: A Background and Literature Review*. Chapter 3: *Methodology for Undertaking Population Studies* discusses the methodology for the project, outlining the individual items and questionnaires used in the collection of data as well as the instrument used to facilitate these assessments, The South Australian Health Omnibus (SAHOS), as well as description of the proposed study plan, which also considers the qualitative component of the project. The analyses are then described, and administrative issues such as ethical approval, intellectual property and acknowledgements of the initial ownership of the data considered. The next two chapters (Chapter 4 and 5) are papers that have been peer reviewed and published. Chapter 4: *Identifying the Quality of Life Effects of Urinary Incontinence with Depression in an Australian Population*, explores the relationship between incontinence, other psychosocial factors and depression. Chapter 5: *Urinary Incontinence: Severity, Perceptions and Population Prevalence in Australian Women*, examines perceptions of seriousness of incontinence and compares this with the behaviours exhibited by women with incontinence to manage their condition.

Section 2 commences with Chapter 6, a bridging chapter linking Sections 1 and 2. Then Chapter 7: *Synthesizing the Meanings: The Rational for Undertaking a Metasynthesis* describes and critiques the method of metasynthesis for reviewing qualitative literature. This is followed by another peer reviewed publication, Chapter 8: *Psychological perspectives of Urinary Incontinence: a Metasynthesis*, where a metasynthesis has been undertaken to provide a review of the qualitative literature in this area as a background for the interview study. Then, Chapter 9: *Exploring Experiences and Meanings: Methods for Undertaking a Qualitative Study for Women with Incontinence and Depression* describes the background, theory and methodology behind the qualitative study.

Chapter 10: *"It's our lot": Resilience and its influence on the experience of depression in women with urinary incontinence,* has been submitted for publication, and describes an in-depth interview study and its findings. Finally Chapter 11: *Overall Conclusions,* summarises and brings together the conclusions for the whole thesis.

Additionally, a bibliography of publications referred to in this thesis is presented (Chapter 12), and Chapters 13 and 1, provide the Appendices for Section 1 and 2 respectively, including various letters, ethics applications, questions, questionnaires and interview schedules, scoring, analyses, as well as the published journal versions of all publications, conference presentation abstracts and media releases.

1.2.1 STUDIES, RESEARCH QUESTIONS AND HYPOTHESES

The research question explored by this suite of mixed method studies is:

> *"How is depression associated with psychosocial factors such as quality of life, help-seeking and social networks in people with incontinence and what are the consequences of these associations in people with incontinence and comorbid depression?"*
>
> *These psychosocial factors include help-seeking behaviour, health-related quality of life, perceptions of symptom severity, social networks, and health services usage; all of which may contribute to the management and treatment outcomes of incontinence.*

Thus, the hypotheses for which quantitative evidence will be collected, to support conclusions are that:

- The help-seeking behaviour of people with incontinence is adversely affected by comorbid depression;
- The quality of life of people with incontinence is adversely affected by comorbid depression;
- Perceptions of symptom severity of people with incontinence are adversely affected by comorbid depression; and
- The social networks and support of people with incontinence are adversely affected by comorbid depression.

Further, the nature of the qualitative studies included here are traditionally not used to test hypotheses, however they are used to understand lived experience. Thus, the aims for this part of the study are:

- To explore the relationship between mental health status and urinary incontinence, focusing on the role of psychosocial factors.
- To explain how mental health and urinary incontinence interact, by exploring the subjective experience of the burden of urinary incontinence in relation to mental health.

SECTION 1

2 POPULATION STUDIES CONCERNING INCONTINENCE, DEPRESSION AND PSYCHOSOCIAL FACTORS: A BACKGROUND AND LITERATURE REVIEW

2.1 INTRODUCTION

Urinary incontinence is not often considered without some mention of the associated psychological effects, such as psychological distress, depression and anxiety[15]. One author has recently commented:

> *"Regardless of how the two disorders are related, the combined impact of urinary incontinence and major depression exceeds the impact of either condition alone…Leaving either of these disorders undiagnosed and thus untreated will clearly have significant impact on the health and quality of life of individual patients and the population as a whole"*[31].

A review concerning studies looking at the combination of depression with any chronic condition found there were further associations with a number of other problems. These included an increase in the use and cost of medical resources, physical symptoms could be amplified, there was an additive effect in the area of functional impairment, decreased compliance with treatment and lifestyle changes, and also increased mortality[32]. However, research concerning incontinence and depression together, and the subsequent impact on health, quality of life, help-seeking and other psychosocial factors, is limited.

The International Continence Society (ICS) takes great care in its definition of urinary incontinence, to include that incontinence is involuntary leakage in the context of type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life[33]. However although the psychosocial aspects of incontinence are repeatedly referred to, its examination in combination with mental health, has been neglected[19,21,30,34-43].

Thus, we do not know if the combination of incontinence with psychosocial outcomes, such as quality of life, social connectedness, perceptions of illness and help-seeking, may have some affect or be affected by someone's mental health, specifically depression.

Associations between incontinence, quality of life and mental health have been demonstrated, but exploration into the implications of this connection with regard to help-seeking and social relationships is necessary and there has recently been a call for research in this area[15,16,27-30,44]. Furthermore, little research around psychosocial factors has considered men with incontinence and depression.

Examining associations between incontinence, psychosocial and mental health may provide an opportunity to address this health problem in a different way. The treatment or management of symptoms can make a significant difference to the impact on individual quality of life, carers of people with incontinence, as well as the whole health system[9-11]. However, there is a belief in the community that treatments do not work, so there is a need for incontinence research to attract funding, increase its profile as a health priority, and correct some of the perceptions about causes and treatment that are held. Unfortunately, both incontinence and mental health problems are associated with stigma, but with dedicated research in both areas, there may be potential for this to be reduced.

There are a number of factors which contribute to the difficulty of studying incontinence and depression epidemiologically. These include the various definitions of the diagnosis of both incontinence and depression, the different epidemiological methods used to estimate the prevalence in the community, and the underreporting of these conditions due to stigma or the perceptions of those experiencing the condition. However this review intends to critically analyse these problems within each of the studies presented, so that a clearer picture of the conditions and outcomes studied may be obtained.

The literature review will examine whether depression impacts the psychosocial factors associated with urinary incontinence, using help-seeking behaviour as an example. Key concepts regarding incontinence and depression will be discussed. A general introduction to help-seeking, quality of life and social capital and connectedness will provide background information, A comprehensive review of the literature with regard to incontinence and depression, help-seeking and incontinence, and help-seeking and depression, as well as the interplay between these three concepts will be presented. The majority of the studies are present in tabular format also, for ease of comparison (Table 2.13, Table 2.14, Table 2.15, and Table 2.16). Finally the absence of research in this area will be highlighted. A systematic search of the literature concerning incontinence, depression and help-seeking, and various combinations of these terms, identified articles written in English using PUBMED. Once articles were identified, individual reference lists derived from these were also searched to discover additional articles.

Methodologically, prevalence data considering individuals' self-reports of illness and disease are most accurately collected using community based population surveys[45], and this review has sought to include primarily these surveys. Samples derived from clinical populations only consider those members of the community who realise or acknowledge they have a problem, excluding the majority of the community who, for various reasons, have not sought consultation. It has been necessary to include clinical surveys in addition to population surveys, as here is where the majority of data exists. However, cross sectional studies, as reported in this review, are not able to infer causality or accurately define the chronology of events for the development of co-morbidities, depression and psychosocial factors that can be associated with incontinence.

2.2 URINARY INCONTINENCE

The lack of bladder control is described by the general term "urinary incontinence". As previously mentioned, the ICS, by consensus, has defined urinary incontinence as "the complaint of any involuntary leakage of urine in the context of type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life"[33]. Descriptions used for urinary incontinence in surveys prior to the ICS consensus reflected the above definition and enabled direct comparison of prevalence rates between studies over time.

Table 2.1: Types of urinary incontinence

Type	Description
Stress incontinence	Involuntary leakage on effort or exertion, or on sneezing or coughing[33]
Urge incontinence	Involuntary leakage accompanied by or immediately preceded by urgency (the sudden compelling desire to pass urine)[33]
Mixed incontinence	Involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing[33]
Functional incontinence	A result of physical, mental or environment problem that affects a person's ability to reach or use the toilet in time[46]
Reflex incontinence	Loss of urine control due to damage to the nerves which control bladder function, the spinal-brainstem-spinal reflex loops. Most commonly found in people with spinal injuries[47]

Table adapted from Avery et al 2004[13]

2.2.1 Types of Urinary incontinence

Urinary incontinence is most commonly broken down further into the categories of stress or urge incontinence, but there are also other types including functional, reflex and mixed incontinence. Table 2.1 above defines each of the different types of urinary incontinence.

2.2.2 Epidemiology

Studies from around the world have estimated the prevalence of all types of urinary incontinence, that is having stress or urge incontinence or both. As incontinence disproportionally affects the older population, and is also a primary reason for the institutionalisation of the elderly[48]. Information collected via a health census of hospitals and residential and nursing homes in the United Kingdom found 44.0% of residents incontinent of urine or faeces or both[49]. Prevalence data has been collected for both institutionalised populations and community samples. However, the overall prevalence of incontinence is generally underreported, as many population surveys do not include hospitals, nursing home and other institutions where the elderly may reside.

Urinary incontinence research has focused primarily on the group it most affects, middle to older aged women[10]. A recent systematic review established the prevalence of urinary incontinence, among women and men in Australian community samples over 18 years, to be 19.3% and 2.2% respectively[50]. In the United Kingdom the prevalence of urinary incontinence has been reported at 23.0% of adults[51]. In European women under the age of 65 years, the prevalence of stress urinary incontinence has been reported to be 12.2% and urge incontinence at 1.8%[52]. Another Australian study reported that 28.0% of men and women, 65 years and younger experienced urgency incontinence and 21.0% reported stress incontinence, with greater rates in the women[53].

Community dwelling Indian women aged 20 to 60 years have been found to have a prevalence of urinary incontinence of 33.8%[54], and in Jordanian women over 30 years a prevalence of 35.4% has been reported[55].

In Australia, the prevalence of ever having urinary incontinence for women over 18 years has previously been reported at 25.8%, and for both male and female adults, 24.0%[11,56]. South Australian data from 1998 reports a prevalence of 20.3% for adults 16 years and over[13]. The most current South Australian data, unpublished from the SAHOS in 2004 gives an overall prevalence of urinary incontinence at 28.0%[57,58] (Table 2.2).

The prevalence of incontinence in South Australia (1998) by a number of demographic variables is described in Table 2.3 below.

Table 2.2: Proportion of South Autralian adults reporting urinary incontinence by type, aged 15 years and over, 2004

	n/N	%	95% CI
Urge Urinary Incontinence	535/3015	17.7	(16.4 - 19.2)
Stress Urinary Incontinence	651/3015	21.6	(20.2 - 23.1)
Overall Urinary Incontinence	846/3015	28.0	(26.5 - 29.7)

Data source: SAHOS Autumn 2004 (Unpublished).
Note: The weighting of data can result in rounding discrepancies or totals not adding

2.2.3 Diagnosis

2.2.3.1 *Measurement*

Primary diagnosis of incontinence is achieved through self-report of symptoms to a health care provider. A number of simple questions describing the characteristic symptoms of the different types of incontinence can be asked of those who volunteer symptoms, and more general questions can be asked of those thought to be at risk. These often relate to the ICS consensus definition[33]. Clinical investigations such as urodynamics exams[59], pad tests[60] and urinalysis can verify diagnosis and shed light on underlying causes whilst also quantifying the level of severity.

There is much stigma and many taboos surrounding incontinence, whereby those experiencing incontinence may not want to admit to it[61-63]. Additionally, it is a subjective problem, in that some people may perceive the impact of their problem differently to others, due to factors such as the psychosocial, other comorbid problems, age and their overall quality of life. These limitations can make the diagnosis and measurement of the severity of incontinence problematic[64,65].

Table 2.3: Prevalence and odds ratio of incontinence, by demographic variables, SAHOS 1998.

	Urinary Incontinence			
	n	%	OR	95% CI
Gender				
Male	65	4.4	1.00	
Female	546	35.3	11.75 *	(8.9 – 15.5)
Age group				
15-29	45	5.7	1.00	
30-39	102	17.2	3.48 *	(2.4 – 5.1)
40-49	136	24.4	5.41 *	(3.7 – 7.9)
50-59	101	26.1	5.90 *	(3.9 – 8.8)
60-69	95	30.9	7.42 *	(4.9 – 11.1)
70-79	105	38.6	10.57 *	(7.1 – 15.9)
80+	28	28.0	6.52 *	(3.8 – 11.6)
Area of residence				
Metropolitan	417	20.1	1.00	
Country	194	20.6	1.03	(0.8 – 1.3)
Highest education level				
Bachelor degree	55	15.4	1.00	
Cert/diploma	131	21.8	1.53 *	(1.1 – 2.2)
Trade qualifications	28	7.5	0.44 *	(0.3 – 0.7)
High school	397	23.6	1.69 *	(1.2 – 2.3)
Marital status				
Married/de facto	439	23.7	1.00	
Sep/divorced	57	26.0	1.12	(0.8 – 1.6)
Widowed	73	39.2	2.06 *	(1.5 – 2.9)
Never married	40	5.4	0.18	(2.1 – 0.3)
Country of birth				
Australia	439	19.4	1.00	
UK/Ireland	91	23.9	1.31 *	(1.0 – 1.7)
Other	81	22.2	1.20	(0.9 – 1.6)
Household income ($A)				
> $40,000	172	15.9	1.00	
$20,001-$40,000	142	19.6	1.29 *	(1.0 – 1.7)
Up to $20,000	216	28.3	2.09 *	(1.7 – 2.6)
Not Stated	82	18.4	---	
OVERALL	611	20.3		

Note: * Statistically significantly different (χ^2 test $p<0.05$) than comparison group (OR=1)
Table adapted from Avery et al 2004[13]

2.2.3.2 ***Screening, Scales and Severity***

There is no consensus about how to quantify the severity of urinary incontinence, as the description of symptoms does not fully capture the effect incontinence has on the social interaction, physical activities and psychological well-being of people with this condition[29,66]. The impact of incontinence on the individual is very subjective, and the “bothersomeness” or effects on the individual vary greatly.

Severity may be gauged in a number of ways such as frequency, amount, use of incontinence protection aids, own perceptions and through the use of clinical tests[67-72]. Frequency volume charts or urinary diaries can assist in the quantification of the amount and the frequency of incontinence episodes[73,74].

However, quantifying the severity of incontinence using the volume of urine lost does not account for the importance the individual may place on the impact incontinence has on their life[41]. One interesting assessment of the severity of incontinence is described in Table 2.4. This classification considers some of the economic and social implications of incontinence, such as whether extra laundry needs to be done, or whether help is needed[75].

There are a number of different clinical examinations and questionnaires which attempt to quantify the severity and impact of incontinence experienced by the individual. These include the Incontinence Impact Questionnaire (IIQ) and the Urodynamic Distress Inventory (UDI)[66,76], the King’s Health Questionnaire[69], the Incontinence Quality of Life Instrument (I-QOL)[77], and the Incontinence Screening Questionnaire (ISQ)[70]. Often however, these instruments do not correlate with clinical tests of severity such as the pad test[78].

Table 2.4: Severity categories for incontinence

Severity	Impact	
Minimal	No extra laundry No restriction in activities because of incontinence	No pads or expenses
Slight	Very small amount of extra laundry No restriction in activities	Pads worn only occasionally
Moderate	Extra laundry or pads or expenses	Some restriction in activities
Severe	Extra laundry or pads or expenses Requires help from others	Activities restricted

Table adapted from Thomas et al 1980[75]

There are also other commonly used questionnaires to determine the prevalence, severity and impact of incontinence. Data corresponding to the Incontinence Symptom Severity Index (ISSI)[79], and the short form of the Urogenital Distress Inventory (UDI-6)[76,80] are also available. These questionnaires were used to collect data via the Autumn 2004 SAHOS by the Department of Health and Ageing's *National Continence Management Strategy*[81].

2.2.3.3 ***Incontinence Symptom Severity Index (ISSI)***

The Incontinence Symptom Severity Index (ISSI)[79] was created as a simple severity index of female urinary incontinence for epidemiological surveys. It has been validated against the 24 hour pad test as an acceptable tool for quantifying the severity of incontinence in women, but has also been used with men[82,83].

The index uses a quantity-frequency approach, and is calculated by multiplying the two responses together, where 1-2 is ‘slight’, 3-4 is ‘moderate’, and 6-8 is ‘severe’. The AIHW's *Australian incontinence data analysis and development* report[81], which originally analysed the Autumn 2004 SAHOS data, calculated severity using this scale as 0 being ‘no incontinence’, 1 ‘slight’, 2 ‘moderate’ , 3 ‘severe’ and 4 ‘very severe’. Table 2.5 outlines the questions and responses for the ISSI.

Table 2.5: Original Items in the Incontinence Symptom Severity Index (ISSI)

Urinary Problems				
1. How often do you experience leakage?				
Sandvik et al.	1 ‘less than one a month’	2 ‘ one or several times a month’	3 ‘ one or several times a week’	4 ‘every day and / or night’
AIHW	0 ‘never’	1 ‘rarely’	2 ‘sometimes’	3 ‘often’
2. How much urine do you lose?				
Sandvik et al.	1 ‘drops or little’		2 ‘more’	
AIHW	1 ‘drops or just a little’		2 ‘more than just drops’	

Table adapted from Sandvik et al 1993[79] and AIHW 2006[81]

2.2.3.4 *Urogenital Distress Inventory Short Form (UDI-6)*

The UDI-6[80] measures the degree to which symptoms associated with urinary incontinence are troubling. This short form has been validated in women and has been found to be reliable for clinical practice and also research with men[22]. The scoring of this scale is also achieved by multiplying the responses together, where 0 indicates no incontinence, 1-3 indicates a ‘slight problem’ with incontinence, 4-6 indicates a ‘moderate problem’, 7-9 a ‘problem’ and 10-18 a ‘major problem’. Table 2.6 outlines the questions and the Likert scale responses used to determine the bothersomeness of symptoms of incontinence.

Table 2.6: Original Items in the Urogenital Distress Inventory Short Form (UDI-6)

Do you experience, and, if so, how much are you bothered by:			
1. Frequent urination			
2. Leakage related to felling of urgency			
3. Leakage related to activity, coughing or sneezing			
4. Small amounts of leakage (drops)			
5. Difficulty emptying bladder			
6. Pain or discomfort in lower abdominal or genital area			
0 ‘not at all’	1 ‘slightly’	2 ‘moderately’	3 ‘greatly’

Table adapted from Uebersax et al 1995[80]

2.2.4 Impact

2.2.4.1 *Psychosocial*

Incontinence impacts greatly on travel, social, physical and emotional activities[19,35,37]. Reports of reduced community activity, prayer and church attendance, and interference with work life have been described[84-87]. Additionally, incontinence can affect relationships and contribute toward sexual difficulties[85,88,89]. Recent investigations have concentrated on psychological issues relating to incontinence such as management and coping behaviours, stigma, social connectedness, and beliefs and knowledge of the condition[15-20,24,67,89,90].

Social isolation can be manifested in limitations where the impact is such that people with incontinence may be prevented from visiting places with unknown restrooms, places where they need to travel more than thirty minutes to reach, visiting friends or relatives, or generally participating in activities outside the home[41,76,85].

2.2.4.2 ***Quality of life***

Incontinence is not life threatening, however it is quality of life threatening[28]. The impact of incontinence primarily concerns quality of life, as significant morbidity and mortality are not associated with the condition[76]. A number of studies have illustrated the significant effects of urinary incontinence on the lives of individuals[51,91-93], as well as the improvement in quality of life after successful interventions for incontinence[17,18,91].

The different symptoms associated with different types of incontinence appear to affect quality of life in different ways. For instance people with urge urinary incontinence tend to score lower on the Short Form 36 (SF 36)[94] those with stress urinary incontinence[28,95-99]

2.2.4.3 ***Risk factors***

Urinary incontinence may result from physiological problems arising from other chronic conditions such as diabetes or multiple sclerosis[100], or can be associated with mobility limitations associated with conditions such as osteoporosis or arthritis. Physiological changes or damage to the pelvic floor due to obesity[101], pregnancy or instrumental delivery[102], drug therapies[103,104], and the menopause[105] may also be major contributing factors.

The number and type of risk factors for incontinence and pelvic floor dysfunction are diverse enough that a model has been created to describe risk factors into predisposing, inciting, promoting, decompensating and intervening categories[106]. Predisposing factors include age and gender, which cannot be modified[106]. Factors which incite urinary incontinence include damage to the pelvic floor due to childbirth[102]; and such inciting factors may be unavoidable[106]. Promoting factors include obesity[92], the menopause[105], surgery and medications[106], and some behavioural factors such as smoking[106] or excess caffeine[107]. Intervening factors include drug therapies[103] and surgery[9].

Interestingly, one review in 2002 found that prevention of incontinence before symptoms appear is not generally effective[17]. However, a further review in 2012 found that antenatal pelvic floor exercises may make labour easier, and accompanied by postnatal exercise may also reduce the likelihood or leaking urine for the first six months after childbirth[14]. There is not enough evidence to say if these effects last for more than twelve months. There are also other potentially modifiable factors that contribute towards incontinence. Populations identified as being at greater risk, such as pregnant and post-partum women, or men who have undergone prostate surgery, may be targeted for intervention[17,106,108,109].

Addressing risk factors, such as other chronic conditions, obesity, the use of some medications, the menopause and physical barriers, may reduce the impact of incontinence[100,103-105]. Potentially, educating patients about coping mechanisms to manage their symptoms and teaching resilience may help lessen severity of their incontinence[89].

2.2.4.4 *Economic*

Urinary incontinence affected approximately 1,840,000 Australian women in 1998 costing A$710.44 million per annum[11], however more recent estimates from 2008–09, have put the total expenditure on incontinence at $1.6 billion per annum[12]. The most recent estimates in Australia of the total health system expenditure by the federal and state governments on urinary incontinence in 2010 has been estimated at A$198.6 million however this did not include the cost of continence aids[110].

One review from the United States has projected the costs in the USA for urge urinary incontinence in 2015 to be US$72.2 billion[111]. This is in addition to other indirect costs, shouldered by the individual with incontinence. An estimated 310,000 community dwelling South Australians had incontinence in 1998, and the potential for this to rise to approximately 450,000 by 2015, as a result of the ageing population, is possible, using the most recent 2004 prevalence data[13,112]. In Australia, population projections have been estimated at 4.5 million people with urinary incontinence in 2015, up to 5.6 million in 2030[110].

Some associated costs for incontinence include consumable items such as absorbent pads, laundry, as well as treatment costs for problems such as urinary tract infections, falls resulting from rushing to the bathroom, and skin conditions[113]. Days lost from work, or the inability to work, also contribute towards the costs associated with incontinence[11].

2.2.5 Treatment

Treatment and management options for urinary incontinence include behavioural therapies such as bladder retraining and pelvic floor (Kegel) exercises, pharmacological therapy, such as musculotrophic relaxants, anticholinergics and tricyclic antidepressants, and also surgery[9].

Previously, a Cochrane review concluded that, at this time, there is insufficient evidence that physical therapies can prevent incontinence in childbearing women, or men following prostate surgery[109]. However there is the potential for treating incontinence once symptoms appear using these therapies[114].

2.2.6 Perceptions

Perceptions about incontinence, particularly its severity, may influence the impact incontinence has on the individual. Some perceptions regarding incontinence may be detrimental to help-seeking[115,116] and contribute towards poorer mental health[24,67]. Particular symptoms may encourage embarrassment, or feelings that discomfort is not reason enough to seek help are just some of the common perceptions surrounding incontinence[71,103]. Others include that incontinence is a natural part of ageing, an inevitable part of childbirth, something to expect as a woman, and that surgery is the only treatment option[117-119]. Another perception surrounding incontinence is the associated stigma attached to such a condition, and the effect this may have on quality of life, mental health or on help-seeking[44,61,90].

2.3 DEPRESSION

Mental health is considered a National Health Priority Area in Australia[120], and of all mental health problems, depression is the most common. Depression is a serious illness which may cause both psychological and physical symptoms[121]. It has been associated with other chronic health conditions[122], including diabetes[123], asthma[124] and cardiovascular disease[125].

Depression is often not identified by either the medical practitioner or by those experiencing the illness. Concern about physical disorders, and a discounting of emotional symptoms by patients, may lead to depression being overlooked. As depression may be linked to a number of physical symptoms[126], disregarding affective indicators may negatively contribute to the holistic care of the patient. However, when consultation time is limited, it is usually impractical to delve deeper than the presenting problem.

Patients themselves may also be unaware of the signs and symptoms of depressive illness, which may impede seeking help for the condition. This concept is referred to as mental health literacy, or "the knowledge and beliefs about mental disorders which aid their recognition, management or prevention"[127].

2.3.1 Types of Affective (Mood) Disorders

When referring to depression, we are usually referring to affective or mood disorders. However there are different categories that come under the heading of affective disorders and these conditions are often identified along with depression in population studies. The major categories of affective disorders are described below.

2.3.1.1 *Depression*

Depression has been described in the International Classification of Diseases, Version 10 (ICD-10) as mild, moderate or severe and it can be characterised by the following symptoms described in Table 2.7.

Table 2.7: ICD 10 Symptoms of a Depressive Episode (F32).

Symptom
Lowering of mood, reduction of energy, and decrease in activity
Capacity for enjoyment, interest, and concentration is reduced
Marked tiredness after even minimum effort is common
Sleep is usually disturbed and appetite diminished
Self-esteem and self-confidence are almost always reduced
Some ideas of guilt or worthlessness are often present
Loss of interest and pleasurable feelings
waking in the morning several hours before the usual time
Marked psychomotor retardation
Agitation
Loss of appetite
Weight loss
Loss of libido

Table adapted from ICD-10 Mood [affective] disorders (F30-F39)[128]

2.3.1.2 *Dysthymia*

Dysthymia is a chronic depression of mood, lasting at least several years, which is not sufficiently severe, or in which individual episodes are not sufficiently prolonged, to justify a diagnosis of severe, moderate, or mild recurrent depressive disorder[128].

2.3.1.3 *Bipolar Depression*

Bipolar affective disorder is characterized by two or more episodes in which the patient's mood and activity levels are significantly disturbed, this disturbance consisting on some occasions of an elevation of mood and increased energy and activity (hypomania or mania) and on others of a lowering of mood and decreased energy and activity (depression)[128].

2.3.2 Epidemiology

The prevalence of depression varies according to the population studied, the instrument used to diagnose or screen for depression, and the definition or severity of depression analysed.

The prevalence of depression in South Australia has been most recently assessed using the face to face population survey, *the South Australian Health Omnibus Survey*[129]. The prevalence of major depression was first assessed in 1998, using the Primary Care Evaluation of Mental Disorders (PRIME-MD) Questionnaire[130]. The prevalence was found to be 6.8% in respondents aged 15 years and over, with 17.4% experiencing some depressive syndrome such as major or minor depression, dysthymia, or bipolar disorder[123]. In 2008, the same survey and questionnaire found the prevalence of major depression to be 10.7%[131]. Additionally, the *South Australian Health Monitor*, a Computer Assisted Telephone Interview (CATI) survey of respondents aged 18 years and over, using the SF-12 Mental Component Summary (MCS) to determine clinical depression, found a prevalence of 11.8% with clinical depression[132].

Overall in Australia, the *Australian National Survey of Mental Health and Well Being*, using an automated version of the Composite International Diagnostic Interview (CIDI-A)[133,134], found the prevalence of one or more depressive disorders (depressive episodes or dysthymia) in adults aged 18 years and over to be 5.8% in the 12 months prior to the interview (women 7.4%, men 4.2%)[135]. This had increased to 6.2% in 2008[136]. The recent Australian Health Survey in 2011/12 found that 9.7% of the population were affected by mood problems which included depression[137].

Recent prevalence studies regarding depression in the United States have included the *National Comorbidity Survey Replication* (NCS-R), a nationally representative face to face survey of respondents aged 18 years and over. This study used an expanded version of the CIDI, and found the prevalence of mood disorders (major depressive disorder, dysthymia, bipolar disorder I or II) in the last twelve months to be 8.9% with a major depressive disorder to be 6.7%[138]. The *National Health and Nutrition Examination Survey III* (NHANES), a combination home interview and biomedical cohort study found, using the Diagnostic Interview Schedule (DIS)[139], that the overall prevalence of a major depressive disorder was 9.5% (Whites 10.4%, African Americans 7.5%, Mexican Americans 8.0%) and for a dysthymic disorder was 6.1% (Whites 7.4%, African Americans 5.7%, Mexican Americans 7.4%)[140]. A third study from the USA, the *National Epidemiologic Survey on Alcohol and Related Conditions* (NESARC), another face to face population survey of respondents aged 18 years and over found a prevalence of lifetime major depressive disorder to be 13.2% and twelve month major depressive disorder to be 5.3%, using the Alcohol Use Disorder and Associated Disabilities Interview Schedule – DSM IV Version (AUDADIS-IV)[141].

Studies undertaken in Europe have found similar prevalences. A recent German study *Transitions in Alcohol Consumption and Smoking* (TACOS), used a German version of the CIDI, and found in a population aged 18-64 years, a prevalence of 2.5% to 3.2%[142]. The *Netherlands Mental Health Survey and Incidence Study* (NEMESIS) also using the CIDI, found a prevalence of major depression of 15.4% for a lifetime measurement and 5.8% in the last 12 months[143]. A review of European studies examining the prevalence of depression found a 12 month prevalence, again mostly using the CIDI, of 3.9% for Europe overall, with other prevalences ranging from 2.1% to 8.3% in populations 18 years and over[144].

A review of studies concerning the prevalence of depression in the Asia Pacific region, including Australia, mostly using the CIDI found rates of major depression in the last 12 months ranging from 1.7% to 6.7%[145].

The prevalence of depression in Australia from recent studies described about ranges from approximately 5.0% to 10.0% of the population

2.3.2.1 ***Comorbidities***

There is very strong evidence for the association of all types of chronic illness, especially for the National Health Priority Areas[120] of heart disease, stroke, diabetes mellitus, asthma, cancer, arthritis and osteoporosis, and depression and anxiety[146.] Depression has also been shown to be a risk factor for physical illness and for premature death[147].

Studies using the *South Australian Health Omnibus Study*, have identified the prevalence of major depression in people who have been diagnosed with asthma to be 22.1%[148], and in those diagnosed with diabetes to be 23.6%[123].

Clinical studies examining depression in conjunction with medical or chronic illness in general include a study from the USA, looking at ambulatory medical outpatients and using the Beck Depression Inventory (BDI)[149,150] with a cut point of 13 or greater for mild depression and 17 for moderate depression, found that of patients attending the clinic for a medical reason, the prevalence of mild depression over their two studies was either 13.6%, or 14.4% and for moderate depression was 8.6% or 6.2%. For those patients receiving a routine physical examination, the prevalence of mild depression was 8.5% and 1.7% for moderate depression[151].

A German study specifically focussing on chronic disease, using a panel of patients with chronic illness, administered the General Health Questionnaire 12 (GHQ-12)[152] and found that patients with chronic somatic disease have a higher probability of a mental disorder, as indicated by the GHQ (mean score 2.01), than patients from a community sample (mean score 1.11)[153]. Interestingly, when screening for depression in chronic conditions, approaches need to be attuned to the differing perceptions held by patients[154].

2.3.3 Diagnosis

2.3.3.1 *Measurement*

The clinical diagnosis of a depressive illness, is usually based on an interview criteria established by the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)[126]. These criteria are outlined in Table 2.8.

Table 2.8: DSM-IV Symptoms of a Major Depressive Episode.

Symptom
A. At least one of the following three abnormal moods which significantly interfered with the person's life:
1. Abnormal depressed mood most of the day, nearly every day, for at least 2 weeks.
2. Abnormal loss of all interest and pleasure most of the day, nearly every day, for at least 2 weeks.
3. If 18 or younger, abnormal irritable mood most of the day, nearly every day, for at least 2 weeks.
B. At least five of the following symptoms have been present during the same 2 week depressed period.
1. Abnormal depressed mood (or irritable mood if a child or adolescent) [as defined in criterion A].
2. Abnormal loss of all interest and pleasure [as defined in criterion A2].
3. Appetite or weight disturbance, either:
i. Abnormal weight loss (when not dieting) or decrease in appetite.
ii. Abnormal weight gain or increase in appetite.
4. Sleep disturbance, either abnormal insomnia or abnormal hypersomnia.
5. Activity disturbance, either abnormal agitation or abnormal slowing (observable by others).
6. Abnormal fatigue or loss of energy.
7. Abnormal self-reproach or inappropriate guilt.
8. Abnormal poor concentration or indecisiveness.
9. Abnormal morbid thoughts of death (not just fear of dying) or suicide.
C. The symptoms are not due to a mood-incongruent psychosis.
D. There has never been a Manic Episode, a Mixed Episode, or a Hypomanic Episode.
E. The symptoms are not due to physical illness, alcohol, medication, or street drugs.
F. The symptoms are not due to normal bereavement.

Table adapted from American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)[126]

2.3.3.3 *Screening and Scales*

In order to identify or diagnose depression, it is useful to screen potential patients to determine whether they may need further psychiatric assessment. A number of different scales have been developed with the purpose of screening for depression and other affective disorders in different populations, using either the criteria mentioned previously, or information based on this.

The Primary Care Evaluation of Mental Disorders (PRIME-MD), is a two part evaluation that was developed in order to diagnose some of the most common mental disorders seen in primary care[130]. There are five different modules included as part of the Clinical Evaluation Guide, and these may or may not be administered as required.

The modules, which reflect the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R)[155], include Mood, Anxiety, Alcohol, Eating Disorder and Somatoform. The PRIME-MD Mood Module, alternatively known as the Patient Health Questionnaire 9 (PHQ-9), has been used and validated in a number of population studies measuring depression[156-159].

Two components of the widely used Short-Form 36 (SF-36)[160], the Mental Health Inventory (MHI-5)[161,162], as well as the Mental Component Summary (MCS)[160] have been evaluated as screening tools for depression. For the MHI-5, a cut point of 52 or below has be shown to screen for depression, and for the MCS, the screen cut point is a score of 42 or below.

Other screening instruments for depression that have been widely used in population studies include the Beck Depression Inventory (BDI)[149,150,163], the General Health Questionnaire (GHQ-12)[152,164], the Composite International Diagnostic Interview (CIDI)[134] and its pre cursor the Diagnostic Interview Schedule (DIS)[139], as well as the Centre for Epidemiologic Studies Depression Scale (CES-D)[165]. These screeners are the most commonly used in the community, however there are others used for specific populations and these are outlined in Table 2.9 below.

Table 2.9: Screening Questionnaires for Depression

Scale	Description
Primary Care Evaluation of Mental Disorders-Patient Health Questionnaire (PRIME MD PHQ)[130]	Evaluates the four groups of mental disorders (mood, anxiety, somatoform, and alcohol) most commonly encountered in the general population and primary care settings and eating disorders
Short Form 36 (SF-36) Mental Health Inventory (MHI 5) or Mental Component Summary (MCS)[160-162]	MHI-5: 5 item Short screening questionnaire for mental health, with a cut-off of 52 in detecting major depression. MCS: screen cut point is a score of 42 or below
Beck Depression Inventory (BDI)[161,162]	Designed to measure the behavioural manifestations of depression, able to discriminate effectively among groups of patients with varying degrees of depression
General Health Questionnaire (GHQ-12)[152,164]	The most widely used screening test, available in versions as short as 12 items and as long as 60
Diagnostic Interview Schedule (DIS)[139]	Used in the Epidemiologic Catchment Area survey. It provides information about the lifetime occurrence of all the symptoms in each of the disorders it covers, and the age at which the first and last symptom of each diagnosis was experienced.
Composite International Diagnostic Interview (CIDI)[134]	Written at the request of the World Health Organization (WHO) and the United States Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA). Allows administration by lay interviewers and scoring of diagnoses by computer and includes severity.
Centre for Epidemiologic Studies Depression Scale (CES-D)[165]	20-Item self-report depression symptom scale to measure depressive mood in the community
Hamilton Depression Rating Scale (HDRS)[166]	Used only on patients already diagnosed as suffering from affective disorder of depressive type.
Major Depression Inventory (MDI)[167]	Measures DSM-IV and ICD-10 diagnoses of major (moderate to severe) depression by self-reported.
Zung Self-Rating Depression Scale (SDS)[168]	Quantitates depression as a disorder, using the diagnostic criteria of the presence of a pervasive depressed affect
Geriatric Depression Scale (GDS)[169,170]	Relevant self-report for the assessment of depression in the elderly
Cornell Scale for Depression in Dementia (CSDD)[171]	Clinician administered instrument that uses information from interviews with both the patient and a nursing staff member, a method suitable for demented patients
Bradburn Affect Balance Scale (BABS)[172]	A depression measure composed of questions from several scales, a question about current happiness, and a question on life satisfaction
General Hospital Depression Scale (GHDS)[173]	Composed of six items. A total score equal to or higher than three is suggestive of depression
Freiburg Personality Inventory (FPI)[174]	German questionnaire focused on anxiety and anger
Wakefield Assessment Inventory[175]	A self-assessment inventory for measuring severity of depressive illness
Crown – Crisp Experiential Index[176]	A short clinical diagnostic self-rating scale for psychoneurotic patients Also called the Middlesex Hospital Questionnaire
Minnesota Multiphasic Personality Inventory (MMPI)[177,178]	Generally applicable to all adult groups, difficulty was experienced in using it with mental defectives
Hospital Anxiety and Depression Scale (HADS)[179]	14-item questionnaire includes 7 items to assess anxiety and 7 to assess depression in a hospital outpatient clinic
Brief Psychiatric Rating Scale (BPRS)[180]	Eighteen 7-point rating scales assess a variety of psychiatric symptoms

2.3.3.4 *Severity*

The severity of depression follows a continuum that has no clear cut-off scores in epidemiological studies, possibly due to the wide range of effects on the individual[181]. A Major Depressive Episode has a specific definition described by the DSM-IV, and there are similar criteria for dysthymia[126].

The CIDI was expanded to include detailed questions about the severity of mental disorders, in order to identify cases that may be self-limiting and have less need for treatment[138]. Table 2.10 describes the criteria used with this questionnaire to identify the severity of cases.

Table 2.10: Severity categories for mental disorders (CIDI)

Severity	Impact
Mild	Other cases not considered below
Moderate	Suicidal gesture, plan or ideation Substance dependence without serious role impairment At least moderate work limitations due to mental or substance disorder Any disorder with at least moderate role impairment in 2 or more domains of the Sheehan Disability Scale (work role performance, household maintenance, social life and intimate relationships)
Serious	12 month suicide attempt with serous lethality intent Work disability or substantial limitation due to a mental or substance disorder Positive screen for non-affective psychosis Bipolar I or II disorder Substance dependence with serious role impairment Impulse control disorder with repeated serious violence Any disorder that resulted in 30 more days out of role in the year

Table adapted from Kessler et al 2004[182]

The International Classification of Diseases has also classified depression by severity considering the symptoms described previously in Table 2.7. The criteria for severity are described in Table 2.11.

Table 2.11: Severity categories for depressive disorder (ICD-10 F32)

Severity	
Mild depressive episode	Two or three of the symptoms are usually present. The patient is usually distressed by these but will probably be able to continue with most activities.
Moderate depressive episode	Four or more of the above symptoms are usually present and the patient is likely to have great difficulty in continuing with ordinary activities.
Severe depressive episode without psychotic symptoms	An episode of depression in which several of the above symptoms are marked and distressing, typically loss of self-esteem and ideas of worthlessness or guilt. Suicidal thoughts and acts are common and a number of "somatic" symptoms are usually present.
Severe depressive episode with psychotic symptoms	An episode of depression as described, but with the presence of hallucinations, delusions, psychomotor retardation, or stupor so severe that ordinary social activities are impossible; there may be danger to life from suicide, dehydration, or starvation. The hallucinations and delusions may or may not be mood-congruent.

Table adapted from ICD-10 Mood [affective] disorders (F30-F39)[128]

2.3.3.5 *Mental Health Literacy*

Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”[183]. The health literate patient is able to understand available treatments and critically appraise the information that they obtain from many different sources[184].

The World Health Organization acknowledges the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy is critical to empowerment as it can improve people's access to health information and their capacity to use it effectively[185].

Often, possibly because of the stigma attached to depression, symptoms are not recognised or reported to the health care provider[186]. This may be due to the lack of awareness about the symptoms of mental illness. Mental health literacy considers one’s ability to recognise mental disorders as well as beliefs about treatment effectiveness. These beliefs may aid in the recognition, management and prevention of mental health conditions[127].

2.3.4 Impact

2.3.4.1 *Psychosocial*

Depression affects most aspects of life including education, career, family, relationships and sleep. Working life may be affected due to absenteeism and reduced productivity. Children may suffer emotionally and cognitively due to a mother's depressive illness, and relationships between spouses may deteriorate. Families need to adapt to accommodate the depressive illness[186-191].

Depression has been found to be significantly associated with lack of social support in the elderly as well as in women[192,193]. It has been recommended that those with depression should be encouraged to establish and maintain supportive relationships which may enhance self-appreciation and skills to cope with negative mood. This is likely to improve psychological well-being and health-related quality of life[194].

2.3.4.2 *Quality of life*

Depression has been found to detrimentally affect the physical, social, role functioning, perceived current health, and bodily pain dimensions in the pre cursor to the SF-36, the Medical Outcomes Study[195]. The functioning associated with depressive symptoms, was comparable with or worse than that associated with eight other chronic medical conditions. It was also found that depression with other chronic medical conditions had unique and compounding negative effects on patient functioning.

2.3.4.3 *Risk factors*

Depression may be a result of biological or psychological factors, however environmental and social factors have a major part to play. There may be a mix of both external and internal factors that may contribute towards depression. Recent life events may trigger a depressive response that may already be inherent. Some of the risk factors for depression have been summarised in Table 2.12.

Table 2.12: Risk factors for depression

Risk Factors	Protective Factors
Environmental and social	
Social disadvantage (e.g. poverty, unemployment)	Good interpersonal relationships (supportive relationship with one person / parent, perceived social support)
Family discord (e.g. relationship break-up, conflict, poor parenting practices)	Family cohesion (e.g. positive parent child relations)
Parental mental illness	Social connectedness
Child abuse (e.g. physical and sexual abuse, neglect)	Academic / sporting achievements
Exposure to adverse life events (e.g. bereavements, family separation, trauma, family illness)	
Caring for someone with a chronic physical or mental disorder	
For older adults, being in residential care	
Biological and psychological	
Parental mental disorder and family history of depression	Easy going temperament
Being a female adolescent	Optimistic thought patterns
High trait anxiety and pre-existing anxiety disorders, substance misuse, conduct disorder	Effective coping skills repertoire (e.g. social skills, problem solving skills)
Temperament – reacting negatively to stressor, and personality trait of neuroticism	
Negative thought patterns(pessimism, learned helplessness)	
Avoidant coping style	

Table adapted from Commonwealth Department of Health and Aged Care, 1998[120]

2.3.4.4 *Economic*

It is estimated that the annual cost of mental illness in Australia in 2006 was approximately $20 billion, which includes the costs from loss of productivity and participation in the workforce[196]. The cost of depression in South Australia has been calculated in 1998 prices at A$1921 million per annum, using a burden of disease service provision perspective, and at A$2800 million per annum, using the Assessment of Quality of Life (AQoL) instrument[197].

In Europe, estimates of costs vary by country and methodology, and in a review that calculated per patient cost at 2003 prices, this varied from €1171 per annum in Spain to €5092 per annum in the United Kingdom, and for total country wide costs, €260 million in Sweden and €450 to €725 million in the United Kingdom[198].

In the United States for 1990, one study has calculated the cost of affective disorders approximately US$30.4 billion[199] using a regression analysis timing model, and another has established a cost of US$43.7 billion per annum looking at direct costs, mortality costs and morbidity costs using a human capital approach[200].

2.3.5 Treatment

There are a number of different options for the treatment of depression. These include drug therapies, such as the use of antidepressants, as well as other therapies. Some common antidepressant drugs include the selective serotonin reuptake inhibitors (SSRIs), the norepinephrine-reuptake inhibitors, the dual action antidepressants, the monoamine oxidase inhibitors (MAOIs), as well as other new and emerging therapies. Often drugs such as mood stabilizers and antipsychotic agents may also be used[201]. Other therapies used to control depression include the controversial electroconvulsive therapy (ECT), as well as psychotherapy[201].

2.4 PSYCHOSOCIAL FACTORS

2.4.1 Help-Seeking

Help-seeking describes the behaviour undertaken by someone experiencing a problem to actively seek assistance from others[202]. Help-seeking relies on other people. As a coping strategy, it requires the use of interpersonal skills to form social relationships. These relationships are either informal or formal, whereby informal help-seeking engages friends and family, and formal help-seeking seeks the advice of experts, those trained to provide help such as health professionals. Help-seeking can contribute to delayed or foregone care[203]. The majority of research in this area has been concerned with mental health problems or research with specific groups of people, such as the elderly or young people, or those with specific conditions. Research has not often been discussed regarding the help-seeking behaviour for any condition using a community sample.

Three different stages in help-seeking for mental health problems have been identified. These are: the recognition that there is a problem; the belief that outside help is needed; and the eventual contact with a helper or helping agency[204]. These stages can also be observed with other chronic conditions.

Delays in seeking appropriate medical attention are known to lead to worse health outcomes for the individual[203]. However, self-reports of delay reflect the subjective experience of help-seeking[205]. It is necessary for the individual to consider that they have problem and that this problem has a solution for them to seek help.

There are a number of barriers to help-seeking, often unique to particular conditions. Most research concerning barriers to help-seeking is also based on specific conditions or populations. These can include a lack of knowledge about a condition and of available treatment[25], or the stigma and beliefs associated with a condition[62,90]. If individuals do not perceive that they are at risk of a condition, they are less likely to seek help[206].

2.4.2 Epidemiology

Help-seeking behaviour varies by different population groups and types of conditions. Literature suggests that men seek help for health problems less than women, even when accounting for women's reproductive health needs[207]. There are a number of different reasons for this, stemming from biological, psychological and sociological explanations[208].

Older adults are less willing to seek psychological services for mental health problems than younger people due to increases in negative attitudes about mental illness[209]. However other cross sectional studies have shown that males, young people and people living in affluent areas, were the least likely to seek help for mental health problems[208,210].

Racial differences in help-seeking behaviours have also been found. One study observed the use of psychological or social services by community college students, and found that black students used these services less than white students[211].

Help-seeking behaviour has also been discussed in the context of a number of different chronic conditions. A study from the Netherlands discussing hearing impairment found that the level of help-seeking associated with this condition was 27.0%, and this was not related to either age or sex[212]. For a condition such as insomnia, an American study found that 48.0% sought help, and this was associated with an increasing number of co-morbid conditions and a poor rating of overall health[213].

Help-seeking in people with incontinence and depression has been found to be below 50% in both cases[214,215]. Many people with these potentially manageable conditions are missing out on advice which may significantly contribute to their quality of life.

2.4.3 Impact

2.4.3.1 ***Quality of Life***

Health related quality of life may be used to assess the health outcomes of chronic conditions, particularly those of physical and mental functioning. Quality of life can be described as a multidimensional concept measured in terms of an individual’s own subjective perceptions. It may include the dimensions of physical health and functioning, mental health, social functioning, role functioning, satisfaction with treatment and concerns about future and general wellbeing[45] and different quality of life scales place different emphasis on each of these concepts. It enables the impact of a condition on the life of the person experiencing it to be quantified, in addition to biomedical measures.

Quality of life can be used as a measure to compare the outcomes of different diseases groups with each other and with the general population, and also between different populations of people with a certain condition, as well as different sub types of a condition.

Quality of life scales can also be used to determine the burden of disease upon an individual or a population. Some can also be used to calculate a utility index, which enables disease states to be ranked in order of burden[216].

The quality of life in people with incontinence[28] and depression[217] has been found to be significantly lower than that of the general population, on many different dimensions.

2.4.3.2 *Social Capital / Cohesion*

Social capital describes aspects of social networks, relations, trust, and power, and can be a function of either the individual or a geographical entity[218]. Social capital also has a role to play in determining health outcomes. In public health, social capital refers mostly to levels of trust, community participation and community or individual networks.

There is a large body of literature discussing the connection of social capital with health[219]. A lack of social capital resulting in social exclusion has an association with poorer self-rated health[220]. Social capital, in the form of informal networks, help, and control, has been found to be directly or indirectly positively associated with better mental health[221]. The ability of the individual to cope with events may be enhanced with social support, as the individuals cognitive appraisal of events may also be changed[222].

The social capital of people experiencing incontinence[86] and mental health problems[218] has been found to have a great impact on health outcomes and management of these conditions, as both conditions often rely on support from others to reduce the overall impact on the course of the illness and their lives.

2.5 URINARY INCONTINENCE AND DEPRESSION

2.5.1 Epidemiology

An association between incontinence and depression has been demonstrated in several studies[15,16,27-30,44]. Explanations proposed for the relationship between urinary incontinence and depression include biochemical models, such that in experimental animals lowering monoamines such as serotonin and noradrenaline in the central nervous system lead to depression and urinary frequency and a hyperactive bladder[223]. Depression may not only be a result of persistent urinary incontinence, but individuals with altered monoamines in the central nervous system could manifest both depression and an overactive bladder[24].

The prevalence of depression in those experiencing urinary incontinence has been consistent across many studies and is similar for both clinically based studies and population surveys internationally[42,224]. Some studies determine actual prevalence, some quote mean scores from depression scales, and some allude to a higher risk of depression in the incontinent population, when compared with the general population[53,225].

Clinical studies include research where the sample is derived from a clinic, hospital or practice where the respondents may already be receiving treatment for incontinence, or for other medical problems, such as gynaecological, or menopause clinics, or even general practices. Studies in this area have generally had a small sample size, and are not useful for determining the overall population prevalence of incontinence. However, a diagnosis of the specific type of urinary incontinence is usually medically verifiable in these situations, instead of relying on self-report. Various instruments have been used to determine depression in those with urinary and anal incontinence, from self-assessment to psychiatric evaluation.

Population studies regarding incontinence and depression have, in general, examined a higher number of cases leading to greater statistical power, and also identified a greater number of people who have not been diagnosed with, received treatment, or even sought help for either of these conditions. However, the majority of these studies have only examined women or the older population.

This review will consider studies where the most common method to determine the associations between incontinence, depression and help-seeking is to find a statistically significant difference. There is general agreement however, that tests of statistical significance do not provide information about the practical importance or clinical significance of research results. There are ways of determining if differences between groups are both statistically and clinically significant. The most common methods used to determine the clinical significance of the difference between two groups is to calculate the effect size (ES), the percent improvement or the number needed to treat (NNT). These studies are outlined in Table 2.13 below.

The research described here is classified a number of different ways. Studies have been classified by the type of incontinence discussed, the population examined, including age, sex and region, and the methodology used. Primarily, the prevalence of depression in those with incontinence has been discussed, commencing with studies that have the most rigorous methodology, such as population studies with face to face interviews using validated questionnaires, through to clinical studies with questionnaires distributed to non-randomised populations.

Some studies comment only on the statistical associations between incontinence and depression, and these have been included. However where a lack of research is found for a particular condition or population group, the review has been extended to include other forms of mental illness. Reviews of the literature for each area have also been commented upon. A comprehensive summary of studies describing the associations between incontinence and depression is provided in Table 2.13.

2.5.2 Population Studies: Men and Women

2.5.2.1 *Telephone Interviews*

Two Computer Assisted Telephone Interviewing (CATI) surveys from the USA, have determined the prevalence of depression in respondents with urinary incontinence. One of the studies found, in people aged 40 years and over, that 20.6% of respondents with urinary incontinence, self-reported feeling depressed[21]. The other study found, using a screening questionnaire for depression in respondents aged 60 years and over, that 43.0% of respondents with urinary incontinence had depression, and this occurred in 24.0% of men and 38.0% of women[224]. An international study (France, Germany, Italy, Spain, Sweden and the UK) concentrating on people with an overactive bladder and incontinence between the ages of 40 to 64 years, found the prevalence of depression in this group to be 39.8%[42].

To determine associations of depression in men and women with urinary incontinence, a number of population studies have used the CES-D, with a cut-off score of 16 or greater. One American study found, administering the CES-D via CATI to adults 53 years and older, a statistically significant association between depression and urinary incontinence[226]. A third American study, this time looking at adults aged 18 years and older, using the CES-D in CATI interviews, had a similar statistically significant finding[225].

2.5.2.2 *Face to Face Interviews*

Another study based in the USA, using the BABS[172] to determine depression found, interviewing respondents aged over 60 years in their own homes, that urinary incontinence was weakly related to depression[227]. A study from Korea using the CES-D looked at incontinence and depression with quality of life, but did not look at the prevalence of these in combination, but did find that Lower Urinary Tract Symptoms (LUTS) and depression were the principal predictors of quality of life in older adults[228].

Another US study aligned with a walking intervention study found that people with depression had a higher prevalence of urinary incontinence[229].

2.5.2.3 *Mixed Methods Population Studies*

Studies that included a combination of face to face and telephone interviews include a study of African Americans in the US aged 52 to 68 years and found a prevalence of depression in those with incontinence of 38.8%[230]. An Australian study of those aged 65 years and over found that women with any incontinence had a higher negative affect, and men with stress urinary incontinence also had a higher negative affect[53].

2.5.2.4 *Internet Panels*

Increasingly, some of the more recent studies have made use of population panels where participants are able to answer questionnaires over the internet. One such study, known as the EpiLUTS from the US, UK and Sweden that interviewed 30,000 men and women aged 40 years and over found that men and women with multiple LUTS reported the lowest levels of urinary-specific quality of life and generic health, and had the highest rates of clinical anxiety and depression[231], and also found that men with mixed urinary incontinence had the highest prevalence of depression (42.1%), and women with stress urinary incontinence plus other incontinence had a prevalence of depression of 34.9%[232].

2.5.2.5 *Other Mental Health Issues*

Other population studies examining mental health issues in both women and men with urinary incontinence include examination of psychological distress using face to face interviews. A psychological distress prevalence of 28.5% in people with urinary incontinence was found in the USA[27,233,234]. The same author looked at anxiety secondary to urinary incontinence and found that people with anxiety disorders were more likely to report urinary incontinence related functional impairment, specifically when there were changes to their day to day routines[235].

2.5.3 Population Studies: Women

2.5.3.1 *Face to Face Interviews*

International population studies considering women only, include three studies from the USA that used the CES-D to determine the prevalence of depression in people with urinary incontinence. The first of these studies interviewed women aged 50 to 69 years, and found a prevalence of depression of 14.2% in those with mild urinary incontinence and 22.3% in those with severe urinary incontinence[236]. The second study found a prevalence of depression in women aged 70 years or more, of 24.0% for those with urinary incontinence less than weekly, and 35.6% in those who were incontinent more than once a week, In those women with urge urinary incontinence, the prevalence of depression was 12.0% and in those with stress urinary incontinence it was 9.0%[237]. A third study found the prevalence of incontinence with depression to be 11.0% and although major depression predicted onset of urinary incontinence in a population-based sample of at-risk, community-dwelling women. Incontinence did not predict onset of depression[238].

A further USA study looked at depression symptoms in women aged 30 to 79 years and found urinary incontinence was associated with depression symptoms[239].

2.5.3.2 *Telephone*

A Canadian CATI study undertaken with 69,000 women aged 18 and over found the prevalence of major depression in those with urinary incontinence to be 15.5% and this was significantly higher than the prevalence in women without incontinence[31]. Another CATI study concerning women over the age of 52 who were veterans found a prevalence of stress urinary incontinence and depression using the CIDI to be 32.8%, and urge or mixed incontinence to be 43.5%[240].

2.5.3.3 *Mailed Questionnaires*

One of the only Australian population studies concerning urinary incontinence and depression, considered women only. The study was part of the ongoing Women's Health Australia (WHA) project, where over 40,000 women between the ages of 18 and 75 years filled out postal questionnaires regarding their health, of which questions regarding incontinence, as well as the SF-36 were included[92]. Respondents with urinary incontinence had lower scores on the MCS of the SF-36 than those without incontinence, and the youngest group had a mean score of 40.7, where a score of 42 or less on the MCS indicates clinical depression[160].

One American study using the BDI though a mailed questionnaires, to detect depression (score > 13) in women aged 27 to 90 years with urinary incontinence, found a prevalence of 22.0%, where the incidence of depression in the general population using this instrument is 6.0%[241]. Another study using the CES-D in a mailed questionnaire, found statistically significant higher scores for depression in women aged 60 years and over with urinary incontinence across time[16].

Another American study, using the PRIME-MD PHQ in women 30 to 90 years, found a prevalence of major depression of 6.1% in women with urinary incontinence, with a prevalence of 3.7% in the general sample[242,243].

A further study from Sweden examining women used self-report of feeling down and blue to determine depression, from mailed questionnaires. Depression in women aged 50 to 64 years was statistically significantly associated with urinary incontinence[244].

In the UK, a study found that in women 40 years and older the prevalence of urinary incontinence with depression using the HADS[179] was 38.0%[245]. Similarly in the Netherlands, women aged 20 to 70 years, had a prevalence of incontinence with depression of 42.8% but urinary incontinence was not found to be a risk factor for depression[246]. In a study of women aged 40-44 years in Norway using the HADS the prevalence of incontinence with depression was 11.8%[247]. The Nurses' Health Study in the USA also examined incontinence with depression. Overall they found a prevalence of 28.9% overall[248], and when split, more frequent urinary incontinence and greater severity were significantly associated with higher prevalence of high depressive symptoms in both black and in white women[249].

2.5.3.4 *Internet Panels*

One women's study was a twin study undertaken via the internet and this found a prevalence of incontinence with depression to be 11.8%[250].

2.5.4 Clinical Studies: Men and Women

One American study examining both men and women presenting to an incontinence clinic with a diagnosis of urinary incontinence, verified using urodynamic tests, found the prevalence of depression, using the BDI (score > 12), to be 30.0%. The prevalence of depression in those with urge urinary incontinence was found to be 60.0%[23]. Another study from the Netherlands with men and women older than 25 years found that depression was associated with urinary incontinence (OR = 1.81)[251].

2.5.5 Clinical Studies: Women

Studies examining women only, include another American study, from a urology and urogynaecology clinic found, using a battery of depression questionnaires including the PRIME-MD PHQ, that the prevalence of depression in women aged 18 to 90 years was 16.0% for women with urinary incontinence, 21.0% for those with urge urinary incontinence, 3.0% for those with stress urinary incontinence and 26.0% for those with mixed urinary incontinence[252].

Another American study found in women aged 30 years and over, that the prevalence of depression (using the BDI) in women with incontinence was 30.0%[253].

A study from Finland, using the HDRS, found for women aged 28 years and over, the prevalence of depression in urinary incontinence was 26.0%, for urge incontinence was 44.0% and for stress incontinence was 17.5%[24]. A large, much publicised study from Canada, using the CIDI-SF found a prevalence of major depression in women to be 15.5% and in those aged 18 to 44 years to be 30.0%, compared with a prevalence in the general sample of 9.4%. However the prevalence of urinary incontinence in this sample was found to be 3.2%[31]. In Brazil, the prevalence of depression (GHDS) in women with incontinence was 39.6%[254], and in Israel, in urge urinary incontinence, 22.0% using the CES-D[255].

Other clinical studies that do not report prevalences, but have found associations between incontinence and depression include a German study of women with a mean age of 54 years, using the BDI and Freiburg Personality Inventory (FPI) [174], that found a statistically significant difference in scores on the FPI of incontinent women, when compared with those not experiencing incontinence (mean age of 38 years)[85]. Two British studies by the same group found, using the Wakefield Assessment Inventory[175] and the Crown – Crisp Experiential Index[176], that the women with incontinence were more depressed than the general population, and 25.0% of these women were as depressed as psychiatric inpatients[256,257]. Another British study examined depression in women with stress urinary incontinence before and after surgery (mean age 52 years), using a depression screener, and found an improvement in their mental health[18].

Comparing the prevalence of depression for the different types of urinary incontinence, a clinical study of Italian women aged 39 to 61 years, using the CES-D, found no difference in scores between patient with stress incontinence, detrusor instability (a similar condition to urge incontinence) and mixed incontinence, although scores for all three were above or close to the cut-off for depression[258]. A similar finding was reported by an American study using the Minnesota Multiphasic Personality Inventory (MMPI)[177], which found that women with incontinence scored higher for depression than controls, but no differences were found between those with detrusor instability and stress urinary incontinence[88].

A number of other clinical studies around the world have examined mental health issues in women with incontinence including anxiety, where no differences in its prevalence between detrusor instability and stress urinary incontinence were found[259]. Another study from the Netherlands examined psychosocial impact, and women with urge incontinence experienced a greater impact than those with stress incontinence, as did those with more severe incontinence[37]. However in the same group of women no difference was found between the types of incontinence for psychological issues[260].

2.5.6 Clinical Studies: Men

A study concerning men only from Sweden, addressed Lower Urinary Tract Symptoms (LUTS) and looked at sadness[261]. The prevalence of sadness in men with urge incontinence was 30.0% and in stress incontinence was 37.0%. No clinical studies looking at the prevalence of depression in an Australian population with urinary incontinence have been undertaken.

2.5.7 Reviews

Reviews of the literature regarding the association between urinary incontinence and depression have been completed. One American review particularly concentrates on articles from the 1980s, not mentioned in this current review, that name psychological distress and depression as outcomes of urinary incontinence, as well as giving reasons why this may be the case[38]. Other more recent reviews of this topic have discussed the psychological impact of incontinence and the management of the associated psychological morbidity[262], the psychosocial and societal burden of incontinence particularly in the aged[263], the cognitive barriers and safety-behaviours involved in the development and maintenance of emotional distress in patients with urinary incontinence[264], and the quality of life in people with incontinence particularly looking at anxiety and depression[265].

2.5.8 Studies with contrary findings

A number of clinical studies have reported findings which have conflicted or do not provide sufficient evidence to support the association between incontinence and depression, or that there is a difference in the prevalence of depression in those experiencing urge incontinence and those with stress incontinence.

One study based in a German urogynaecological clinic found a statistically significant difference in the prevalence of depression between women with stress incontinence and healthy women using the FPI, and no association for urge incontinence. However the incontinent and healthy groups in this case were not homogenous, and this study concentrated on sexual dysfunctions and pelvic floor symptoms[85].

Another study from Dutch general practice, found no difference in the psychological characteristics of patients with urge incontinence and other types of incontinence, however they did not specifically measure depression and again the groups compared were not homogenous[260].

2.5.9 Summary of studies about Urinary Incontinence and Depression

Table 2.13 summarises the studies described above. The studies outlined here have been undertaken in both men and women, together and separately, using different methodologies, and instruments, in different countries, cultural and age groups. Whenever possible the prevalence of comorbid depression in the presence of urinary incontinence has been stated, and this has been reported here at anywhere from 6.0% to 43.0%. The gold standard methodologies, such as face to face population surveys report a prevalence of 15.0% to 30.0% for women, depending on the scales used, the age group and the year. The studies describe here usually report a significantly higher rate of depression amongst those with incontinence. Comparing the rates of depression in those with urinary incontinence, with that of the overall population (ranging from 5.0% to 15.0% as discussed previously), we can estimate that the burden of depression in those with urinary incontinence is greater. However, in order to conclude that this is the case within our population, we must undertake research that explores the difference in the prevalence of depression in those with and without urinary incontinence, using quality population studies and validated instruments.

Table 2.13: Urinary Incontinence and Depression Studies

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Urinary – Population Studies – Women and Men - Telephone						
Dugan, E. et al (2000)[224]	USA, North Carolina	230/668 >60 years	Community residents RCT of primary care practices: CATI survey	Self-report, last 3 months plus severity	Screener for depression	UI 52.5% **D & UI** 43.0% D & UI (W) 38.0% D & UI (M) 24.0%
Fultz, N et al (2001)[21]	USA, Michigan	206/1322 ≥40 years	CATI, population study	Self-report, past 6 months, severity	Self-report past week	UI 15.6% **D & UI** 20.6%
Stewart, W. F. et al (2003)[225]	USA, Baltimore	538/5204 ≥18 years	CATI, population study	OAB, UI, self-report	SF36 CES-D	OAB 16.5% OAB & UUI 6.1% OAB & D ss Higher CES-D scores
Fultz, NH. et al (2005)[226]	USA, Michigan	?/4987 ≥53 years	CATI, population study	Self-report, last month	CES-D	UI (W) 21.0% UI (M) 6.0% SS assoc with dep
Irwin D.E. et al (2006)[42]	France, Germany, Italy, Spain, Sweden, UK.	1272/11521 40–64 years	CATI cross-sectional population-based survey (Spain direct interviews)	OAB with UI (frequency, urgency, urge incontinence, or nocturia) Self report, past 12 months	Asked about the negative impact associated with OAB symptoms on emotional well-being.	OAB with UI & D 39.8%
Urinary – Population Studies – Women and Men – Face to Face						
Herzog, A. R. et al (1988)[227]	USA, Michigan	1288 >60 years	Community residents qnairre in own home	Self-report, past 12 months	Bradburn Affect Balance Scale	**D & UI** Weakly related to dep
Bogner, H. R. et al (2002)[235]	USA, Baltimore	747 ≥ 50 years	As above	As above	Emphasis on Anxiety	
Bogner, H R. et al (2002)[233]	USA, Baltimore	158/781 ≥ 50 years	Community residents, highly structured interviews	Self-report, past 12 months	Psychological distress GHQ score ≥ 4 for caseness	UI 20.0% PD & UI 28.5%
Bogner,H R. et al (2004) [27]	USA, Baltimore	747 ≥ 50 years	As above analysis by race	As above	As above	As above
Smith et al (2010)[229]	USA, Los Angeles	572 Latinos >= 60 years	Randomised trial of a walking intervention Face to face	Self-report – how often do you leak urine	Geriatric Depression Scale (GDS)	UI = 26.9% UI W = 29.5% UI M = 18.3% D assoc with higher UI

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Song et al (2012)[228]	Korea, Jeju	171 61-94 years	Cross sectional Face to face	Involuntary urine loss once per month or more frequently during the previous 6 months.	Korean CES-D	D = 18.6% UI = 22.2% (no combination – only looked at QoL)
Urinary – Population Studies – Women and Men – Mixed Methods						
Malstrom T.K. et al (2010)[230]	USA, Missouri	853 African Americans 52 -68 years	Cross sectional in home and CATI	Self-report, past 12 months	CES-D	UI 12.1% **D & UI 38.8%**
Sims et al (2011)[53]	Australia, Melbourne	796 >= 65 years	Cohort Study, Face to face / CATI	Self-report: Ever accidently passed urine Plus urgency question.	Psychogeriatric Assessment Scales	UUI 28.0% SUI 21.0% W UI Higher negative affect M SUI Higher negative affect
Urinary – Population Studies – Women and Men – Internet Panels						
Coyne et al (2009)[231]	USA, UK, Sweden	30000 >= 40 yrs Mean M = 53.9 yrs Mean W = 60.3 yrs	EpiLUTS Cross sectional population study via internet panels	Patient Perception of Bladder Condition (PPBC) OAB Questionnaire Short Form (OAB-q SF)	The Hospital Anxiety and Depression Scale (HADS)	D M 29.8% D W 37.6% M and W with multiple LUTS reported the lowest levels of urinary-specific HRQL and generic health, and had the highest rates of clinical anxiety and depression
Coyne et al (2012)[232]	USA, UK, Sweden	30000 >= 40 yrs Mean M = 53.9 yrs Mean W = 60.3 yrs	EpiLUTS 2ndary analysis of Cross sectional population study via internet panels as above	Patient Perception of Bladder Condition (PPBC) OAB Questionnaire Short Form (OAB-q SF)	The Hospital Anxiety and Depression Scale (HADS)	UI M 45.8% UI W 67.6% M: D highest with MUI (42.1%), D & UUI plus OI (33.8%), D & SUI plus OI (31.5%). W: D highest with SUI plus OI (34.9%), D & MUI (34.7%)
Urinary – Population Studies- Women - Face to face						
Nygaard, I. et al (2003)[236]	USA, Iowa	905/5701 50 to 69 years	Population based face to face	Self-report	CES-D ≥ 16 CIDI	UI 16% **D & UI^{mild}** 14.2% **D & UI^{sev}** 22.3%

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Jackson, R. A. et al (2004) [237]	USA, Pennsylvania and Tennessee	1558 70 to 79	Health ABC Longitudinal cohort study	Self-report, Frequency (d,w,<w) Used ≥ weekly	CES-D >15	UI<w 24.0% UI≥w 35.6% D & UUI 2.0% D & SUI 9.0%
Melville J.L et al (2009)[238]	USA, Michigan	5820 Mean 59.3 years	Health and Retirement Study (HRS) Longitudinal cohort - Interviews	Self-report past year	CES-D and CIDI-SF	**UI & D 11.0%, D & UI 18.0%.** Major depression predicted onset of urinary incontinence in a population-based sample of at-risk, community-dwelling women. Incontinence did not predict onset of depression
Maserejian N. N. et al (2014)[239]	USA, Boston	3,201 30 – 79 years	Boston Area Community Health Survey, observational cohort longitudinal population survey, in person interview	Self-report and treatment status, monthly, weekly.		UI at baseline, persistence was associated with depression symptoms [monthly UI, odds ratio (OR)=2.39,
Urinary – Population Studies- Women - Telephone						
Vigod S. N. et al (2006)[31]	Canada	69,003 18 years & over	Canadian Community Health Survey Population study CATI	Do you suffer from urinary incontinence?	CIDI-SF, CCHS, HUI III	UI 3.23% D[12] 9.4% **D & UI** **(maj dep) 15.5%** **Younger + inc risk (30%).**
Bradley et al (2012)[240]	USA, Iowa	968 <=52 years Mean 38.7 years	2ndary analysis of Veterans CATI	Self-report	CIDI-SF	SUI 18.9% MUI 16.2% UUI 3.5% SUI & D 32.8% UUI/ MUI & D 43.5%
Urinary – Population Studies- Women - Mailed						
Chiverton, P. A. et al (1996) [241]	USA, New York	125 27 to 90 years	Community residents, mailed qnairre	Self-report: Uncontrolled urine loss. Excessive day toileting frequency.	BDI ≥13	**D & UI** 22.0%

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Chiarelli, P. et al (1999) [92]	Australia, Newcastle, Aust wide study	?/41724 18 to 75	Australian Longitudinal Study on Women's Health: cohort study, Population based mailed generic qnairre	Self-report	SF-36	UI by agegroup 12.8%, 36.1%, 35.0% Lower scores on MCS and PCS
Heidrich, S. M. et al (2004) [16]	USA, Wisconsin	26/103>60 years	Longitudinal study, community dwelling, mailed qnairre	Self report	Bradburn Affect Balance Scale CES-D ≥ 15	UI 25.0% **D & UI** Over time ssh dep scores
Melville, J L. et al (2005) [242]	USA, Washington	1458/3438 30 to 90 years	Population based mailed generic qnairre	Leakage at least monthly	PRIME-MD	UI 45.0% **D & UI** 6.1%
Melville, J. L. et al (2005) [243]	USA, Washington	1458/3536 30 to 90 years	Population based mailed generic qnairre	Leakage at least monthly Major Depression	PRIME-MD	UI 45.0% **D & UI (maj dep)** 6.1%
Moghaddas, F et al (2005)[244]	Sweden, Lund	2145/6642 50 to 64	Population based mailed generic qnairre and lab exam	Self-report occurrence of UI plus severity	Generic questionnaire: self-report feeling down and blue	UI 31.0% D 52.0% **D & UI** SSH
Perry S et al (2006)[245]	UK, Leiceister and Rutland	12,568 => 40 years	Leicestershire MRC Incontinence Study longitudinal postal survey (recruited from general practices)	Self-report	HADS	UI 15.3% D 20.3% **UI & D 38%** UUI & D 37.6%
Van der Vaart et al (2007)[246]	The Netherlands, Utrecht,	2042 20 to 70 years	Population based, mailed questionnaires	UDI	CES-D	UI 51.1% **UI & D 42.8%** UI not a risk factor for depression
Felde G et al (2012)[247]	Hordaland, Norway	5,321 40 – 44 years Mean 42 years	HUSK population study Mailed questionnaire	Self-report	HADS	UI 26.2% D 10.8% **UI & D 11.8%** UUI & D 11.7%

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Matthews et al (2013)[248]	USA, Boston	64,396	Nurses' Health Study Mailed questionnaire	Self-report	history of depression or diagnosis or antidepressant medication use or a score >than 5 on Geriatric Depression Scale	UI 37.8% **UI & D 28.9%**
Townsend M. K. et al (2014)[249]	USA, Boston	72000 58 -83 years Mean 70 years	Nurses' Health Study Mailed questionnaire	Self-report	CES-D	UI b 30.9%, D b 13.7% UI w 46.7%, D w 16.3%
Urinary – Population Studies- Women - Internet Panels						
Tettamanti et al (2014)[250]	Stockholm, Sweden	42852	STAGE Twin study, web based	Self-report	CES-D CIDI-SF	UI 7.0% D 23.8% **UI & D 11.8%**
Urinary – Clinical Studies – Women and Men						
Zorn, B. H. et al (1999) [23]	USA, Virginia	115 (21 m, 93 w) (plus 80 controls) Mean age: 58.3 years	Urology clinic	History, urodynamics	Beck Depression Inventory (BDI) > 12 and/or a history of depression	**D & UI 30.0%** D & UUI 60.0%
Van Gerwen M. et al (2007) [251]	The Netherlands, Nijmegen	1707 >= 25 years	Case Control, Second Dutch National Survey of General Practice (DNSGP-2), Medical records	contact diagnosis (International Classification of Primary Care [ICPC] code U04 [urinary incontinence]), and ICPC-coded comorbidity]	contact diagnosis Medical records	D associated with UI OR:1.81

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Urinary – Clinical Studies – Women Only						
Melville, J et al (2002) [252]	USA, Washington	218 18 to 90 years	Community dwelling Urology clinic	Self-report Urine loss at least 2 times per month and a physician diagnosis of UI Patient severity assessment PISA, IQoL, UDI	SF12 PRIME MD PHQ Depression Port Medical Comorbidity Scale	**D & UI 16.0%** D & UUI 21.0% D & SUI 3.0% D & MUI 26.0%
Stach-Lempinen, B. et al (2003) [24]	Finland, Tampere	82 (57 SUI 14 UUI 11 MUI) 28 years and over	Clinic	History and urodynamics exam, cystoscopy Urgency score UI Severity score	Hamilton Depression Scale ≥ 16	**D & UI 26.0%** D & UUI 44.0% D & SUI 17.5%
Bodden-Heidrich, R. et al (1999) [85]	Germany, Dusseldorf	72/106 Mean age: Cases ~ 54, Controls ~ 38	Urogynecological clinic	urodynamic	BDI	SUI & D SSdiff
Macaulay, A. J. et al (1987) [256]	UK, London	211	Urodynamics unit, qnairres	History, urodynamics	Wakefield Self Assessment inventory, Crown-Crisp Experiential Index	More depressed than normal population
Macaulay, A. J. et al (1991) [257]	UK, London	150	Urodynamics unit	Clinical – cystometry	Wakefield Self Assessment inventory, Crown-Crisp Experiential Index	**D & UI** More dep than general pop. 25.0% same as psych inpx
Chiara, G. et al (1998) [258]	Italy, Turin	88 39 to 61 years	Urodynamics unit	ICS definition, Urodynamics exam,	CES-D	No diffs between SUI and UUI No prevs
Walters, M. D. et al (1990) [88]	USA, Texas	63/100	Case control study, gynaecology and menopause clinics	Urodynamics	MMPI	DI scored higher than controls for dep No diff between DI and SUI
Norton, K. R. et al (1990) [259]	UK,Surrey	117	Urodynamics unit		Anxiety, psychiatric assessment	DI

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instrument	Depression definition / instrument	Prevalence / Results
Lagro-Janssen, T. et al (1992) [37]	Netherlands	110 20 to 65 years	Recruited from General Practice	As above	Psychosocial consequences	
Lagro-Janssen, A. L. et al (1992)[260]	Netherlands	110 20 to 65 years	Recruited from General Practice	Complained of UI, complete urodynamics exam, ICS criteria, more than twice per month, sev.	Psychometric tests, ICD E list, use of psychotropic drugs	No diffs between SUI and UUI in psych characteristics
Sung V.W. et al (2009)[253]	USA, Providence	338 UI >=30 years	PRIDE study	UDI	BDI	**UI & D 30.0%**
Knorst M R et al (2011)[254]	Brasil, Porto Alegre	50 consecutive	Cross sectional from a physical therapy clinic	Medical diagnosis of UI	General Hospital Depression Scale (GHDS)	**UI & D 39.6%**
Kafri R et al (2013)[255]	Israel, Rishon Lezion,	164 UUI 45 – 75 years	A secondary analysis of an assessor-blinded randomized controlled trial	at least three episodes of UUI, a complaint of involuntary loss of urine associated with urgency that was not explained by stress UI symptoms	CES-D Excluding clinical depression	UUI & D 22.0%
Urinary – Clinical Studies –Men Only						
Engstrom, G. et al (2005) [261]	Sweden, Surahammer	748 40 to 80 years	Case control study, qnairre to those with one or more LUTS & controls	LUTS: DAN-PSS	SF36 sadness	S & LUTS 29.0% UUI & S 30.0% SUI & S 37.0% OUI & S 39.0%

Table Abbreviations: UI: Urinary Incontinence UUI Urge Urinary Incontinence SUI Stress Urinary Incontinence MUI Mixed Urinary Incontinence OUI Overflow Urinary Incontinence DI: Detrusor Instability
LUTS Lower Urinary Tract Symptoms OAB: Overactive Bladder D: Depression S: Sadness PD: Psychological Distress qnaiire:: questionnaire px: patient
W: Women M: Men b: Black w: White SS: Statistically Significant SSH: Statistically Significantly Higher Prevalence of D and UI highlighted in **BOLD**

2.6 URINARY INCONTINENCE AND HELP-SEEKING

2.6.1 Epidemiology

Due to the nature of help-seeking the relationship between incontinence and help-seeking has generally been examined using population studies. If respondents are already attending a clinic, then it is likely that they have approached health professionals about medical problems, including incontinence. However, some studies have been designed in a clinical setting, using convenience samples that examine patients with incontinence not currently being treated for their condition. Surveying the general population gives insight into the correct prevalence of help-seekers in the community, because those who have not sought help for incontinence, or any other condition, are able to be interviewed. Incontinence has many disturbing symptoms, however many people still do not seek help[266]. Table 2.14 provides a comprehensive summary of studies describing the associations between incontinence and help-seeking.

2.6.2 Population Studies: Men and Women

2.6.2.1 *Face to Face Interviews*

Three studies have been identified, interviewing respondents in their own homes, face to face. One from the UK, and another from Belgium, interviewing men and women over 30 years of age, with similar prevalence of urinary incontinence found that 60.0% and 29.9% of respondents with urinary incontinence respectively, sought help[214,267]. A third face to face study from the USA interviewed both men and women aged 65 to 79 years, found that only 37.6% had told their physician about their urine loss[268]. This study found that greater severity or impact, type of urinary incontinence, other health care utilisation, health habits, social networks, functional status, cognitive function and depression were predictive of help-seeking.

Two other studies form The Netherlands found that 50.0% of people with incontinence had not sought help[269], (54.0% men and 50.0% women[270]), and the most important reasons for not help-seeking were that they consider the incontinence not serious enough and that they believe that there are no treatment options available. Overall help-seeking was related to the distress experienced in daily life.

2.6.2.2 *Mailed Questionnaires*

A Japanese study using a mailed questionnaire, examined men and women aged 40 to 75 years, and found that only 3% had ever consulted doctors or other health care professionals about their incontinence[271]. An American study also using mailed questionnaires, but examining a group of men and women aged 50 years and older, as well as a group of men only aged 40 to 79 years, found that 12.9% of the women had sought health care for urinary symptoms in past year, where 28.9% and 12.8% on men in the first and second studies respectively had sought help. It was thought that the lower rate of help-seeking in women was due to their familiarity with dealing with problems of a sanitary nature by themselves[272].

2.6.3 Population Studies: Women

2.6.3.1 *Face to Face Interviews*

Three studies have been identified interviewing women. The first interviewed women aged 18 years and over, randomly selected from a defined geographical area in South Wales, in their own homes. This Welsh study found that only half of the women interviewed had sought help for their incontinence[273]. Another concerned Nigerian women, where a prevalence of only 3.6% reporting incontinence was found and of these only 12.9% had sought help[274]. Further, a Brazilian study found that 22.0% of women had reported incontinence to their doctor[275].

2.6.3.2 *Telephone Interviews*

Four studies were found using telephone interview methodology. These studies interviewed women only, came from New Zealand, Sweden, Hong Kong and France. The New Zealand study concerned women 18 years and over and found that 35.0% of these women had sought help[116]. The women in this study who had not sought help did not see incontinence as abnormal. The study from Sweden interviewed women between the ages of 23 and 51 years, and found that 26.0% had sought help, primarily because they were tired of the leakage[276].

The study from Hong Kong telephoned Chinese women of all ages, of whom 35.1% had sought help, and those who had not, did not have the time and thought that their symptoms were not serious[277].

A French population study found in women with stress urinary incontinence (SUI) (19.5% of the population) that the majority of women with severe symptoms (80.8%) or with severe impairment (69.0%) had previously reported their SUI symptoms to a doctor. However, around half of the women with low intensity symptoms (42.8%) or functional impairment (43.0%), had never discussed their SUI symptoms[278].

2.6.3.3 ***Mailed Questionnaires***

The most common types of population studies looking at urinary incontinence and help-seeking are those that have surveyed women only using mailed questionnaires. A study from New Zealand surveyed women 18 years and over of European, Maori and Pacific Islander decent, most of whom thought that urinary incontinence was a normal occurrence. A third of these women had sought help for their urinary incontinence[279].

In a postal study from the USA, it was found in women aged 19 to 93 years, that those who had ever talked to a physician about leakage or involuntary loss of urine numbered 38.0%[280]. In another American study looking at middle aged women aged 42 to 50 years, only 25.5% had sought help[281].

Two UK studies, using postal questionnaires, looked at women. The first study based in London found 32.0% of women, 45 years and older, had sought help and the second from Northern Ireland found only 19.9% of women between 35 and 74 years had sought help[282,283].

A two stage European study encompassing women 18 years and over from France, Germany, Spain, as well as the United Kingdom, found that overall 31.0% of women sought help. By country, the rate of help-seeking for incontinence was 33.0% for France, 40.0% in Germany, 24.0% in Spain, and 25.0% for the United Kingdom[284]. One study from the Netherlands, interviewing women aged between 35 to 79 years of age, found that 28.2% of women with incontinence had visited a doctor for their problem[285].

Studies originating from Scandinavian countries using mailed out questionnaires, include a study from Sweden surveying women between the ages of 18 to 72 years. This study found that only 14.0% of the women with incontinence consulted a health service because of problems with their incontinence, with 10.0% of the women with stress urinary incontinence and 41.0% with urge urinary incontinence seeking help[95].

Three papers originating from Norway from the same group of authors have examined help-seeking in incontinence in women aged 20 years and over. The first study, conducted in a Norwegian rural community found that only 20% of women with incontinence had consulted a doctor, but 18% had planned to consult in the future[286]. The other two articles described the EPICONT (Epidemiology of Incontinence in the County of Nord-Trøndelag) Study, a very large community based study, performed during 1995 to 1997. Both papers reported that 26.0% of women with incontinence had sought help, with 54.0% of those with severe incontinence and 64.0% of those who were bothered by their incontinence seeking help[287,288].

A further study form the UK considered women from primary care practices and found 21.0% with stress urinary incontinence. They also found that 47.0% of women with any incontinence had sought help[289]. Another study form Sweden looking at women in 1991 and 2007 found there was no real change in the prevalence of incontinence over time, and only 6.0% and 7.0% of these women had sought help for their incontinence[290].

2.6.4 Clinical Studies: Men and Women

One American study carried out in physicians' offices, distributed a questionnaire to all patients 20 years and over. Of those patients with urinary incontinence, 28.0% had told a health care provider about their incontinence, and of those who had not sought help, 37.0% said they would if they knew more about tests and treatment options[291].

2.6.5 Clinical Studies: Women

Five studies using samples derived from clinical situations interviewing women only have been identified. A study carried out in rural Crete, directing questions at women aged 35 to 75 years with urinary incontinence, who had visited their general practitioner for any reason, found that 15.9% had contacted health services about their problem[292]. An Israeli study, had general practitioners distribute questionnaires to women aged 30 to 75 years visiting their clinic, and found that 32.0% of the women had sought help for their incontinence[266]. A third study from Southern Taiwan was based in urologic or gynaecologic outpatient clinics from three teaching hospitals. This study, using a written questionnaire looked at "treatment seeking behaviour", but defined this as receiving treatment, and before participating in the study, 72.0% had not received treatment[293].

A study from Egypt found only 20.0% of women with incontinence had sought help, but this excluded women attending the clinic where the study was carried out, who had incontinence as their chief complaint[294]. A further study where data was obtained from patient records and questionnaires in the Netherlands found of women 55 years and over with incontinence (31.0%), 64.0% had not sought help or had been recorded by their general practitioner (GP) as having incontinence[295,296].

2.6.6 Other Studies: Men and Women

Studies where the methodology cannot be described as population or clinical quantitative studies include those studies carried out in the respondents own home, where the sample has been derived in a non-random fashion, or from a non-clinical sample of convenience.

2.6.6.1 *Face to Face Interviews*

One Canadian study of both men and women age 55 to 89 years, recruited respondents via advertisements for an educational intervention study. Two groups of volunteers who experience incontinence received an educational pamphlet about incontinence. The first of these groups received one on one education for an hour in conjunction with the pamphlet.

Both qualitative and quantitative data were collected; it was found that 23.3% of all respondents had previously sought help, and this was stratified by the duration of incontinence, where the majority who had sought help had been incontinent for more than five years. After the intervention, of those in the pamphlet plus instruction group, 46.0% sought help, however of those in the pamphlet only group 29.0% sought help[297].

Medical students in a study from Singapore, interviewed respondents aged 65 years and over from a public housing estate. One third of incontinence subjects had not previously consulted medical personnel about their problem, however almost all were agreeable to receiving medical attention for their problem[298].

2.6.6.2 ***Mailed Questionnaire***

An early study from the United Kingdom surveyed people aged five years and over who were under the care of a health or social service agency. In patients aged 15 years and over, those who were under care for their incontinence were defined as recognised incontinence, or those that had sought help. It was difficult to obtain an exact prevalence of help-seeking from this paper, although the expected prevalence would be very low[75]. Another study from the United Kingdom, concerned the implementation of continence management guidelines, using pre and post implementation mailed questionnaires to evaluate the guidelines. It was found from the pre implementation questionnaire that 39.0% of respondents, aged 18 years and over had talked to a professional about their incontinence[299]. A third study from the United Kingdom, including men and women 18 years and over, used mailed questionnaires to compare a health authority with an established continence advisory service with one that did not. It was reported that in the health authority with the continence advisory service, 68.0% of respondents had sought help, whereas in the other health authority, 74.0% had spoken to their general practitioner about their condition[86].

2.6.6.3 ***Other Methodology***

One article from the United States refers to four different studies of various methodologies sponsored by the National Association for Continence (NAFC), two concerning both women and men and two concerning women only[117].

The first study interviewed men and women 30 to 70 years in a shopping mall found that 26.0% of people with incontinence had discussed their bladder health with a doctor (18.0% of men and 33.0% of women). The second study interviewing a similar group online found that 43.0% of men and 40.0% of women sought a diagnosis for their symptoms. The third study used CATI to interview women 18 years and over and found that 50.0% of those with stress incontinence consulted a doctor about their symptoms. The fourth study did not assess help-seeking.

2.6.7 Other Studies: Women

2.6.7.1 *Face to Face Interviews*

Three studies interviewing women at home have been identified. The first study from the Netherlands interviewed women between the ages of 50 and 65 years, randomly selected from the files of general practitioners. Of the women with moderate to severe incontinence 44% were known to the general practitioner[300]. A study from the United States using unstructured interviews with eight female volunteers aged 31 to 50 years discussed the reasons for and against seeking help for incontinence. These included seeking help because their incontinence was problematic, there was leakage when they coughed or exercised, or not seeking help because their incontinence was an expected outcome of having a baby, and they were able to emotionally block their problem out[301].

The third study looked at women from the United Arab Emirates, with half the sample selected from health care centres and half from the community, specifically looking at multiparous and climacteric women. Of the women, with a mean age of 51 years, 30.9% of the women identified as incontinent reported that they had sought medical advice about their incontinence.

2.6.7.2 *Mailed Questionnaire*

A study observing women from a rural general practice in the United Kingdom, mailed questionnaires to women aged 25 years and over as well as a few under the age of 21 years. No prevalence of help-seeking was reported but reasons for not seeking help were obtained including: the problem was not serious, the symptoms were too infrequent for treatment, it was a usual female complaint and that they were embarrassed[302].

Another study from the United Kingdom surveyed women aged 20 years and over from one general practice. Incontinent women were invited to a women's clinic to discuss their incontinence, and 12.8% of these women took up the offer. The main reason given for not taking up the offer to discuss the problem was the feeling that their incontinence was a minor inconvenience only[303]. A study examining Qatari women aged from 45 to 65 years, using a sample derived from primary health care centres as well as the community, found that 45.8% of women had sought help for their incontinence[304].

2.6.7.3 ***Qualitative Methodologies***

One interesting study, although not quantitative, used a citizen's jury elicit to research ideas, priorities and outcome measures from women who experienced urinary incontinence, and they concluded that more research, similar to this study, needs to be carried out to confirm that these research areas are important to women. These research areas included: Making it easier to seek and get help; Making life more manageable; Find out the true costs of incontinence; More information on causes; and Lifestyle factors and what are the roles of these in the development and treatment of incontinence in women.[305].

2.6.7.4 ***Reviews***

Three reviews considering help-seeking for urinary incontinence have been identified. A review from the United Kingdom looked at the psychosocial predictors of help-seeking behaviour and impact on quality of life in people with urinary incontinence, and found that lack of knowledge of cause and treatment was a barrier to help-seeking[34]. . From Canada, a review including studies from North America, Asia, Europe, Africa, and Australasia found that there was a median prevalence of 26.0% of people with incontinence seeking help[306]. An Argentinean review examining stress urinary incontinence found that the majority of patients suffering from urinary incontinence postpones looking for medical help for years, or may never consult a physician, despite the negative impact on quality of life. This review found a prevalence of help-seeking of between 25.0% to 33.0%[307].

2.6.8 Summary of studies about Urinary Incontinence and Help-seeking

A summary of studies that have examined urinary incontinence and help-seeking is provided in Table 2.14. Again the methodologies, instruments and groupings are different between studies, so we have a range of results. Where possible the prevalence of help-seeking in the presence of urinary incontinence is stated. In the large face to face population studies of both men and women, it can be determined that 30.0% to 55.0% of those with the symptoms of incontinence seek help. These results are replicated in other studies, with diverse methodologies in different population groups, finding help-seekers are about on third to one half of those with symptoms of incontinence.

Barriers to help-seeking for urinary incontinence have also been discussed which have included perceptions that it was not serious enough, not seeing incontinence as abnormal, not having the time to seek help, or a belief that there are no treatment options available or wanting more information about tests and treatment options.

It is important to identify those not seeking help through the use of population surveys, as once those with incontinence have contacted a health professional about their symptoms, they have then sought help. We thus cannot distinguish the barriers to help-seeking in most clinical populations, such as the perceptions and stigma surrounding incontinence, which may delay seeking help.

Table 2.14: Urinary Incontinence and Help-seeking Studies

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Population Studies Men and Women Face to face						
Brocklehurst, J. C. et al (1993)[214]	UK	284/4007 125/1883 159/2124 30 years and over	Random sample throughout UK interviewed in their own homes.	Ever suffered from bladder problems e.g. leaking, wet pants, damp pants	What did you do when you had the problem for some time: action taken	UI 7.0% UI W 14.0% UI M 6.6% **UI & HS 52.0%** Not important enough
Burgio, K. L. et al (1994)[268]	USA, Alabama Pennsylvania	1104/3884 65 to 79 years	Community residents, Health Risk Appraisal Qnairre in own home	Self report in last year. Severity	"Told physician about loss of urine"	UI 28.4% **UI & HS 37.6%** Greater severity or impact, Type Health care utilisation Health Habits, Social network Functional Status, Cognitive function and Depression NOT: age, marital status, gender, income, employment status, educations, distance. LR: px perceived inc as problem
Schulman, C. et al (1997)[267]	Belgium	130/2499m 442/2770w 30 years and over	Face to face qnairre in their own homes		Discuss the problem with their general practitioner	UI W 16.3% UI M 5.2% **UI & HS 29.9%**
Teunissen D et al (2004)[269]	The Netherlands, Nimegen	>=60 years 56 men 314 men	Independently living from 9 family practices Face to face interviews plus qualitative	Self-report , type of incontinence, UDI	Did you seek help?	**50.0% never HS** W: HS in is determined by the duration of the symptoms, the presence of concomitant complaints and the severity of incontinence. M: HS related to the distress experienced in daily life. The most important reasons for not HS are: • that they consider the incontinence not serious enough • that they believe that there are no treatment options available.

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Teunissen D et al (2005)[270]	The Netherlands, Nimegen	>=60 years 56 men 314 men	Independently living from 9 family practices Face to face interviews plus qualitative	Self-report , type of incontinence, UDI	Did you seek help?	**54.0% M NHS** **50.0% W NHS** Seeking help is particularly determined by the impact experienced and presence of concomitant symptoms. When patients perceive their incontinence as not very serious or distressing and have a lack of knowledge about cause and treatment options, they usually do not seek help. When they perceive an increase in severity or distress or require incontinence materials, they usually do seek help.
Population Studies Men and Women Mailed questionnaire						
Roberts, R. O. et al (1998) [272]	USA, Minnesota	1. /1540 2. /2115 1. Men and Women 50 years and older 2. Men 40 to 79 years	Random selection of population Mailed qnairre	1. UI:"In the last years have you had slow leakage or dribbling of urine throughout the day" SUI: "have you.. when you coughed or sneezed" UUI: "were you aware of the need to urinate before the leakage occurred" 2. leaked more than a few , drops of urine	1. sought health care for urinary symptoms in past year 2. told their doctor or health professional about trouble controlling urination or seen a physician for urinary symptoms in the past year	1. UI W 48.7% UI M 24.3% 2. UI M 17.3% 1. UI & HS W 12.9% UI & HS M 28.9% 2. UI & HS M 12.8% Women more likely to control with pads, ie have done for menstruation Men have no knowledge or experience of this, thus can't manage well by themselves.

Author	**Country**	**Participants n/N**	**Survey Setting**	**Incontinence definition / instruments**	**Help-seeking definition**	**Prevalence and Help-seeking Related factors**
Ueda, T. et al (2000)[271]	Japan	1786/ M 86/818 F 520/968 40 to 75 years	Mailed qnairre	Do you suffer from involuntary loss of urine Do you ever leak when you cough , sneeze or laugh Do you often have difficulty holding your urine until you can get to a toilet?	Willingness to seek clinical consultation - ever consulted doctors or health professionals	UI W 53.7% UI M 10.5% **UI & HS 3%** Unavoidable consequence of ageing Embarrassing, Didn't know where to seek treatment
Population Studies Women only face to face						
Yarnell, J. W. et al (1981) [273]	UK, Wales	/1060 18 or over	Interviewed at home			UI 45.0% **UI & HS half**
Rios et al (2011)[275]	Brazil, Londrina	292 20 to 82 years	Cross sectional descriptive Family Health Strategy Clients, random sample Interview questionnaire	ICQ-SF	Symptoms reported to doctor	**U & HS 22.0%** SUI & HS 18.0% MUI & HS 36.0%
Adedokun et al(2012)[274]	Nigeria, Ibadan	5001 18/179 15 years and over	Ibadan Urinary Incontinence Study Face to face	Have you ever leaked urine?' 'Currently – 1 month"	Have you ever sought help for the leakage of urine	UI 3.6% **UI & HS 12.9%** Very few sought help
Population Studies Women only Telephone						
Holst, K. et al (1988)[116]	New Zealand, Dunedin	267/851 18 and older	Telephone interview	ICS definition plus severity determined, social implications	Asked if had sought help	UI 31.4% **UI & HS 35%** Not seen as abnormal Low expectations of benefit of treatment Self help exercise Unaware of treatment options Inc related to other med condition Can't afford to see doctor

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Hagglund, D. et al (2003)[276]	Sweden, Surahammer	95 23 to 51 years	CATI recruited from previous study	Known persistent UI Severity	"Have you sought help for your problems with urine leakage?"	**UI & HS 26%** Reasons for: Tired of leakage, Increased with time Afraid of odour Shameful and embarrassing Has worsened Reasons against: A minor problem I manage problem myself
Yip, S. K. et al (2003)[277]	Hong Kong, Sha Tin	194/1500 Chinese all ages	telephone	ICS defn involuntary loss of urine, soc or hyg unacceptable	Ever sought advice for urinary symptoms, gp, tcm herbalist, specialist	UI 3.0% **UI & HS 35.1%** No time Symptoms weren't serious Did not know help was available
Gasquet, I.et al (2006)[278]	France, Paris	5160 18 – 70 years	Telephone, national population based	Screened for SUI over the phone	Health care seeking was explored by asking whether they had ever discussed their SUI symptoms with relatives, general practitioners, specialists, or other health care professionals	SUI 19.5% SUIsev sym & HS 80.8%, SUIlow sym & HS 42.8% SUIsev imp & HS 69.0%, SUIlow imp & HS 43.0%
Population Studies Women only Mailed questionnaire						
Burgio, K. L. et al (1991)[281]	US	541 42 to 50	community-based sample questionnaire	incontinence on a regular basis at least once per month		UI 30.7% **UI & HS 25.5%**
Rekers, H. et al (1992) [285]	Netherlands	35 to 79 years 344/1299	Stratified community sample	Involuntary loss of urine	Medical consultation Visited a doctor for their problem	UI 26.5% **UI & HS 28.2%** symptoms were not considered to be so serious.

Author	**Country**	**Participants n/N**	**Survey Setting**	**Incontinence definition / instruments**	**Help-seeking definition**	**Prevalence and Help-seeking Related factors**
Lara, C. et al (1994)[279]	New Zealand	/1028 European, Maori and Pacific Island descent aged 18 years and over	Mailed qnairre			UI UI Maori 46.8% UI Pacific 29.2% UI Euro 31.2% **UI & HS third**, Normal occurrence
Seim, A. et al (1995)[286]	Norway, Rissa	535/182020 and over	Community dwelling Mailed qnairres	leakage	Ever consulted doctor, what treatment	UI 29.0% **UI & HS 20.0%** Planned HS 18.0% HS: Increasing age, duration, urge/mixed pHS: incr sev,impact
Dolan, L. M. et al (1999)[283]	UK, Northern Ireland	392/68935-74 years	Mailed qnairre		Consulted gp	UI: 56.9% **UI & HS: 19.9%**
MacKay, K. et al (2000)[282]	UK, London	45 years and older 227/489	Cross sectional community survey, postal qnairre	Identify women with significant symptoms of incontinence "often leaking when laughing, coughing or getting up form a chair" "leaking before reaching toilet".	Symptoms were a problem requiring help, sought help, told GP	UI 46.0% **UI & HS 32.0%** Cope with problem themselves Came with age/inevitable Too embarrassed to go to GP Felt doctors were too busy Did not want treatment No reason given
Hannestad, Y. S. et al (2000) [287]	Norway, Nord-Trondelag	20 years and over	EPICONT Study, collected qnairre and mailed back			UI 25.0% **UI & HS 26.0%** HS + sev 54.0% HS both 64.0%
Hagglund, D. et al (2001)[95]	Sweden, Surahammer	511/1107 18 to 72 years	Population based case control, recruited from previous prevalence study mailed	"For the present time do you have a problem with incontinence when you laugh, jump , cough or sneeze?" SF36 Detrusor instability score	Professional consultation with a health service because of problems associated with urinary incontinence	**UI & HS: 14.0%** UUI &HS: 41.0% SUI&HS: 10.0% SS Lower QoL Older
Hannestad, Y. S et al (2002) [288]	Norway, Nord-Trondelag	6876/2793620 years and over	EPICONT Study, collected qnairre and mailed back	Experienced involuntary loss of urine, any leakage. Severity	Ever seen a doctor for her urinary incontinence	UI 24.6% **UI & HS 26.0%** Age Frequency Amount Impact Duration Lower education Seen doc in last year Decreased with SUI

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Kinchen, K. S. et al (2003)[280]	USA, Various	1970 19 to 93 years	Cross sectional survey “NFO” stratified. Qnaire sent to women id as inc	Incontinence symptoms past 30 days Type Severity Frequency Duration Medication Pads IQoL	“ever talked to physician about leakage or involuntary loss of urine”	**UI & HS 38.0%** Worse urinary symptoms, duration, frequency Greater impact on life (IQoL) Ask about another condition Seek out medical info Not embarrassed to talk to physician about UI Talked to someone else More likely to accept surgery/ medication as treatment option Schedule visits for routine physicals HS: condition might get worse Wear pads Condition not normal Possibility of accident
O'Donnell, M et al (2005)[284]	France, Germany, Spain, UK	5976/ 17080 (1st) 18 years and over	Community dwelling Mailed qnairres: 1st gen UI questions, 2nd qol, health status, help-seeking qs	Any leakage or involuntary loss or urine, ICS definition in last 30 days	Consulted a doctor about their condition	UI: 34.9% France, 44.2% Germany, 41.2%, Spain, 22.6% UK 41.9% **UI & HS: 31.0%** France, 33.0% Germany, 40.0% Spain, 24.0% UK 25.0% Use pads ssh Mixed incontinence Increased with age Willing to take lt medication Discussed with other than doctor Routine physicals and preventatives Moderately to extremely bothersome Disagree that UI would get worse with ageing no matter what they did.

Author	**Country**	**Participants n/N**	**Survey Setting**	**Incontinence definition / instruments**	**Help-seeking definition**	**Prevalence and Help-seeking Related factors**
Shaw C. et al (2006) [289]	UK, West Yorkshire, London, Glasgow and Leicestershire	3273	Cross Sectional Self completion questionnaire	Symptom Frequency and Bothersomeness (SFB) questionnaire. IQoL	service use and treatment seeking behaviours	21.0% SUI 3.5% UUI 21.0% MUI 47.0% UI & HS
Wennberg A L. et al (2009)[290]	Sweden, Gothenberg	>=20 years	Self completion questionnaire Two cohorts 1991,2007	LUTS symptoms freq of UI		18.0% with UI no detectable change in the prevalence of UI over time 6.0% and 7.0% of the population had HS for UI
Clinical Studies Men and Women						
Lagace, E. A. et al (1993)[291]	USA	934/2830 20 years and over	family physicians' offices seeking health care for any reason	any degree of incontinence in the past 12 months	told a health care provider	UI 33.0% UI M 11.0% UI W 43.0% **UI & HS 28.0%**
Clinical Studies Women						
Lionis, C. et al (2000) [292]	Greece, Crete	69/251 35-75	Visited gp who asked questions	Experienced symptoms of involuntary urine leakage		UI 27.5% **UI & HS 15.9%** symptoms were not considered serious
Vinker, S. et al (2001)[266]	Israel	148 /418 30 to 75 years	Gps distributed qnairre			UI 36.0% **UI & HS 32.0%**
Lin, S. Y. et al (2002)[293]	Taiwan	106 > 20 years	Women who had visited uro/ gyn clinic questionnaire	Self report of experiencing involuntary urine loss.	Had already consulted physician Treatment seeking behaviour – receiving a treatment including medication, PFME, biofeedback, surgery etc	
El Azab et al (2010)[294]	Egypt, Assiut	348/1231 20 years and over	Screening at an OP Urology and Gynaecology clinic excluded those with UI as their chief complaint	UDI-6	"What prevented you from seeking medical consultation for urine leakage?"	**UI & HS 20.0%**

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Visser et al (2012)[295]	The Netherlands, Groningen	225 UI 55 years and over	URINO project RCT Records and questionnaires Data from first 225 participants	Involuntary leakage of urine once a month or more	whether the patients were known by their GP as suffering from urinary incontinence, their consultation behaviour in the three months preceding the inclusion	**UI & HS 36.0%**
Visser et all (2013)[296]	The Netherlands, Groningen	744 /2390 >=55 years	The URINO Trial cluster randomized trial Screening and treatment uptake	Do you have involuntary loss of urine, once a month or more often?	Known by their family physician as suffering from urinary incontinence.	UI 31.0% 36.0% had not told their doctor.
Other studies Interview at home-Men and women						
Ju, C. C. et al (1991)[298]	Singapore	42/919 65 years and older	Detailed interview Residents in public housing estate	Regular UI		UI 4.6% **UI & HS 2/3**
Milne, J. et al (2000)[297]	Canada, Calgary	45 55 to 89 years	RCT Interviewed in own home then intervention	Experienced a degree of UI	Could not have sought help in last 2 years	Did not perceive their incontinence as a personal problem Changes made to routine were insignificant Misconceptions about UI exist and perpetuated by health care professional
Urinary – Other studies questionnaire Men and Women						
Thomas, T. M. et al (1980)[75]	UK, London	5 years and over	Practice lists of GPs, postal survey	Involuntary excretion or leakage of urine in inappropriate places or at inappropriate times twice or more a month, regardless of quantity of urine lost	Patients under care of health or social services for the condition	UI No HS prev Very low prev

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Button, D. et al (1998) [299]	UK	206/150318 years and over	One gp Mailed Pre and post implementation qnairres	Involuntary loss of urine social or hygienic	Whether px had spoken to health professional about problem	UI 13.7% UI W 35% UI M 9.9% **UI & HS 39%**
Roe, B. et al (1999)[86]	UK	254/3429 265/271018 years and over	2 healthcare authorities Mailed qnairres One practice had continence advisory service	Self report, modified Thomas(1980)	Spoke to or contacted GP	Did not want treatment or help Too embarrassed UI 9.0% **UI & HS 71%**
Other studies Interview at home-Women						
Lagro-Janssen, T. L. et al (1990)[300].	Netherlands, Nijmegen	325/1445 50 to 65 years	Files of gps Interviewed at home	Involuntary loss of urine more than 2x per month	Known or Recognised by doctor	UI 22.5% HS moderate and severe 44.0%
Skoner, M. M. et al (1993)[301]	USA	8 31 to 50 years	Unstructured interviews, grounded theory		Talked to a physician about UI	Reasons for: Problematic: leakage when coughs, exercise Reasons against: Expected outcome of having a baby Emotionally blocking it out
Rizk, D. E. et al (1999) [84]	UAE	81/400 Mean age 51 years	Cohort study of women at risk, multiparous and climacteric 200 community sample, 200 in outpx dept Face to face interview	ICS defn involuntary loss of urine, soc or hyg unacceptable last 12 months	Sought medical advice	Embarrassment, Self treat as low exp of med care Discuss with friends It is normal UI 20.3% **UI & HS 30.9%**
Other studies questionnaire Women						
Jolleys, J. V. et al (1988)[302]	UK, Leicester	343/833 25 and over and some less than 21	Rural practice Mailed qnaires	Leakage of urine on coughing, laughing, exercise, lifting, climbing stairs, a full bladder, or other occasion	Why have you not spoken to a doctor about your incontinence	Problem not serious Symptoms too infrequent for treatment Usual female complaint Embarrassed UI 41.0% HS No prev
Harrison, G. L. et al (1994) [303]	UK	/314 20 years and over	One gp qnairres mailed	Any leakage		UI 53.0% **UI & HS 13.0%** minor inconvenience only

Author	**Country**	**Participants n/N**	**Survey Setting**	**Incontinence definition / instruments**	**Help-seeking definition**	**Prevalence and Help-seeking Related factors**
Saleh, N. et al (2004) [304]	Qatar, Doha	164/798 45-65 years	Cross sectional, primary health care centres and community based qnairre	ICS defn involuntary loss of urine, soc or hyg unacceptable last 12 months	Seeking treatment Consult a doctor	UI 20.6% **UI & HS 45.8%** nHS: embarrassment male physician HS: abnormal, worth reporting
Other studies- other methodology						
Muller, N. et al (2005) [117]	USA, Various	1. N=1001 2. N=1420 3. N=1029 4. N=12281, 2. Men and Women 30 to 70 years 3. Women 18 years and over 4. Women 40 to 65 years	4 NAFC sponsored Surveys 1. interviewed in malls 2. online interview 3.CATI 4. online interview	2. Loss of bladder control symptoms at some point in life plus further clarification 3. SUI involuntary loss of urine when coughing, sneezing, laughing or phys act in last 30 days 4. OAB	1. Discussed bladder health with doctor 2. seek dx for symptoms 3. consulted doctor about symptoms	1. HS 26.0% HS M 18.0% HS W 33.0% 2. UI 32.0% HS M 43.0% HS W 40.0% 3. SUI 26.0% HS 50.0% 2. Loss of bladder control is a disease Natural part of ageing 3. Not enough of a problem Supposed to happen with age

Author	Country	Participants n/N	Survey Setting	Incontinence definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Herbison P et al (2008)[305]	New Zealand, Dunedin	Women with UI 14 with SUI 14 with UUI	Citizens Juries			More research, similar to this study, needs to be carried out to confirm that these research areas are important to women. • Making it easier to seek and get help: • Making life more manageable • Find out the true costs of incontinence • More information on causes: • Lifestyle factors: what are the roles of these in the development and treatment of incontinence in women

Table Abbreviations: UI: Urinary Incontinence UUI: Urge Urinary Incontinence SUI: Stress Urinary Incontinence qnaiire:: questionnaire px: patient
HS: Help-seeking W: Women M: Men Prevalence of D and UI highlighted in **BOLD**
SS: Statistically Significant SSH: Statistically Significantly Higher

2.7 DEPRESSION AND HELP-SEEKING

2.7.1 Epidemiology

Help-seeking in association with depression has also been examined in the context of population studies, as well as in clinical studies retrospectively. Another interesting way help-seeking and mental health has been examined is via the use of examples and vignettes, using them to prompt respondents to examine situations and describe their potential help-seeking behaviour. Some of the studies below are not about the proportion of help seekers in the depressed population, rather about psychosocial barriers which may prevent help being sought. A comprehensive summary of studies describing the associations between depression and help-seeking is provided in Table 2.15.

2.7.2 Population Studies

Population studies can provide prevalence estimates from the general population regarding help-seeking in respondents with the symptoms of depression, particularly when they have not sought help or have obtained a diagnosis. Of people, who were found to have depression according to the CIDI, 30.0% had voluntary contact with a professional for emotional or substance abuse problems, in the National Comorbidity Study in USA[308]. Also interviewing people in their own homes, a study from Germany found that people, not necessarily suffering from mental illness would recommend a sufferer of depression to seek help first from a psychiatrist, then a psychoanalyst and then a general practitioner for depressive symptoms.

In South Australia, data analysed from the face to face Autumn 1998 Health Omnibus Survey, found using vignettes and the PRIME MD, that of the 6.8% of respondents with depression, 45.8% had received professional help or treatment for mental health problems[309]. This study was repeated in the 2008 Health Omnibus Survey, where they found 10.7% of respondents reported major depression, and that 75.0% of those who were depressed with suicidal ideation and 66.0% of those without suicidal ideation had sought treatment[131].

The following face to face studies concentrated their interest on the psychosocial factors and barriers relating to depression and help-seeking, without providing prevalence data. A German study of 25 students used the PRIME MD to identify depression. It found that in these people, personal stigmatizing attitudes pose an important barrier to help, impairing appraisal of depressive symptoms as potential, mental health problem and decreasing perceived need for professional help[310].

A study of 84 Mexican Americans, found those with depression, often do not receive the help necessary to overcome their depression. Their families typically represent the most likely and accessible target for help-seeking, but perceived utility of seeking help and comfort with seeking help is negatively related to depression[311]. In Estonia, they also found that depression was associated with structural and functional factors of social support and locus of control. Help-seeking of depressed persons depends on locus of control, interactions of emotional loneliness and contact with the parental family[312]. A Belgian study looking at experiences with the mental health system found that anticipated self-stigma and perceived public stigma about depression appeared to have a differential impact on attitudes toward formal and informal help-seeking[313].

A number of recent population telephone surveys have also been undertaken in this area. The diamond Consortium in Melbourne have undertaken a longitudinal study regarding depression in primary care patients and recommend that when considering how to tailor therapies to the individual patient, or implementing community education programmes for depression, the role of stigma needs to be taken into account[314]. The Australian Rural Mental Health Study found an average delay in help-seeking for those in rural areas to be 18.7 years[315]. A third Australian study using vignettes found that beliefs that respondents thought that mental illness is a sign of personal weakness and preference for social distance were associated with less intention to seek professional help and less endorsement of their helpfulness[316].

A European study undertaken in German, Hungary, Ireland and Portugal with 4,011 people found that there was a moderate degree of personal stigma toward depression and a strikingly high degree of perceived social stigma. Although a substantial majority showed openness to seek professional help, only half of the respondents perceived professional help as valuable[317].

Two Australian postal studies from the same author look at different aspects of help-seeking and depression using mailed questionnaires. The first using the GHQ-12 found that 35.0% of people with depression had sought help from a general practitioner[318]. The second study analysed strategies used to cope with depression at different levels of severity, as defined by psychological distress, and found that professional help-seeking was most prevalent in depression with severe psychological distress[319].

A major biomedical study from Norway also used mailed questionnaires, with the HADS, to determine depression. A prevalence of 5.0% of respondents experienced depression, with only 12.8% of these people ever requesting help for mental health problems. These respondents were more likely to be women, aged 40 to 59 years, those who had seen their general practitioner in the last year, had a low education, or did not have ‘good’ friends[320].

A social marketing survey of college students in the USA and their mental health help-seeking behaviours, found evidence to suggest that anyone who creates a Depression Public Service Announcement (D-PSA), targeting people with depression, without considering how the mind of a person with depression operates, is engaging in behaviour akin to reckless endangerment[321].

2.7.3 Clinical Studies

Clinical studies, which measure help seeking behaviour, often examine this behaviour retrospectively. Once someone has entered treatment for a condition such as depression, then they will have most likely sought help. This provides an endpoint such that the person with depression may have had symptoms for a long time before seeking help. Thus clinical studies cannot determine the proportion of people with depression that do not seek help, as they are not concerned with those in the community who are not undergoing treatment.

One study from the USA that attempted to identify help-seeking retrospectively, interviewed new mental health clients, and used the CES-D to identify depression. Of new mental health patients, 49% had previously failed to seek help when they thought they had needed it in the past.

Another study from the USA, administering a questionnaire to patients in waiting rooms explored attitudes towards seeking help for psychological problems and found that help-seeking was less likely in those respondents who believed that depression was able to be self-controlled[322].

An Australian study, carried out in a specialist clinic determined that the mean delay in help-seeking for a mental health problem was 9.4 years, by determining the age that the respondent first experienced symptoms and their current age now[323].

2.7.4 Reviews

Two recent reviews in this area have been undertaken. One focused on help-seeking attitudes, intentions or behaviours and found that mental health literacy interventions were promising[324]. A further study examined the literature and also found that the limited evidence suggested that mental health literacy may improve attitudes, anxiety and psychological distress[325].

2.7.5 Barriers

Barriers to help-seeking include beliefs about mental illness and treatment, as well as lack of time, financial resources and unavailability of treatment may prevent help-seeking. Additionally, mental health literacy or not recognizing the symptoms of a mental illness has been found to have an impact on delaying help-seeking[323].

2.7.6 Summary of studies about Depression and Help-seeking

Table 2.15 provides a summary of a number of studies that have addressed help seeking in those experiencing depression. The majority of these studies are population studies, using screening questionnaires as well as vignettes to identify people with depressive symptoms. Some clinical studies have assessed the delay in help-seeking in their patent groups.

The prevalences of help seeking in those with depression also varies due to the methodology used, different screeners for depression, the severity of the mental illness, and different definitions of help seeking, as well as the cultural group where the studies are undertaken . However, it seems that the proportion of the depressed population seeking help ranges from 30.0% to 60.0% of those with depression seeking help. Additionally barriers to help-seeking were discussed by many of the studies including perceiving their need for help, stigmatizing attitudes, family situations, locus of control and belief that help would be of little value.

Table 2.15: Depression and Help-seeking Studies

Author	Country	Participants n/N	Survey Setting	Depression definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Population Studies Men and Women Face to face						
Mojtabai, R. et al (2002)[308]	USA	15 to 54 years 1792	Interviews in private homes National Comorbidity Survey	CIDI Mood disorder	Any voluntary contact with a professional for emotional or substance abuse problems	**D & HS 30.0%** D & HS $^{\text{mental health professional}}$ 13.0% Perceived a need for help 49.0% Older age (45-54y), Physical condition, Positive attitude to HS
Riedel-Heller, S. et al (2005) [326]	Germany	18 years and over /5025	Interviews in private homes with lay public	Vignettes	preferences	No prevs Ranking: Psychiatrist, Psychotherapist Family Physician
Goldney, R. D. et al (2002) [309]	Australia, Adelaide	15 years and over /3010	1998 South Australian Health Omnibus survey. Face to face representative population survey Vignettes	Vignettes PRIME MD	Have you received professional help or treatment for these problems?	D 6.8% **D & HS 45.8%**
Schomerus G et al (2012)[310]	Germany, Stralsund	25	Population recruitment and students via newspaper article and emails	PRIME MD Untreated depressed persons	"Do you think you need any medical or therapeutic help for your present complaints?"	Personal stigmatizing attitudes in persons suffering from a depressive syndrome, pose an important barrier to help, impairing appraisal of depressive symptoms as potential, mental health problem and decreasing perceived need for professional help.
Chamberlain P et al (2012)[131]	Australia, Adelaide	323/3034 15 years and over	2008 South Australian Health Omnibus survey. Face to face representative population survey Vignettes	PRIME MD PHQ	Respondents were also asked about contact with persons with similar symptoms to those of the vignette and whether or not they themselves had had similar experiences	10.7% Maj Depression 75.0% of depressed with suicidal ideation, and 66.0% of depressed without suicidal ideation had sought treatment,

Author	Country	Participants n/N	Survey Setting	Depression definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
					or had sought treatment for them.	
Keeler A.R. et al (2013)[311]	USA, Claremont	84 Mexican Americans	Recruited at a swap meet, Spanish	BDI-II	Familism rate how likely family support could aid in their recovery if they became depressed. how comfortable they would be asking an immediate family member for help if they became depressed	Mexican–Americans with depression often do not receive the help necessary to overcome depression. Family typically represents the most likely and accessible target for help-seeking, but perceived utility of seeking help and comfort with seeking help is negatively related to depression
Kleinberg A. et al (2013)[312]	Estonia, Tartu	345/ 6105 18–84 years	2006 Estonian Health Survey Community face to face structured interviews	Mini-International Neuropsychiatric Interview	Have you sought help due to your emotional problems (depression, anxiety) during the previous 12 months?	Depression is associated with structural and functional factors of social support and locus of control. Help-seeking of depressed persons depends on locus of control, interactions of emotional loneliness, and contacts with the parental family
Pattyn E. et al (2014)[313]	Belgium, Ghent	728	2009 Stigma in a Global Context– Belgian Mental Health Study Face to face, representative sample Vignettes	Personal experience with mental health system	Respondents were asked to rate how important it was for the person in the vignette to consult each type of care provider to deal with the problem	Anticipated self-stigma and perceived public stigma appeared to have a differential impact on attitudes toward formal and informal help-seeking.

Author	Country	Participants n/N	Survey Setting	Depression definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Population Studies Men and Women Telephone						
Boardman F et al (2011)[314]	Australia, Melbourne	161 / 575 Mean age 44.8 years	Diamond Longditudinal cohort study – Primary care patients Mixed methods, Telephone Structured interviews	CES-D	Questions about interactions with health professionals	When considering how to tailor therapies to the individual patient, or implementing community education programmes for depression, the role of stigma needs to be taken into account.
Green, A. C. et al (2012)[315]	Australia, Sydney	124 / 2,639 19 – 85 years	Australian Rural Mental Health Study (ARMHS) Telephone	CIDI	PSS (Perceived Stigma Scale) CIDI gives treatment seeking history ‘‘did you ever in your life talk to a medical doctor or other professional about your (relevant symptoms)?’’	Average length of delay in HS 18.7 years
Yap M.B.H et al (2013)[316]	Australia, Melbourne	3021 15 to 25 years	Telephone Vignettes	Kessler 6 (Psychological distress)	If you had a problem right now like (John/Jenny), would you go for help? Where would you go	Beliefs that mental illness is a sign of personal weakness and preference for social distance were associated with less intention to seek professional help and less endorsement of their helpfulness
Coppens, E et al (2013)[317]	Germany, Hungary, Ireland, and Portugal,	4011	Representative Cross sectional population survey	each participant was asked whether he or she suffered from any form of depression in the past Depression Stigma Scale	Assessed via the Attitude Toward Seeking Professional Psychological Help-	A moderate degree of personal stigma toward depression and a strikingly high degree of perceived social stigma. Although a substantial majority showed

Author	**Country**	**Participants n/N**	**Survey Setting**	**Depression definition / instruments**	**Help-seeking definition**	**Prevalence and Help-seeking Related factors**
				(DSS)	Short Form (ATSPPH-SF)	openness to seek professional help, only half of the respondents perceived professional help as valuable.
Population Studies Men and Women Mailed questionnaire						
Jorm, A. F. et al (2000)[318]	Australia Rural NSW	20 to 59 years 3109 screened, 422 followed up	Postal survey from electoral role	GHQ>4		**D& HS GP 35.0%**
Jorm, A. F. et al (2004)[319]	Australia Canberra and NSW	18 and over 6529	Postal survey from electoral role	Depression and Psychological distress		No Prevs Strategies to cope at levels of psych distress
Roness, A. et al (2005)[320]	Norway Nord-Trondelag	20 to 89 years 60869	HUNT Study Mailed questionnaire and biomedical	Hospital Anxiety and Depression Scale (HADS)	Have you ever requested help for mental problems?	D 5.0% D& HS 12.8% Age 40-59, Women, Low education Seen GP last year, not enough good friends
Lienemann, B. et al (2013)[321]	USA, Claremont	271 18 – 46 years	College students randomly assigned to received public service announcement (PSA)	BDI-II	Self-Stigma of Seeking Help scale (SSOSH) How likely or unlikely would you be to seek help from each of the following sources if you were depressed?”	Anyone who creates a D-PSA targeting people with depression without considering how the mind of a person with depression operates is engaging in behaviour akin to reckless endangerment.
Clinical Studies Men and Women -Interview						
Hahm, H. C. et al (2005)[215]	USA, California	Mean age 39.2 year 673	Interview of new mental health clients- seeking mental health assistance i.e. have sought help	CES-D Brief Psychiatric Rating Scale (BPRS)	Have you had times when you thought you should have gone to a doctor or other health provider but have not?	HS in past year 50.8%

Author	**Country**	**Participants n/N**	**Survey Setting**	**Depression definition / instruments**	**Help-seeking definition**	**Prevalence and Help-seeking Related factors**
Clinical Studies Men and Women -questionnaire						
Halter, M. J. et al (2004) [322]	USA	18 to 80 years 117	Waiting rooms of health care facilities i.e. have sought help	DSM 4 vignette description	Attitudes toward seeking professional psychological help scale (ATSPPHS)	No prev Less likely to HS is believe dep is within personal control
Thompson, A. et al (2004)[323]	Australia	18 to 77 years 233	Specialist Anxiety Clinic i.e. have sought help	Patients referred to clinic for anxiety or depression 79% anxiety, 20.6% primary mood disorder.	History of HS retrospectively reported: all delayed HS by at least a month: Age first experienced symptoms, first contacted health professional. What most delayed HS	HS Delay Mean 9.4 years Attitudinal barriers: beliefs about mental illness and treatments Structural Barriers: lack of time, financial resources and unavailability of treatment, stigma. Mental Health Literacy

Table Abbreviations: UI: Urinary Incontinence UUI: Urge Urinary Incontinence SUI Stress Urinary Incontinence HS: Help-seeking QoL: Quality of Life qnaiire:: questionnaire px: patient
W: Women M: Men GP: General practitioner GE: Gastroenterologist, SS: Statistically Significant SSH: Statistically Significantly Higher Prevalence of D and HS highlighted in **BOLD**

2.8 URINARY INCONTINENCE, DEPRESSION AND HELP-SEEKING

The prevalences reported upon so far are mostly for those who have sought help for either incontinence or depression, however not for help-seeking in the presence of both conditions. The following studies outlined in Table 2.16 below, have measured both urinary incontinence and depression, as well as help seeking for one of these conditions.

2.8.1 Studies

One American study of middle aged women found no association between psychological factors, except for anger, and help-seeking in women with incontinence[281]. Another study by the same author, interviewed rural women and men aged 65 to 70 years in their own home, and found using the CES-D that people who reported their loss of urine to a physician had higher, but not statistically significant, depression scores than those who had not reported their incontinence[268].

Two studies from Sweden observed why women with incontinence did not seek help. One found that women with urinary incontinence who had consulted a health professional scored significantly lower on the mental health dimension of the SF-36, than those who had not sought help[95], and the other study, just under half the women who sought help, did so because they "felt depressed about their urine leakage"[276].

A more recent study from the USA, of people were visiting a continence related website, discussed quality of life and help-seeking, and found 75.3% were seeking help. However the other 24.7% of people not seeking help, were still visiting this website. This indicated that information about self-management, medical, psychological, and social information related to incontinence should be made more accessible via the internet[44].

2.8.2 Summary of studies about Urinary Incontinence, Depression and Help-seeking

A comprehensive summary of studies describing the associations between incontinence, depression and help-seeking is provided in Table 2.16. Help-seeking has usually been measured for urinary incontinence, and we find that in the presence of 30.0% incontinence, approximately a quarter of these people are seeking help. Commonly the reasons for help seeking in these studies includes being depressed and the reasons against include that the incontinence is a problem they manage themselves.

Table 2.16: Incontinence, Depression and Help-seeking Studies

Author	Country	Participants n/N	Survey Setting	Incontinence type/ definition / instruments	Help-seeking definition	Prevalence and Help-seeking Related factors
Burgio K.L et al (1991)[281]	US	541 42 to 50 years	Community-based sample questionnaire	Incontinence on a regular basis at least once per month	Framingham Anger Scale	UI 30.7% **UI & HS 25.5%** **HS not related to psych factors except higher anger scores**
Burgio, K. L. et al (1994)[268]	USA, Alabama Pennsylvania	1104/3884 65 to 79 years	Community residents, Health Risk Appraisal qnaire in own home	Self report in last year	CES-D “Told physician about loss of urine”	UI 28.4% HS 37.6% **D & UI** HnSS
Hagglund, D. et al (2003)[276]	Sweden, Surahammer	95 23 to 51 years	CATI recruited from previous study	Known persistent UI Severity	“Have you sought help for your problems with urine leakage?”	**UI & HS 26.0%** **Reasons for:** Tired of leakage, Increased with time Afraid of odour Shameful and embarrassing Has worsened Feel depressed because of it **Reasons against:** A minor problem I manage problem myself
Hagglund D. et al (2001)[95]	Sweden, Surahammer	511/1107 18 to 72 years	Population based case control, recruited from previous prevalence study mailed	“For the present time do you have a problem with incontinence when you laugh, jump , cough or sneeze?” SF36 Detrusor instability score	Professional consultation with a health service because of problems associated with urinary incontinence	**UI & HS: 14.0%** UUI &HS: 41.0% SUI &HS: 10.0% SS Lower QoL 7/8 **UIw with HS scored lower on all QoL but Role Emotional** Older
Rozensky R et al (2013)[44]	USA, Florida	374 18 and over, US or Canadian	Recruited via an incontinence website	Enrolled in a “Continence Comprehensive Health and Life Assessment” link on Simon foundation webpage		**UI & HS 75.3%**

Table Abbreviations: UI: Urinary Incontinence UUI: Urge Urinary Incontinence SUI Stress Urinary Incontinence Prevalence of UI and HS highlighted in **BOLD**
HS: Help-seeking QoL: Quality of Life qnaiire:: questionnaire px: patient
W: Women M: Men
SS: Statistically Significant SSH: Statistically Significantly Higher

2.9 CONCLUSION: GAPS IN THE RESEARCH

There is a paucity of research identifying associations between incontinence, help-seeking and depression, with only one very recent study[44]. A number of studies had the potential to examine this relationship, but did not do so. One study found no significant relationship, and another examined an observational relationship, with no particular conclusions.

With a prevalence of urinary incontinence in Australia of approximately 30.0%, that is 35.0% for women and 5.0% for men, with 15.0% to 30.0% of these women also being depressed, psychosocial barrier to treatment such as help-seeking present a dilemma.

The psychosocial factors that are associated with incontinence may be adversely impacted upon by depression. Incontinent people experiencing co-morbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[15,16,27-30,327]. For the 15-30% of those with incontinence who also suffer from depression, an opportunity to reduce the burden of incontinence is presented, as treating depression may be more successful than treating incontinence[21-24].

In both those with only incontinence and those with only depression, only 30.0% to 60.0% of these groups seek help; there are many in the community who experience these conditions without any help. Incontinence costs at least A$200 million[110] and depression, more than A$20 billion[196], representing a great economic burden on the community. It is unclear what impact, when these conditions are combined has on the community.

Both urinary incontinence and depression have an impact on quality of life[28,328] however this review has shown that little recent research has considered the associations between incontinence, psychosocial factors such as help seeking and quality of life, with depression. We do not know if the effect of incontinence and depression combined has a greater effect on psychosocial factors than when these conditions stand alone.

This thesis will explore the relationship between incontinence, other psychosocial factors and depression in a community sample more explicitly, as well as considering possible explanations for the reasons behind the differences in the severity of depression in a smaller group of women with incontinence.

3 METHODOLOGY FOR UNDERTAKING POPULATION STUDIES

3.1 INTRODUCTION

Incontinence is not often considered without some mention of the related psychological effects, such as psychological distress, depression and anxiety[15,329] as well as the associated stigma and perceptions[61,62,330]. The International Continence Society (ICS) takes great care, in its most recent definition of urinary incontinence, to encompass its association with psychological and psychosocial factors[33]. However, an examination of mental health in combination with the psychosocial aspects of incontinence, has generally be neglected[19,21,30,34-43].

The psychosocial factors that are associated with incontinence may be adversely impacted by depression. Incontinent people experiencing co-morbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[15,16,27-30,327]. For the 15-30% of those with incontinence who also suffer from depression, an opportunity to reduce the burden of incontinence is presented, as treating depression may be more successful than treating incontinence[21-24].

The following research question was explored by a suite of mixed method studies:

> *"How is depression associated with psychosocial factors such as quality of life, help-seeking and social networks in people with incontinence, and what are the consequences of incontinence with comorbid depression for the individual's psychosocial factors, identities, and social relationships?"*

This chapter describes the methodology used for the quantitative component of the research undertaken for this thesis. The theoretical frameworks underpinning the research will also be discussed and an introduction to the qualitative component of the research will also be presented, with a further discussion of this in later chapters.

3.2 RATIONALE FOR MIXED METHODS DESIGN

This thesis utilises mixed methods, which incorporates both qualitative and quantitative research techniques. These methods allowed the wider research questions to be examined in more depth than with population studies alone. Each research method has both advantages and disadvantages for the design of this study[331,332]. The research questions proposed for this thesis could not be answered with a quantitative study or qualitative study by themselves[333,334]. A mixed method study can use qualitative and quantitative designs together at the same time, or have them occur sequentially[331]. Additionally, the qualitative study included a new technique of metasynthesis, as well as extending my qualitative interviewing and analysis skills.

The secondary analysis of quantitative data was undertaken initially for this thesis from population data that had been collected in the Health Omnibus Surveys of 1998 and 2001. Here, we were able to gain perspectives surrounding incontinence within a population sample, and these included depression, quality of life, and perceptions of seriousness and severity. The design of the Health Omnibus Surveys enabled an analysis of cross sectional data with enough power to draw some conclusions around the interactions of incontinence, quality of life and depression, and the association between the seriousness, severity and limitations of urinary incontinence. Undertaking the analysis of population data initially provided the context in which the subsequent qualitative studies could be framed.

The associations between incontinence, depression and quality of life found in the 1998 SAHOS data, and well as the perceptions about incontinence derived from the 2001 SAHOS data, informed the exploration of literature used, and clarified the resultant themes discovered in the subsequent metasynthesis of qualitative studies in this area. Further, the metasynthesis was undertaken to assist the design of the qualitative interview study schedule, providing common themes which could be used as a discussion point for women with incontinence and depression. Both qualitative interview studies were very much concerned with women who were actively sharing their experiences of incontinence, which expanded on the population studies which asked women (and men) closed-ended questions about their condition, and it was up to me, as the researcher to make informed decisions about which data to analyse to support my hypotheses.

Combining qualitative and quantitative methodologies has been seen in the past as epistemologically challenging[335]. However, I was not triangulating the data from the three studies, that would involve checking the validity of each part using the other[336]. I wanted to clarify and extend the findings from the surveys using in-depth interviews[335].

Thus undertaking this thesis using mixed methods had benefits both for the research questions and my development and training as a researcher.

3.3 THEORETICAL FRAMEWORKS

In order to develop a theoretical framework to explain the research question examined here, a review was undertaken to identify gaps and weaknesses in the literature (Chapter 2). A number of models have also been postulated to describe the psychosocial associations between urinary incontinence and depression, including the Health Threat model, the theory of Learned Helplessness, and the concept of Resilience.

3.3.1 Health Threat

One author who has explored coping, illness behaviour, outcomes, help seeking and quality of life in people with urinary incontinence is Shaw[34,337]. Shaw's 1999 model attributes the experience of a health threat to an individual's own assessment of a situation. It is influenced by many different factors that may interact and produce certain behaviours and has a varying impact on symptoms. These factors include: illness representation; appraisal of coping resources and plans; perceived severity of the threat; behavioural intentions; and actual behaviour.

An extended version of this model may help to explain the research question of this thesis, whereby those with incontinence and co-morbid depression, experience impacts to a number of these factors: adverse effects to behaviour such as help seeking; increased perceptions of symptom severity; and decreased social support and control.

3.3.2 Learned Helplessness

Another model which may explain why those with incontinence may experience comorbid depression is the psychological phenomenon of learned helplessness. Learned helplessness is a model of depression in which exposure to a series of unforeseen adverse situations gives rise to a sense of helplessness or an inability to cope with or devise ways to escape such situations, even when there is potential for escape[338].

One study discussing this model in urinary incontinence and its particular effects on quality of life, found that mastery had a direct effect on quality of life, however depression did not emerge as a mediator of quality of life[241]. This model may explain why those with incontinence and depression may be less likely to seek help, may have greater symptom severity, diminished quality of life, increased social isolation and a reduction in the use of health services.

Drawing on the theory of learned helplessness[338], depression may affect psychosocial factors such as help seeking, quality of life, socially isolation, symptom severity and health service use, in that these factors require effort to undertake and overcome, and having depression may impact upon this. Other demographic factors, as well as the type and severity of incontinence, and whether the depression is treated or untreated, may also affect this association. This relationship is conceptualised in Figure 3.1 below.

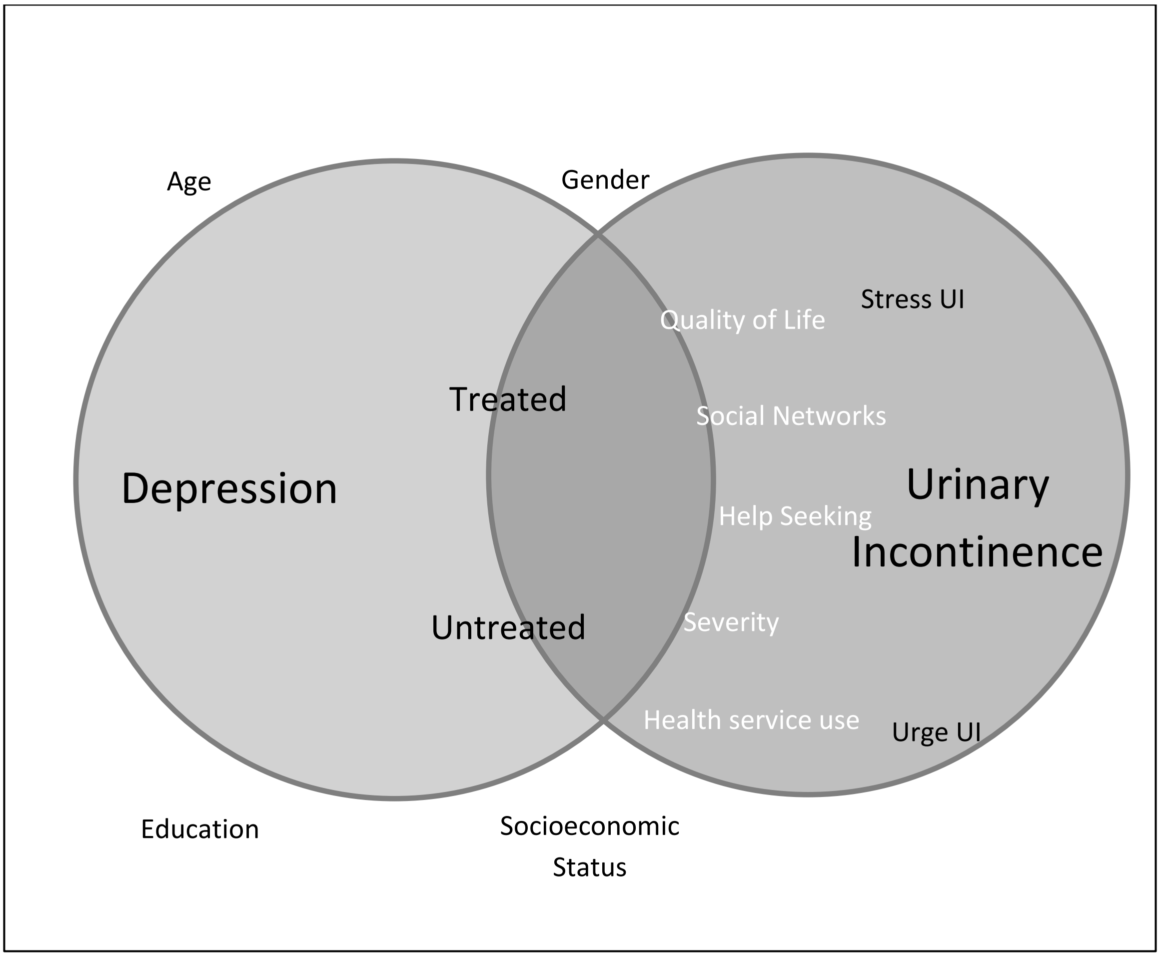


Figure 3.1 The relationship between Urinary Incontience, Depression and Psychosocial Factors

3.3.3 Resilience

A further concept that was explored, primarily in the qualitative studies of this research, is that of resilience. Resilience is a concept which has been used in the area of child psychology, particularly looking at how children fare after surviving adverse circumstances whilst growing up, such as disease, war, abuse, or neglect. Why are some children able to overcome adversity and succeed in life, where others fail[339]? Resilience describes the combination of abilities and characteristics that interact dynamically to allow an individual to bounce back, cope successfully and function in an above average way in spite of significant stress and adversity[340].

Resilience has been studied in relation to a number of different diseases, injuries and situations[341-343]. For people with urinary incontinence it has been found that increased resilience may contribute towards a buffering effect on depressive symptoms[344], and if we are able to increase resilience, we could lessen the overall impact of depression in those with incontinence.

These three theories have contributed to the development of the study design for this research, particularly with regard to exploring some of the psychosocial components that may contribute to reduced quality of life in those with incontinence and depression.

3.4 AIMS AND OBJECTIVES

The aims of this thesis are:

- To explore the relationship between depression and urinary incontinence, and demonstrate the effects of this association on psychosocial factors associated with incontinence, including help-seeking, quality of life, perceptions of symptom severity, and social networks.
- To explore the subjective experience of the burden of urinary incontinence in relation to mental health;
- To explore how people understand the relationship between urinary incontinence and depression.

The objectives of this thesis include:

- To explore the relationships between urinary incontinence and depression;
- To identify the psychosocial factors that are associated with chronic conditions, particularly urinary incontinence;
- To examine whether depression, experienced by those with urinary incontinence, is associated with other psychosocial factors, such help seeking behaviour, quality of life and social networks;
- To investigate how variables such as gender, age, socioeconomic status and other demographic factors, as well as type and severity of urinary incontinence, affect the mental health and psychosocial factors of those with urinary incontinence; and
- To analyse how mental health and urinary incontinence interact.

3.5 METHODOLOGY

3.5.1 Introduction to the Quantitative Component

Community based population surveys collect data about individuals' self-reports of illness and disease[45]. They enable information to be captured from respondents who do not consider that they have a problem, or may experience some other barrier to help seeking. The respondents include people from wide range of population groups living in different areas.

Accurate prevalence estimates for incontinence and depression inform who is at greatest risk so that preventive measures can be applied. Samples derived from clinical populations only consider those members of the community who have already sought help for their incontinence, thus excluding the majority of the community who for various reasons have not sought help.

The examination of data that have already been collected is known as secondary data analyses, and it involves and can be used for a variety of research study designs[345]. It allows for growth of the evidence base. Although, the researcher who undertakes the secondary an analysis is not usually involved in the design of the initial study, a secondary analysis is an opportunistic way to undertake research, as it is usually inexpensive, efficient and does not involve having to contact respondents.

South Australian population health data, that included questions regarding incontinence, mental health and psychosocial variables, were identified and used to answer the proposed research questions.

3.6 SPECIFIC INSTRUMENTS AND QUESTIONS ADMINISTERED

3.6.1 The South Australian Health Omnibus Survey

Quantitative data examined in this thesis were obtained retrospectively from the South Australian Health Omnibus Surveys (SAHOS) of Autumn 1998, and Spring 2001. As SAHOS is a user paid survey, the questions were purchased by a number of different users to answer different research questions. Therefore a number of questions although not originally linked could be subject to secondary combined analysis. Permission was obtained to use the majority of these data from the original purchasers.

Designed to investigate a range of health and health service issues, the Health Omnibus Surveys have been undertaken in South Australia every year since 1990. Questions submitted for SAHOS are reviewed by a management committee. The methodology has been peer reviewed and ethics approval for the questions used in these studies was obtained from the Women's and Children's Hospital Human Research Ethics Committee and the South Australian Department of Health Human Research Ethics Committee.

The following is a brief description of the methodology of SAHOS, however a more detailed description has been reported elsewhere[129]. SAHOS is a representative population survey conducted on an annual or biannual basis. It uses a clustered, self-weighting, systematic, multistage area sample of metropolitan and country areas with populations of more than 1000 people. However, hospitals, hotels and nursing homes are not included in the sample. There is also no replacement made for non-response.

Ten households are chosen from Australian Bureau of Statistics (ABS) collection districts via a random starting point and a fixed skip interval system. A collection district consists of approximately 225 dwellings. A letter of introduction is sent to each household from the study manager, who at the time of the data collection was the South Australian Department of Health (SAHOS 1998 and 2001 letters available in Appendix 1). Trained interviewers facilitate face to face interviews in each respondent's household. If the respondent is the person in the household to have the next birthday and they are aged fifteen years or over, then they are selected to be interviewed. In an attempt to secure an interview with the selected person, up to ten call backs are made. Approximately 3000 interviews are undertaken in each survey. Data from each survey are weighted by age, gender and geographical location to the most recent estimated residential population, correcting for any sample bias and providing accurate estimates for the South Australian population as a whole. The most recent Australian Bureau of Statistics Estimated Residential Population (ERP) data, (from 1997 and 2000) were used for the process of weighting. The response rates for the 1998 and 2001 surveys are given in Table 3.1.

Table 3.1: Response rates for South Australian Health Omnibus Survey (SAHOS)

Year	Number interviewed	Response rate (%)
1998 (Autumn)	3010	70.2
2001 (Spring)	3037	71.3

The data for these analyses were derived from a number of commonly used instruments, as well as from questions designed by the original users of the data to answer their own questions, over each of the two SAHOS studies. The instruments and questions assessing incontinence, depression and associate psychosocial outcomes are described briefly below (SAHOS 1998 and 2001 incontinence questions available in Appendix 1). Descriptions of the specific topics addressed in each dataset are described in the next section.

3.6.2 Diagnosis and Severity of Incontinence

The initial incontinence questions were used to estimate the prevalence of self-reported urinary incontinence, as well as its subtypes. Other questions assessed the seriousness, causes, severity as measured by use of incontinence protection aids, the costs of these aids, and information about help seeking, treatment, management and limitations. These questions were originally purchased by Professor Alastair MacLennan, Department of Obstetrics and Gynaecology, University of Adelaide from the Autumn 1998 SAHOS and the Spring 2001 SAHOS.

These questions are consistent with the definition of urinary incontinence by the International Continence Society (ICS), as being “the complaint of any involuntary leakage of urine in the context of type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life”[33]. The prevalence questions enabled direct comparison of prevalence rates between the South Australian and other populations and are described in Table 3.2. Respondents were considered to have urinary incontinence if they answered “yes” to either or both of these questions.

Table 3.2: Incontinence Prevalence Questions

Urinary Incontinence
Do you ever lose any urine when you don’t mean to, for example when you cough, sneeze or laugh?
Do you ever suddenly feel the urge to go to the toilet but accidentally wet yourself before reaching the toilet?

Table adapted from MacLennan et al 2000[102]

3.6.3 Diagnosis and Severity of Depression

3.6.3.1 *PRIME MD*

The dataset from the Autumn 1998 SAHOS also contained responses to the Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME MD)[130]. The PRIME MD has also been used in the qualitative component of the study to ascertain depression status. The PRIME MD is a reliable and valid screening tool for the assessment of depression using DSM-IV criteria[126]

The Primary Care Evaluation of Mental Disorders (PRIME-MD), is a two part evaluation that was developed in order to diagnose some of the most common mental disorders seen in primary care[130]. The first part of the questionnaire, the Patient Questionnaire (PQ), was designed to be completed by the patient or subject alone, and answers from this trigger follow-up modules in the Clinical Evaluation Guide (CEG), administered by a physician. There are five different modules included as part of the CEG, and these may or may not be administered as required. The modules, which reflect the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R)[155], include Mood, Anxiety, Alcohol, Eating Disorder and Somatoform. However, it was found that the time required for a clinician to administer the instrument was too long, so the PRIME MD Patient Health Questionnaire (PHQ) was developed for self-administration[156]. Self-administration enables the questionnaire to be used for population health studies as it is able to be mailed to the participant, read out either over the phone or in a face to face interview situation. The PRIME-MD Mood Module, alternatively known as the PHQ-9, has been used and validated in a number of population studies measuring depression[156-159]. In this study, the various mental disorders that can be identified with this questionnaire have been collapsed to indicate major depressive syndrome, other depressive syndrome or no depressive syndrome (The full PRIME MD questionnaire as well as scoring syntax used are available in Appendix 1).

3.6.4 Health Related Quality of Life Assessment

3.6.4.1 *The Short Form 36 (SF36)*

Respondents in the 1998 survey also completed the Australian Version 1 of the Medical Outcomes Study SF-36, in order to assess their health-related quality of life over the last four weeks.

This instrument has been validated for use in an Australian population and the well-documented interpretation and scoring methods of the SF-36 were followed[346,347] (The full SF-36 questionnaire as well as the scoring syntax used are available in Appendix 1).

Using multiple analysis of variance, mean scores were derived for this study, for each of the eight scales of the SF-36, adjusting for age and gender. To compare the scores of people with incontinence in relation to the total population distribution of scores, standard scores were calculated by dividing the difference between the score of the comparison group and that of the general population, by the standard deviation of the general population[348].

The mean score of the population was set at zero, and the deviation from this score was shown as a standard score. This means that 50% of the population score above zero and 50% score below. Additionally, component SF-36 dimensions were translated into two summary dimensions, the physical and mental component summaries (PCS and MCS)[349].

3.6.5 Help-Seeking

Behaviour undertaken by someone experiencing a problem to actively seek assistance from others can be described as help-seeking[202]. Help-seeking is most often measured in population surveys by directly asking respondents whether they had sought help or discussed symptoms of their problem with their physician or general practitioner. Help-seeking can also include talking to other health professional, family, friends or even seeking information from books, pamphlets or the Internet.

Research has concentrated largely on barriers to help-seeking experienced by different population groups including men[207,208,210,350,351], women[352,353], older people[354], young people[202], and different racial groups[211]. Barriers to help-seeking may include perception of need, stigma, and education, socioeconomic and attitudinal issues.

Questions regarding help-seeking were only asked of respondents with urinary incontinence. Data were available from the Autumn 1998 SAHOS, and the Spring 2001 SAHOS.

3.6.6 Demographics

Demographic information was collected on sex, age, marital status, household size, country of birth, highest education level achieved, annual household income, work status and area of residence. This information gives insight into differences in psychosocial factors with regard to inequalities and other barriers which may also be associated with depression and incontinence. Demographic data were available from the Autumn 1998 SAHOS, and the Spring 2001 SAHOS (recoding syntax used for analysis is available in Appendix 1).

3.7 ETHICS

The methodology of the Health Omnibus Survey has been peer reviewed and ethics approval for these particular studies was obtained previously from the Women's and Children's Hospital Human Research Ethics Committee and the South Australian Department of Health Human Research Ethics Committee[129]. Additionally, all submitted questions in SAHOS are reviewed by the SAHOS management committee. As the analyses described here for Studies 1 and 2 are secondary analyses of data, ethics approval was not obtained for these analyses.

Examples of the invitation letter and study information brochure sent to households for the Health Omnibus Study are included in Appendix 1.

3.8 SAMPLE SIZE CALCULATION (FOR STUDIES 1 AND 2)

General sample size calculations were calculated for both the linear regression and the logistic regression component of this analysis.

For the logistic regression analyses, a sample size of 196 was needed to detect a difference of 10% in the proportion of subjects who indicated they did seek help. This assumed an alpha of 0.05; power of 80% and a squared multiple correlation of depression with the other covariates in the model of 0.3. Working calculations are shown in Table 3.3.

Table 3.3: Sample Size calculation workings for logistic regression analyses

Logistic regression, test that Ç = 0 for one normal covariate, x, adjusting for prior covariates						
Column	1	2	3	4	5	6
Test significance level, alpha	0.05	0.05	0.05	0.05	0.05	0.05
1 or 2 sided test?	2	2	2	2	2	2
Proportion of observations at mean value of covariate	0.3	0.25	0.3	0.25	0.3	0.25
At I SD above mean, Proportion	0.15	0.15	0.15	0.15	0.15	0.15
Odds ratio = pß (1 - pÜ) / [pÜ (1 - pß)]	0.412	0.529	0.412	0.529	0.412	0.529
Coefficient, B = ln(odds ratio)	-0.887	-0.636	-0.887	-0.636	-0.887	-0.636
Squared corr. of x with included covariates	0.3	0.3	0.4	0.4	0.2	0.2
Power (%)	80	80	80	80	80	80
n	124	196	145	229	109	172

For the linear regression analyses, for power of 80% and alpha of 0.05, assuming that there were 3 control variables in the linear regression model with an R^2 of 0.2, a sample of 73 was required to detect an increase in R^2 of 0.08 when depression is added to the model. Working calculations are shown in Table 3.4.

Table 3.4: Sample Size calculation workings for multiple linear regression analyses

Multiple regression, test 0 increase in R^2 for B covariates adjusting for A covariates				
Column	1	2	3	4
Test significance level, alpha	0.05	0.05	0.05	0.05
Number prior covariates, A	3	3	3	3
Correlation, Rsquared, for A covariates	0.2	0.2	0.15	0.15
Number of covariates to add, B	1	1	1	1
Increase in Rsquared when B is added	0.05	0.08	0.05	0.08
Power (%)	80	80	80	80
n	120	73	128	78

The South Australian Health Omnibus Survey, with a sample size of 3000, provided enough cases for analysis so that sufficient statistical power can be achieved.

3.9 WEIGHTING OF SAHOS DATA

The following describes the process which is used to weight the sample data derived from the South Australian Health Omnibus Surveys (SAHOS). The sample data are weighted to correct for the disproportionality of the sample, with respect to the target population of interest. The weight reflects unequal sample inclusion probabilities as well as compensating for differential non-response and sampling frame undercoverage.

This weighting formula is based on a random selection of households and only one person within the household. The data are weighted by area (or region), age, sex, and probability of selection in the household to the most recent ABS Estimated Residential Population (ERP) or Census data.

The variables required for weighting are usually:

- area or region;
- age;
- gender; and
- the number of people in the household who were 15 years and older at their last birthday.

Records are removed from the sample if any of these variables were missing. If the respondent lives outside the surveyed area, then that record is also removed from the sample. The variables required form the ERP or Census are age and gender.

The survey gathered information on the location of the household: postcode, LGA or suburb. If the respondent lived outside of region survey then that record was removed from the sample.

Areas regions or boundaries are usually determined by postcode. Age is recoded into either 5 or 10 year age groups.

Thus, let

N_h	The population size of stratum *h*
N_h	The sample size of stratum *h*

From this information the following can be derived:

N	The total population size
n	The total sample size

The weighting formula for a particular region, where there are different probabilities of selection within each household *i* for each strata *h* (strata is area or region, gender and age). The weighting applied is:

$$\boxed{w_{h,i} = d_{h,i} \times \frac{N_h}{\sum_{i=1}^{n_h} d_{h,i}} \times \frac{n}{N}}$$

Equation 3.1: Weighting Formula for SAHOS

Where

$w_{h,i}$	is the weighting value for respondent *i* in stratum *h*.
$d_{h,i}$	is the household size of people age 15 years and over for respondent *i* in stratum *h*.

If the weighting formula is applied correctly, then the sum of all the weights should equal the sample size. The sample size for each cell (i.e. area/region by sex by age group), are greater than five.

3.10 ANALYTICAL METHODS

3.10.1 Univariate Analysis

3.10.1.1 *Odds Ratios, Chi-Square test and p-values*

After calculating prevalence data for each of the conditions of interest, as well as determining prevalences and counts for different population groups within these conditions, it was necessary to determine the associations between the outcome of interest (a dependant variable such as depression) and the exposure to other variables of interest (an independent variable such as age group).

SAHOS uses a cross sectional design, so the most appropriate method for analysis at the univariate level, was to produce odds ratios (OR) to measure the association between an exposure and an outcome. Put simply, the odds ratio is the ratio of the odds of an event occurring in one group to the odds of it occurring in another group. Odds Ratios are a measure of the level of effect. The OR for a given exposure is obtained within logistic models while controlling for confounders[355].

In these analyses confidence intervals (CI) were also produced for each odds ratio above 1.00. The confidence interval indicates the level of uncertainty around the measure of effect (precision of the effect estimate) which in this case is expressed as an OR. Most studies report the 95% confidence interval (95%CI).

In order to test the null hypothesis, that is that there is no significant difference between the expected and observed counts for our variables of interest, a chi-square ($\chi 2$) test can be used. A chi-square is a non-parametric statistical test, commonly used to compare observed data with data we would expect to obtain, according to a specific hypothesis.

A chi-square is the sum of the squared difference between observed (o) and the expected (e) data (or the deviation, d), divided by the expected data in all possible categories. The degrees of freedom can then be determined, and a *p*-value calculated.

A *p*-value is a common index for the strength of evidence. If this *p*-value is greater than say, 0.001, then the hypothesis can be accepted. If the *p*-value is less than 0.001, then we have not proved the null hypothesis and there is a significant difference between the groups of interest.

3.10.1.2 ***Analysis of Variance***

The mean scores of the dimensions of the SF36 were required for different populations, so the statistical test of choice was the Analysis of Variance (ANOVA). An F statistic is calculated which is the ratio of two independent variance estimates of the same population variance. It allows the means of various groups to be calculated in one overall evaluation.

Further, a factorial experiment was undertaken, where the effects of two or more factors are assessed in one experiment. This two way Analysis of variance allows us in one experiment to evaluate the effect of two independent variables (incontinence and depression) and the interaction between them. Also of interest were the interaction effects, when the effect of one factor is not the same at all levels of the other factor. An interaction occurs when the effect of one of the variables is not the same at each level of the other variable. These interactions can be explained visually on an interaction plot.

3.10.1.3 ***MANOVA***

Multivariate analysis of variance or multiple analysis of variance (MANOVA) is a statistical test procedure for comparing multivariate (population) means of several groups. Unlike univariate ANOVA, it uses the variance-covariance between variables in testing the statistical significance of the mean differences. It is a generalized form of univariate analysis of variance. It is used when there are two or more dependent variables. It helps to answer:

1. Do changes in the independent variable(s) have significant effects on the dependent variables?
2. What are the interactions among the dependent variables? and
3. Among the independent variables?

Statistical reports, however, will provide individual p-values for each dependent variable, indicating whether differences and interactions are statistically significant.

Multivariate analysis of variance is simply an ANOVA with several dependent variables (i.e. age and sex). ANOVA tests for the difference in means between two or more groups, while MANOVA tests for the difference in two or more vectors of means.

3.10.3 Multivariable Analysis

3.10.3.1 *Collinearity Diagnostics*

A model to describe the association, between the variables of interest, and their influence on this relationship was created.

Before commencing modelling, collinearity among the predictor variables was checked. Collinearity is one condition that can destroy a regression model as it introduces instability in the coefficients as a result of the similarity (high correlation) between variables that are presumed to be independent. So, when undertaking any kind of multivariable analysis the problem of collinearity (or multicollinearity) may arise. This undesirable situation where the correlations among the independent variables maybe very strong; when two X variables are highly correlated, essentially they both convey the same information. When this happens, the X variables are collinear and the results show multicollinearity. The Variance Inflation Factor (VIF) can be calculated in SPSS to measures multicollinearity in the model.

Multicollinearity increases the standard errors of the coefficients. Increased standard errors mean that coefficients for some independent variables may be found not to be significantly different from 0. Without multicollinearity and with lower standard errors, these same coefficients might have been found to be significant and the researcher may not have come to null findings in the first place. In other words, multicollinearity misleadingly inflates the standard errors.

Thus, it makes some variables statistically insignificant when they would be otherwise significant. In Study 1 and Study 2, multicollinearity was tested using the SPSS Collinearity diagnostics function in linear regression, before undertaking logistic regression.

3.10.3.2 *Logistic Regression*

Logistic regression models the relationship between a categorical dependent and one or more independent variables, which are usually (but not necessarily) continuous, and allows us to look at the fit of the model as well as at the significance of the relationships (between dependent and independent variables) that we are modelling. The underlying principle of binomial logistic regression however, and its statistical calculation, are quite different to ordinary linear regression.

Ordinary regression uses ordinary least squares to find a best fitting line, and comes up with coefficients that predict the change in the dependent variable for one unit change in the independent variable, however, logistic regression estimates the probability of an event occurring.

We want to predict from a knowledge of relevant independent variables the probability (p) that it is 1 (event occurring) rather than 0 (event not occurring). We do not want to predict a precise numerical value of a dependent variable. In linear regression, the relationship between the dependent and the independent variables is linear, and this assumption is not made in logistic regression.

Logistic regression is based on the probability of an event occurring, and allows us to calculate Odds Ratios, which are defined the ratio of the odds of an event occurring to it not occurring.

3.11 STUDY PLAN

This thesis used mixed methods[356] and thus it has into two parts. The first part was an analysis of existing South Australian data, comprising Studies 1 and 2. The second part consists of Study 3, which was a qualitative study examining themes arising out of the findings of the studies in Part 1.

The analyses primarily examine incontinence and depression and its relationship to a number of different psychosocial outcomes. Initially help seeking behaviour is examined, but health related quality of life and social capital are also discussed in order to determine if psychosocial factors influence the associations between incontinence and depression. Some of the variables analysed in each study are similar, however this serves to clarify the findings across years, as well as contribute to the reliability of the results.

3.11.1 **Study 1: SAHOS 1998**

In this study males and females, 15 to 95 years (n = 3010, response rate 70.2%) were interviewed face to face in the 1998 Autumn South Australian Health Omnibus Survey (SAHOS)[129]. Urinary incontinence was reported by 610 respondents. A full outline of the questions regarding incontinence in the 2001 SAHOS is included in Appendix 1.

3.11.1.1 ***Key Variables***

- *Urinary incontinence prevalence (stress and urge);*
- *Urinary incontinence, perceptions of cause and severity, limitations, management and help seeking; and*
- *Mental health - depression (PRIME MD).*

3.11.1.2 ***Other Variables***

- *Health related quality of life (SF-36);*
- *Health service usage*;
- *Social Capital / Networks; and*
- *Work status, Occupation, Education, Country of birth, Marital Status, Annual household income, Postcode.*

This preliminary study analyses data from the South Australian Health Omnibus of Autumn 1998 in order to answer the main question of whether incontinence in combination with depression has a greater association with quality of life that for the conditions by themselves. It concentrates on examining urinary incontinence and depression, as well as help seeking for urinary incontinence, and the association of quality of life and social capital with incontinence and depression. Both male and female subjects were included in this analysis. Using these data, the following univariate analyses were possible:

- Determine the prevalence of depression in people with different types and severity of urinary incontinence, using different measures of depression.
- Determine the prevalence of help seeking in people with different types of urinary incontinence.
- Determine the prevalence of help seeking in people with different types of urinary incontinence according to their depression status.
- Examine health related quality of life in people with urinary incontinence and depression, who have or have not sought help for incontinence.
- Examine differences in the socioeconomic status of people with urinary incontinence and depression, who have or have not sought help for their incontinence.
- Examine other demographic differences in people with urinary incontinence and depression, who have or have not sought help for their incontinence.
- Examine the use of social networks in people with urinary incontinence and depression, who have or have not sought help for their incontinence.
- Examine the health service usage of people with urinary incontinence and depression, who have or have not sought help for their incontinence.

3.11.1.3 ***Response Rates***

The response rate for the Autumn 1998 SAHOS was calculated at 70.2% due to the reasons presented in Table 3.5.

Table 3.5: SAHOS Autumn 1998 Response Rate Calculation

Response Rate Calculation HOS 1998		
Initial sample drawn		**4400**
less :		
Sample Loss		
Vacant houses (including holiday homes)	111	
Remaining sample		**4289**
less :		
Non Response		
Refusal (not interested, too busy etc.)	658	
Contact could not be established after six visits at different times of day/evening and different days of the week	408	
Respondent unable to speak English	73	
Selected respondent away for duration of survey	71	
Illness/mental incapacity	69	
Total interviews		**3010**
Response Rate		***70.2%***

3.11.1.4 *Analyses*

After recoding the incontinence data and determining a scoring methodology for the PRIME MD PHQ, and the SF36, the analysis described below was undertaken. Examples of the syntax used for recoding and scoring from SPSS are included in Chapter 13 Appendices for Section 1, Part 13.7.

Univariate analyses were conducted using SPSS Version 15.0[357]. Initial exploration of these data consisted of calculating odds ratios and statistical significance ($p<0.05$) for each demographic subgroup to find which had the highest prevalence of incontinence with depression. Then, multivariable analysis using SPSS[357] enabled an investigation into the associations of urinary incontinence and depression, considering help seeking behaviour, quality of life, social networks, health service usage and socio-demographic variables.

A model was constructed using variables related to incontinence and depression at the univariate level ($p<0.25$). In order to determine a model to predict statistically significant urinary incontinence with comorbid depression, related variables ($p<0.25$) were entered into a logistic regression[358]. Variables determined to be insignificant were progressively omitted until a satisfactory model was obtained. The associations were also examined to ensure there were no multicollinearity effects.

For the analysis of health related quality of life, means were generated for each dimension of the SF36 for the following groups: the overall population; those with no incontinence and no depression; those with incontinence only; those with depression only; and those with incontinence and depression.

Analysis of variance with a factorial structure (for depression and incontinence) was used to determine whether the mean scores of each of the eight dimensions of the SF36 were significantly different for each group effects using SAS[359], and to determine any interaction. Interaction plots were produced to illustrate these relationships.

This study provides evidence about the psychosocial outcomes experienced by people with incontinence and mental health problems, in terms of help seeking behaviour, limitations to life, quality of life and social networks.

3.11.2 **Study 2: SAHOS 2001**

Data analysed in Study 2 were collected from the 2001 Autumn SAHOS. There were 3037 respondents to the survey. The response rate was 71.3%.

For this study, UI was defined as a positive response to either of the first two questions shown in Box 1. For this analysis we only considered responses of the 1549 women respondents (51.0% of the sample). ‘Severe incontinence’ refers to use of incontinence management aids, which was defined as “using aids or products to help with the problem”. A full outline of the questions regarding incontinence in the 2001 SAHOS is included in Appendix 1.

3.11.2.1 *Key Variables*

- *Urinary incontinence prevalence (stress and urge), severity, perceptions of cause and seriousness, limitations, management and help seeking*

3.11.2.2 *Other Variables:*

- *Country of birth, ATSI status, Marital Status, Education, Occupation, Annual household income, Postcode.*

This study analysed data from the South Australian Health Omnibus of Spring 2001 and considered urinary incontinence and help seeking, perceptions surrounding incontinence, quality of life, social networks, health service usage, limitation on life and socio-demographic variables.

Using these data, the following univariate analyses were possible:

- The prevalence of help-seeking in people with different severities of urinary incontinence;
- Examine the seriousness and severity perceptions of women with urinary incontinence;
- Differences in the socioeconomic status of people with incontinence and whether this relates to their help seeking behaviour; and
- Demographic differences in people with incontinence and help seeking behaviour.

3.11.2.3 *Response Rates*

The response rate for the Spring 2001 SAHOS was calculated at 71.3% (see Table 3.6).

Table 3.6: SAHOS Spring 2001 Response Rate Calculation

Response Rate Calculation HOS 1998		
Initial sample drawn		**4400**
less :		
Sample Loss		
Vacant houses (including holiday homes)	141	
Remaining sample		**4259**
less :		
Non Response		
Refusal (not interested, too busy etc.)	588	
Contact could not be established after six visits at different times of day/evening and different days of the week	411	
Respondent unable to speak English	63	
Selected respondent away for duration of survey	83	
Illness/mental incapacity	75	
Terminated interview	2	
Total interviews		**3037**
Response Rate		***71.3%***

3.11.2.4 *Analyses*

Univariate and multivariate analysis enable an investigation into the associations between incontinence and help seeking behaviour, allowing for perceptions of severity and seriousness, limitations on life and socio-demographic variables.

For simplicity in this analysis, a simple random sample was undertaken. SAHOS uses a complex sampling methodology which typically increases estimates of variance and the width of confidence intervals compared to this simpler analysis. The extent of this is measured by the so-called design effect which in SAHOS was relatively small, between 1.1 and 1.2.

Logistic regression was used to explore the association of the response variable, the perception of seriousness of UI, in relation to possible explanatory variables: SPSS Version 19.0 was used for analyses[357].

This study provided evidence about the psychosocial outcomes experienced by people with urinary incontinence with an emphasis on barriers to help seeking behaviour.

3.11.3 Study 3: Qualitative Study

A qualitative study using a framework approach[360] to examine in-depth interviews with individuals regarding their experiences with psychosocial outcomes including help seeking for those with urinary incontinence and a mental health condition was also undertaken. A qualitative component of this study was useful so that the complexity and in-process nature of meanings can be explored[76,361]. The interview schedule was developed from a review of the literature (Chapter 8), as well as from the results of the initial quantitative studies. The methodology for this study is described in Chapter 9 and the results in Chapter 10.

4 IDENTIFYING THE QUALITY OF LIFE EFFECTS OF URINARY INCONTINENCE WITH DEPRESSION IN AN AUSTRALIAN POPULATION

PUBLICATION:

Avery J, Stocks N, Duggan P, Braunack-Mayer A, Taylor A, Goldney R, MacLennan A. Identifying the quality of life effects of urinary incontinence with depression in an Australian population. *BMC Urology*. 2013; 13(11).

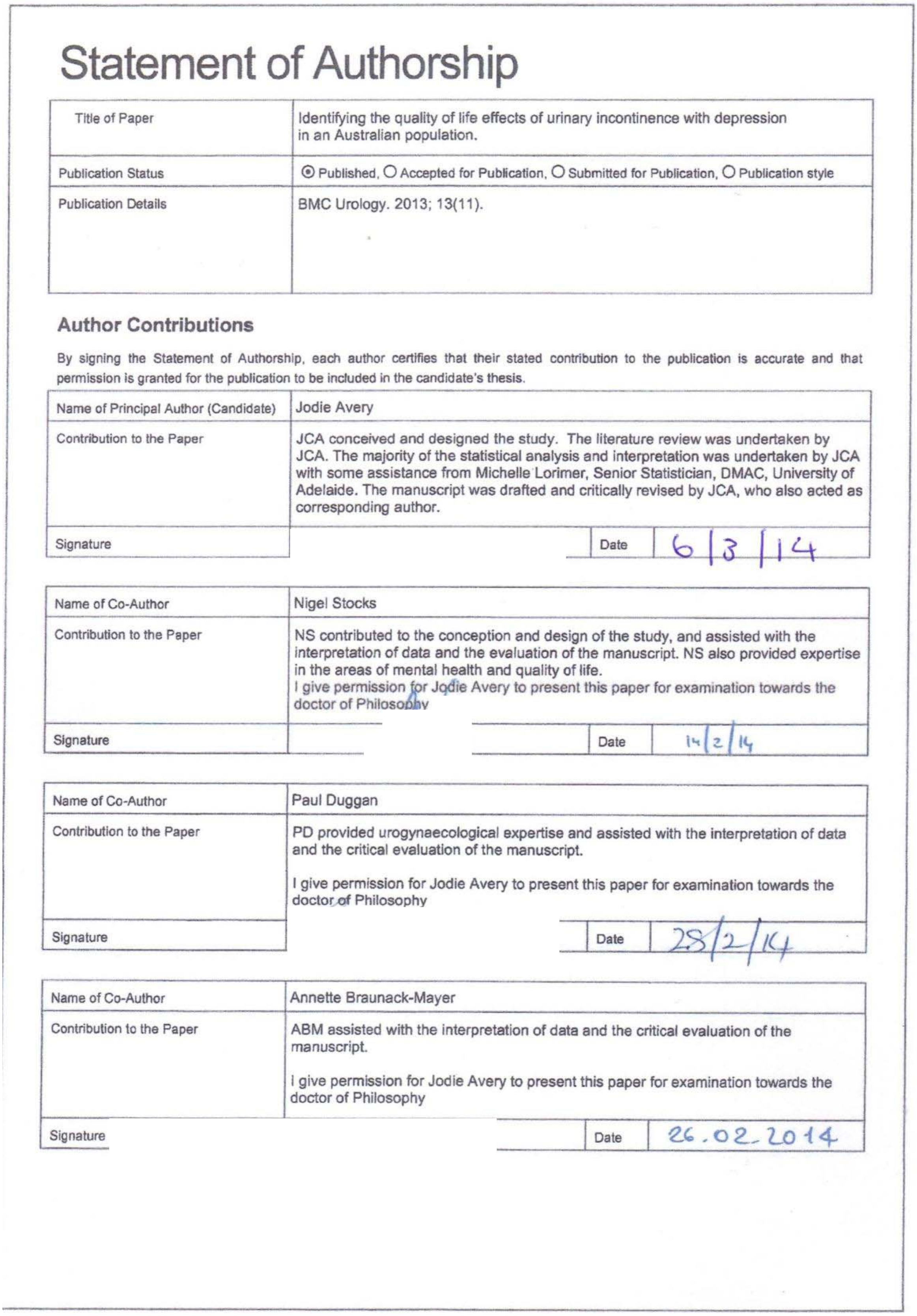
4.1 CONTEXTUAL STATEMENT

The following publication concerns one of the main aims of this thesis, that is: To explore the relationship between depression and urinary incontinence, and demonstrate the effects of this association on psychosocial factors associated with incontinence, including help-seeking, quality of life, perceptions of symptom severity, social networks and health service use. The main objective of the paper was to explore the relationships between urinary incontinence and depression; to examine whether depression, experienced by those with urinary incontinence, is associated with other psychosocial factors, such help-seeking behaviour, quality of life and social networks; and also analyse how mental health and urinary incontinence interact. We were also able to estimate the prevalence of depression in men and women with incontinence in Australia.

Little recent research has explored the associations between incontinence, psychosocial factors such as quality of life, and depression. This paper quantifies the relationship between incontinence, other psychosocial factors and depression in a community sample more explicitly. It found that depression and incontinence both reduce health-related quality of life. Occurring together they appear to create an additive effect which can affect both physical and mental health. From these findings we recommend that clinicians should identify and manage comorbid depression when treating patients who have incontinence to improve overall quality of life.

The published version of this paper as well as any citations of this paper, is available in Appendix for Section 1, at the end of this thesis, and a statement of authorship follows.

4.2 STATEMENT OF AUTHORSHIP



Statement of Authorship

Title of Paper	Identifying the quality of life effects of urinary incontinence with depression in an Australian population.
Publication Status	● Published, ○ Accepted for Publication, ○ Submitted for Publication, ○ Publication style
Publication Details	BMC Urology. 2013; 13(11).

Author Contributions

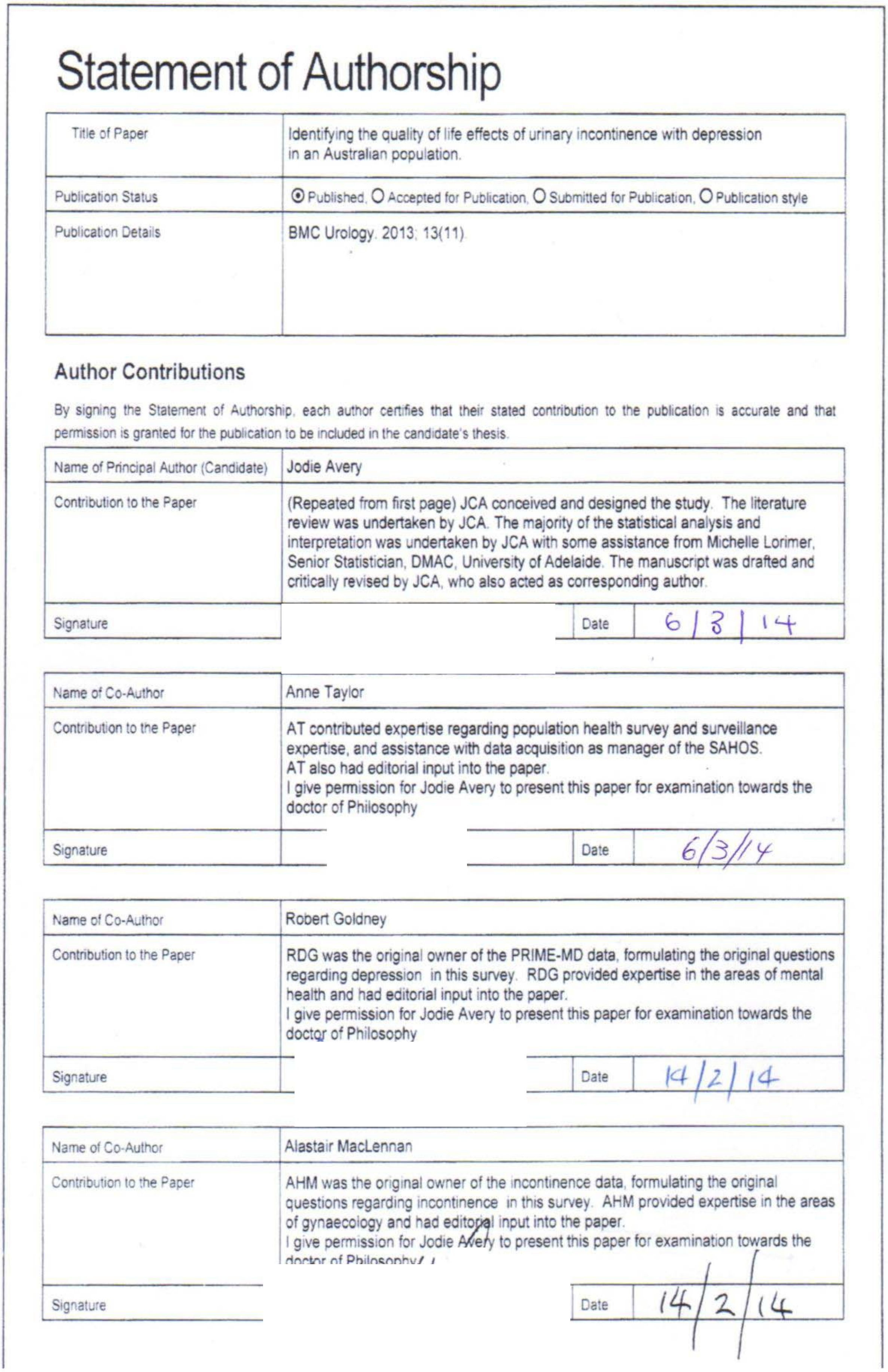
By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Jodie Avery		
Contribution to the Paper	JCA conceived and designed the study. The literature review was undertaken by JCA. The majority of the statistical analysis and interpretation was undertaken by JCA with some assistance from Michelle Lorimer, Senior Statistician, DMAC, University of Adelaide. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author.		
Signature		Date	6/3/14

Name of Co-Author	Nigel Stocks		
Contribution to the Paper	NS contributed to the conception and design of the study, and assisted with the interpretation of data and the evaluation of the manuscript. NS also provided expertise in the areas of mental health and quality of life. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	14/2/14

Name of Co-Author	Paul Duggan		
Contribution to the Paper	PD provided urogynaecological expertise and assisted with the interpretation of data and the critical evaluation of the manuscript. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	28/2/14

Name of Co-Author	Annette Braunack-Mayer		
Contribution to the Paper	ABM assisted with the interpretation of data and the critical evaluation of the manuscript. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	26.02.2014



Statement of Authorship

Title of Paper	Identifying the quality of life effects of urinary incontinence with depression in an Australian population.
Publication Status	● Published, ○ Accepted for Publication, ○ Submitted for Publication, ○ Publication style
Publication Details	BMC Urology. 2013; 13(11).

Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Jodie Avery		
Contribution to the Paper	(Repeated from first page) JCA conceived and designed the study. The literature review was undertaken by JCA. The majority of the statistical analysis and interpretation was undertaken by JCA with some assistance from Michelle Lorimer, Senior Statistician, DMAC, University of Adelaide. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author.		
Signature		Date	6/3/14

Name of Co-Author	Anne Taylor		
Contribution to the Paper	AT contributed expertise regarding population health survey and surveillance expertise, and assistance with data acquisition as manager of the SAHOS. AT also had editorial input into the paper. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	6/3/14

Name of Co-Author	Robert Goldney		
Contribution to the Paper	RDG was the original owner of the PRIME-MD data, formulating the original questions regarding depression in this survey. RDG provided expertise in the areas of mental health and had editorial input into the paper. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	14/2/14

Name of Co-Author	Alastair MacLennan		
Contribution to the Paper	AHM was the original owner of the incontinence data, formulating the original questions regarding incontinence in this survey. AHM provided expertise in the areas of gynaecology and had editorial input into the paper. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	14/2/14

4.3 ABSTRACT

4.3.1 Background

To explore the additive effect of urinary incontinence, in people with comorbid depression, on health-related quality of life.

4.3.2 Methods

Males and females, 15 to 95 years (n = 3010, response rate 70.2%) were interviewed face to face in the 1998 Autumn South Australian Health Omnibus Survey.

4.3.3 Results

Self-reported urinary incontinence was found in 20.3% (n=610), and depression as defined by the PRIME-MD in 15.2% (n=459) of the survey population. Urinary incontinence with comorbid depression was found in 4.3% of the overall population. Univariate analysis showed that respondents with urinary incontinence and comorbid depression were more likely to be aged between 15 and 34 years and never married when compared to those with incontinence only. Multivariate analysis demonstrated that in people with incontinence, the risk of having comorbid depression was increased by an overall health status of Fair or Poor, or the perception that their incontinence was moderately or very serious. Respondents reporting that they experienced incontinence with comorbid depression scored significantly lower than those experiencing incontinence without depression on all dimensions of the SF-36. The interaction of the presence of incontinence and the presence of depression was significantly associated with the dimensions of physical functioning.

4.3.4 Conclusions

Depression and incontinence both reduce QOL. When they occur together there appears to be an additive effect which affects both physical and mental health, perhaps by increasing a person’s negative perceptions of their illness. Clinicians should identify and manage comorbid depression when treating patients who have incontinence to improve their overall QOL.

4.4 BACKGROUND

Associations between urinary incontinence and depression have been found previously[31,223]. Explanations for this relationship include biochemical factors[223], or the severity of incontinence[242]. For instance in animal models, lowering monoamines such as serotonin and noradrenaline in the central nervous system lead to depression, urinary frequency and a hyperactive bladder[223]. Alternatively depression may be a result of persistent urinary incontinence, and individuals with altered monoamines in the central nervous system could manifest both depression and an overactive bladder[24]. It is also likely that psychosocial factors can help explain why people with incontinence may become depressed[227].

The prevalence of depression in those experiencing urinary incontinence varies in both clinical and population surveys from 20% to 40%[21,23,224]. Most studies consider the occurrence of depression and incontinence, without giving consideration to the chronological order or causal pathway of these comorbidities[16,21,224,227,236,237]. Some studies determine actual prevalence[21,23], some quote mean scores from depression scales[92], and some suggest a higher risk of depression in those with incontinence[244]. Many studies report the association between incontinence and depression, but venture no further[224,227,236].

Clearly incontinence and depression can affect quality of life (QOL) but only a few studies report this outcome. One population study of women with incontinence found that those with major depression reported significantly lower incontinence-specific quality of life using the I-QOL questionnaire[252]. A second telephone study of women with a mean age of 59 years, reported that major depression predicted the onset of urinary incontinence, but incontinence did not predict the onset of depression[238]. No studies have explored the impact on QOL due to the interaction between incontinence and depression.

This paper examines the QOL in people with urinary incontinence and depression in a population sample of Australian men and women. Our research focuses on psychosocial factors that could explain why people with urinary incontinence get depressed. Potentially this may be a result of incontinence limiting what they are able to do in their everyday lives. We hypothesized that the health-related QOL of people with urinary incontinence and depression would be lower than that of people experiencing one of these conditions alone.

4.5 METHODS

Data analysed in this study were collected in the 1998 Autumn South Australian Health Omnibus Survey (SAHOS)[129]. SAHOS has investigated a range of health issues since 1990 on an annual basis. It is a representative population survey using a clustered, self-weighting, systematic, multistage area sample of metropolitan and country areas with populations of more than 1000 people and interviews are conducted face-to-face with those aged fifteen years or over. The nature of an omnibus survey means that a number of not necessarily related questions regarding different topics are included from different users. Thus a number of questions not originally intended to be studied together may be analysed to answer a research question.

Data for this survey were weighted by age, sex and geographical location, correcting for any sample bias and providing accurate estimates for the local population overall[362]. The response rate was 70.2% (n = 3010). Questions submitted for SAHOS are reviewed by a management committee. The methodology has been peer reviewed and ethics approval was obtained from the Women’s and Children’s Hospital Human Research Ethics Committee and the South Australian Department of Health Human Research Ethics Committee[129].

In order to determine whether respondents experienced urinary incontinence, they were asked whether they had ever lost any urine when they did not mean to, when they coughed, sneezed or laughed, or if they had ever suddenly felt the urge to go to the toilet, but had accidentally wet themselves before reaching the toilet. Respondents were considered to have urinary incontinence if they answered “yes” to either or both of these questions. These questions reflect the definitions of urinary incontinence used by the International Continence Society (ICS) at the time of the survey, as being “the complaint of any involuntary leakage of urine in the context of type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life”[33].

An assessment of depression over the last month was made using the Primary Care Evaluation of Mental Disorders Questionnaire Patient Health Questionnaire (PRIME - MD PHQ)[130]. In this study, the various mental disorders that can be identified with this questionnaire have been collapsed to indicate major depressive syndrome, other depressive syndrome or no depressive syndrome.

The Medical Outcomes Study SF36 was also completed by all respondents in order to assess health-related quality of life over the last four weeks. Standard interpretation and scoring methods for the SF-36 were used, and the instrument has been validated for use in an Australian population[363,364].

Demographic information collected for this analysis included gender, age, marital status, household size, country of birth, highest education level achieved, annual household income, work status and area of residence.

Univariate analyses were conducted using SPSS Version 15.0[357]. Odds ratios and statistical significance ($p<0.05$) were determined for each demographic subgroup to find which had the highest prevalence of incontinence with depression.

The relationship between a number of variables, incontinence and depression were also explored using multivariate logistic regression analyses. A model was constructed using related variables ($p<0.25$) In order to determine a model to predict statistically significant urinary incontinence with comorbid depression, related variables ($p<0.25$) were entered into a logistic regression[358]. Variables determined to be insignificant were progressively omitted until a satisfactory model was obtained. The associations were examined to ensure there were no multicollinearity effects.

For the analysis of health-related quality of life, means were generated for each dimension of the SF36 for the following groups: the overall population; those with no incontinence and no depression; those with incontinence only; those with depression only; and those with incontinence and depression. Analysis of variance with a factorial structure (for depression and incontinence) was used to determine whether the mean scores of each of the eight dimensions of the SF36 were significantly different for each of these groups effects using SAS[359] and to determine any interaction.

4.6 RESULTS

4.6.1 Sample characteristics

Of the n=3010 participants in this study, 48.7% were male and 51.3% were female. The sample is described in Table 1 and these proportions are representative of the sex and age groups of the South Australian population.

4.6.2 Prevalence of urinary incontinence and depression

Table 2 examines the prevalence of urinary incontinence, depression (major or other depressive syndrome) and urinary incontinence with depression by various demographic variables. Urinary incontinence affected 20.3% (n=610) of the study population (male 4.4%, female 35.3%). Female respondents, born in the UK or Ireland, or who were widowed were significantly more likely to experience incontinence when compared with other groups. Those younger than 55 years, with trade or degree qualifications, never married, or a household income of above A$40,000 per annum, were significantly less likely to experience incontinence.

Table 4.1: Overall Sample Demographics

	Sample Demographics		
Variable	**n**	**%**	**95% CI**
Sex			
Male	1466	48.7	(46.9–50.5)
Female	1544	51.3	(49.5–53.1)
Age Group			
16–39 years	1388	46.1	(44.3–47.9)
40–59 years	1002	33.3	(31.6–35.0)
55 plus years	677	22.5	(21.0–24.0)
Country of Birth			
Australia	2267	75.3	(73.7–76.8)
UK/Ireland	382	12.7	(11.5–13.9)
Other	382	12.7	(11.5–13.9)
Marital Status			
Married / De facto	1851	61.5	(59.7–63.2)
Separated / Divorced	220	7.3	(6.4–8.3)
Widowed	187	6.2	(5.4–7.1)
Never Married	749	24.9	(23.4–26.5)
Income			
Up to $40,000	1484	49.3	(47.5–51.1)
$40,001 to $80,000	834	27.7	(26.1–29.3)
$80,001 plus	247	8.2	(7.3–9.2)
Not stated	445	14.8	(13.6–16.1)
Overall	3010	100.0	

Data Source: South Australian Health Omnibus Survey Autumn 1998
Note The weighting of the data can result in rounding discrepancies or tables not adding

Table 4.2: Univariate Analysis of Urinary Incontinence and Depression

	Population with Incontinence*				Population with Depression*				Population with Incontinence and Depression**			
Variable	n	%	OR (95% CI)	p value	n	%	OR (95% CI)	p value	n	%	OR (95% CI)	p value
Sex												
Male	65/1464	4.4	1.00		194/1464	13.3	1.00		19/65	29.3	1.00	
Female	546/1546	35.3	11.74 (8.97–15.37)	<0.001	264/1546	17.1	1.35 (1.11–1.65)	<0.001	106/546	19.5	0.58 (0.33–1.03)	0.065
Age Group												
55 plus years	272/853	31.9	1.00		118/853	13.9	1.00		50/272	18.4	1.00	
35–54 years	256/1070	23.9	0.67 (0.55–0.82)	<0.001	154/1070	14.4	1.04 (0.80–1.35)	0.753	50/256	19.5	1.08 (0.70–1.66)	0.742
16–34 years	83/1087	7.6	0.18 (0.13–0.23)	<0.001	186/1087	17.1	1.28 (1.00–1.65)	0.050	25/83	30.7	1.97 (1.13–3.45)	0.017
Area												
Metropolitan	417/2068	20.1	1.00		324/2068	15.7	1.00		92/417	22.1	1.00	
Country	194/942	20.6	1.03 (0.85–1.25)	0.758	134/942	14.2	0.89 (0.72–1.11)	0.742	33/194	17.2	0.73 (0.47–1.14)	0.163
Education												
No post school education	397/1682	23.6	1.00		298/1682	17.7	1.00		90/397	22.6	1.00	
Trade Qualifications	28/373	7.5	0.26 (0.17–0.39)	<0.001	53/373	14.1	0.76 (0.56–1.05)	0.096	6/28	21.5	0.94 (0.37–2.38)	0.889
Certificate/Diploma	131/599	21.8	0.90 (0.72–1.13)	0.373	74/599	12.4	0.66 (0.50–0.87)	0.003	24/131	18.1	0.76 (0.46–1.25)	0.280
Degree or higher	55/356	15.4	0.59 (0.43–0.80)	0.001	33/356	9.3	0.48 (0.33–0.70)	<0.001	6/55	10.6	0.41 (0.17–0.99)	0.047
Country of Birth												
Australia	439/2266	19.4	1.00		340/2266	15.0	1.00		88/439	20.0	1.00	
UK/Ireland	91/381	23.9	1.31 (1.01–1.69)	0.042	58/381	15.3	1.02 (0.76–1.38)	0.889	21/91	22.9	1.19 (0.69–2.05)	0.524
Other	81/363	22.2	1.19 (0.91–1.55)	0.209	60/363	16.5	1.11 (0.83–1.51)	0.478	17/81	20.6	1.04 (0.58–1.87)	0.894
Marital Status												
Married / De facto	439/1851	23.7	1.00		248/1851	13.4	1.00		78/439	17.7	1.00	
Separated / Divorced	57/221	26.0	1.13 (0.82–1.55)	0.453	52/221	23.7	2.01 (1.43–2.82)	<0.001	14/57	24.2	1.49 (0.77–2.85)	0.233
Widowed	73/187	39.2	2.07 (1.52–2.83)	<0.001	26/187	14.1	1.06 (0.69–1.64)	0.783	17/73	23.4	1.42 (0.78–2.57)	0.249
Never Married	40/748	5.4	0.18 (0.13–0.26)	<0.001	129/748	17.3	1.35 (1.07–1.70)	0.011	16/40	39.5	3.03 (1.54–5.97)	<0.001
Income												
Up to $40,000	357/1484	24.1	1.00		284/1484	19.2	1.00		96/357	26.8	1.00	
$40,001 to $80,000	132/834	15.8	0.59 (0.48–0.74)	<0.001	96/834	11.5	0.55 (0.43–0.70)	<0.001	12/132	9.2	0.28 (0.15–0.52)	<0.001
$80,001 plus	40/247	16.1	0.61 (0.42–0.87)	0.006	22/247	9.1	0.42 (0.27–0.66)	<0.001	6/40	16.3	0.53 (0.22–1.27)	0.155
Not stated	82/444	18.4	0.71 (0.55–0.93)	0.013	56/444	12.6	0.61 (0.45–0.83)	0.002	11/82	13.4	0.42 (0.21–0.83)	0.012
Overall	610/3010	20.3			459/3010	15.2			125/610	20.5		

Data Source: South Australian Health Omnibus Survey Autumn 1998 Note The weighting of the data can result in rounding discrepancies or tables not adding

*Of the total population **Of those with Incontinence

Respondents with a major (6.7%) or other depressive (8.6%) syndrome made up 15.2% (n=459) of the study population (male 13.3%, female 17.1%). Females, those separated or divorced, or never married were more likely to experience depression compared to other groups, whereas those with a certificate or diploma or degree or higher, or with a household income greater than A$40,000 per annum were less likely to experience depression.

Overall it was found that 4.3% of the population experienced urinary incontinence with comorbid depression. There was a statistically significant higher rate of major or other depressive syndrome in the urinary incontinent (20.5% [n=125/610]) compared with those without urinary incontinence (13.9% [n=333/2399]). Of these respondents with urinary incontinence, 29.3% of males and 19.5% of females experienced a major or other depressive syndrome. It was found that those aged 16 to 34 years and never married were significantly more likely to experience depression if they also had urinary incontinence, whereas those with a bachelor’s degree or higher, a household income of A$40,001 to A$80,000 per annum or did not state their income, were significantly less likely to experience depression if they were urinary incontinent.

Multivariate analysis showed that variables jointly identified as increasing the risk urinary incontinence with depression were those with Fair or Poor overall health and those who thought that their urinary incontinence was moderately or very serious. Respondents who had a household income between A$40,001 and A$80,000 per annum or did not state their income, were not current smokers, and had a lifetime occupation of being a tradesperson were less likely to have incontinence with depression (model $\chi^2 = 167.22$, df = 53, $p < 0.001$) (Table 3).

Table 4.3: Multivariate analysis of variables which determined incontinence with comorbid depression

Variables	n	%	OR (95% CI)	p value
Overall health status				
Excellent	9/106	8.7	*1.00*	
Very Good	24/198	12.3	1.48 (0.61–3.62)	0.385
Good	20/154	13.2	1.32 (0.51–3.38)	0.568
Fair	51/116	44.1	9.84 (3.80–25.48)	<0.001
Poor	20/37	54.6	12.74 (3.78–42.95)	<0.001
Income				
Up to $40,000	96/357	26.8	*1.00*	
$40,001 to $80,000	12/132	9.2	0.30 (0.14–0.68)	0.004
$80,001 plus	6/40	16.3	0.38 (0.12–1.22)	0.106
Not stated	11/82	13.3	0.41 (0.18–0.95)	0.037
Smoking status				
Current smoker	40/115	34.5	*1.00*	
Ex-smoker	32/188	16.8	0.46 (0.23–0.95)	0.035
Non smoker	54/308	17.5	0.46 (0.24–0.89)	0.021
Lifetime Occupation				
Not employed	31/119	26.3	*1.00*	
Managers & Administrators	6/33	18.3	0.70 (0.21–2.33)	0.561
Professionals	9/56	15.3	1.00 (0.29–3.47)	0.995
Para-Professionals	5/39	12.8	0.34 (0.08–1.40)	0.135
Tradespersons	7/42	16.9	0.25 (0.07–0.90)	0.034
Clerks	23/141	16.1	0.82 (0.37–1.84)	0.636
Sales or Service workers	19/87	21.8	1.01 (0.43–2.36)	0.989
Drivers & Machine Operators	4/16#	23.9	--	--
Labourers	22/76	28.2	0.65 (0.26–1.58)	0.337
Not stated	0/1#			
How serious				
Not very, not serious, refused	92/504	18.3	*1.00*	
Very/moderately serious	33/102	32.6	2.30 (1.20–4.41)	0.012
Overall	125/610	20.5		

Data Source: South Australian Health Omnibus Survey Autumn 1998
Note The weighting of the data can result in rounding discrepancies or tables not adding
Numbers too small for statistical analysis

4.6.3 UI, depression and quality of life

Health-related quality of life was assessed for people with different combinations of urinary incontinence and depression. Groups that were mutually exclusive were compared using analysis of variance for significant differences. Mean scores adjusted for age and sex for each of the eight dimensions of the SF-36 scale were calculated and results are presented in Table 4.

Table 4.4: SF36 Mean Scores for people with urinary incontinence, depression and combinations of these conditions (adjusted for age and sex)

	n	PF	RP	BP	GH	VT	SF	RE	MH
No Incontinence and No Depression	2066	88.07	84.93	75.55	77.92	69.39	92.67	95.16	85.04
General Population	*3010*	*85.31*	79.82	72.54	73.91	64.35	87.90	87.83	79.99
Incontinence without Depression	486	85.00[aa]	78.58[aa]	72.72[aa]	74.25[aa]	65.46[aa]	91.10	91.53[aa]	82.40[aa]
Depression without Incontinence	333	77.49[aabb]	64.29[aabb]	61.84[abb]	60.13[ab]	43.90[ab]	67.56[ab]	58.12[ab]	58.37[ab]
Incontinence with Depression	125	66.33[abc]	49.88[abcc]	56.11[ab]	50.60[abcc]	40.94[ab]	61.41[ab]	46.72[abcc]	55.28[ab]
p-value for interaction term		0.0002	0.046	0.27	0.02	0.54	0.09	0.02	0.97

[a] Statistically significantly lower (*t* test p<0.001) than those with no incontinence and no depression
[aa] Statistically significantly lower (*t* test p<0.05) than those with no incontinence and no depression
[b] Statistically significantly lower (*t* test p<0.001) than those with incontinence but no depression
[bb] Statistically significantly lower (*t* test p<0.05) than those with incontinence but no depression
[c] Statistically significantly lower (*t* test p<0.001) than those with depression but no incontinence
[cc] Statistically significantly lower (*t* test p<0.05) than those with depression but no incontinence

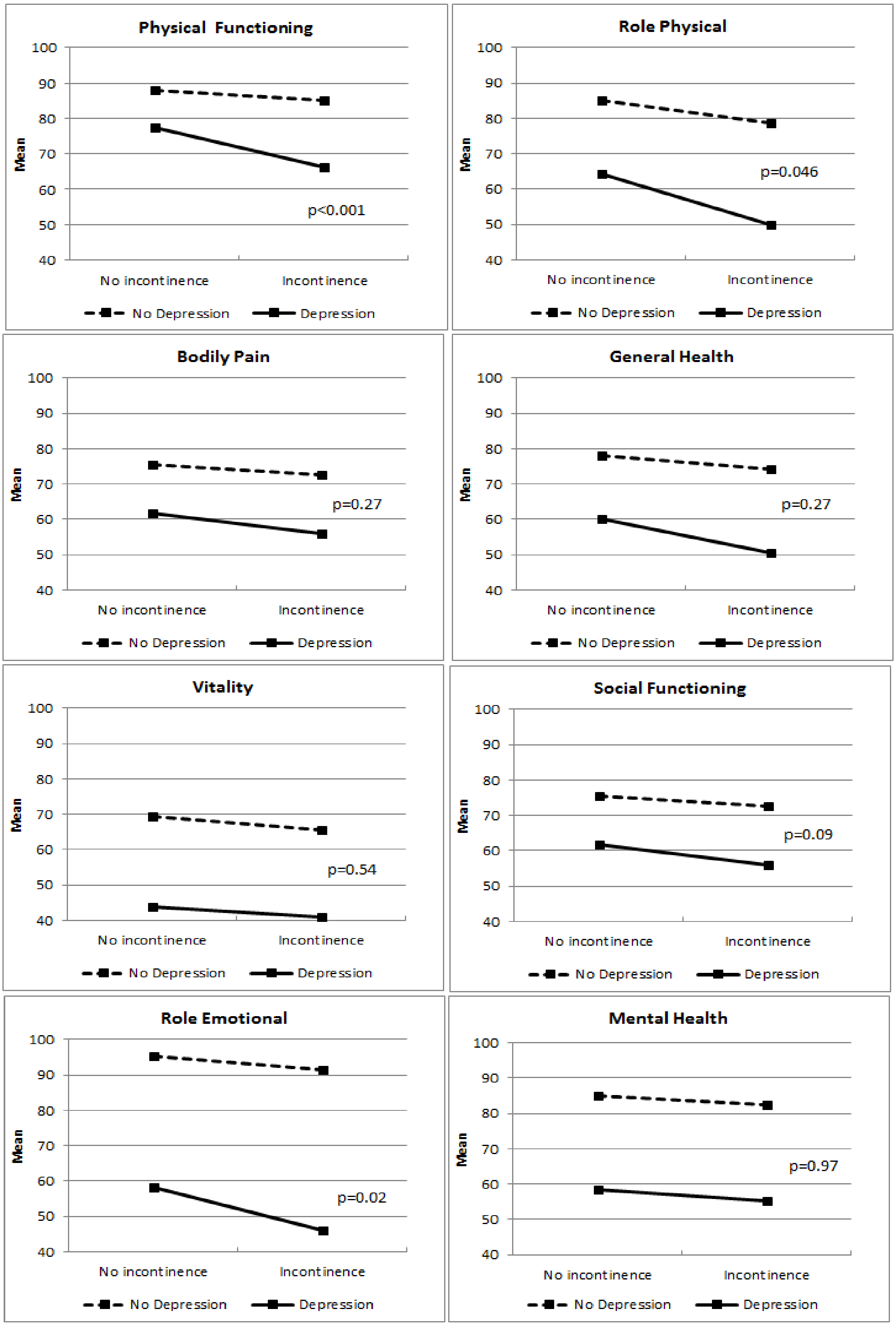
Respondents who reported that they experienced urinary incontinence with depression scored significantly lower than those experiencing neither urinary incontinence nor depression, and also with those with urinary incontinence but no depression, on all dimensions of the SF-36 (Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH) (Vitality (VT), Mental Health (MH), Social Functioning (SF), Role Emotional (RE) ($p < 0.05$)). Additionally this group scored significantly lower on most dimensions than those with depression only (PF ($p < 0.001$); RP, GH, RE ($p < 0.05$)).

Overall, respondents with depression only, scored significantly lower across all dimensions of the SF-36 (PF, RP, ($p > 0.05$) BP, GH, VT, RE, MH ($p<0.001$)), when compared with those respondents who had no depression and no urinary incontinence, and significantly lower than those with urinary incontinence only (PF, RP, BP ($p > 0.05$), GH, VT, SF, RE, MH ($p<0.001$)).

Those respondents with incontinence only, scored significantly lower across most dimensions of the SF-36 except for Social Functioning (PF, RP, BP, GH, VT, RE, MH ($p > 0.05$)), when compared with those respondents who had no depression and no urinary incontinence.

The interaction term was statistically significant for PF, RP, GH, and RE. For BP, VT, SF and MH the main effect for depression and the main effect for urinary incontinence were both statistically significant. For ease of interpretation the interaction means for all standardized scores are presented in Table 4.

Figure 4.1: Quality of Life interaction plots for people with and without Incontinence, and with and without Depression (adjusted for age and sex).



For each of the standardized scores, the mean score for each combination of depression and urinary incontinence is presented graphically in an interaction plot (Figure 1). The lines drawn between the means allow visual interpretation of the interactions.

The effect of depression results in a much greater reduction in mean score for both the not incontinent group and the incontinent group. However, the significance of the interaction (for PF, RP, GH and RE) is most likely due to those who have both depression and urinary incontinence having a significantly greater reduction in score, compared to those with depression who are not urinary incontinent. Although this reduction in mean score was observed for the other SF36 score variables (BP, VT, SF and MH) also, the difference was not large enough to be statistically significant.

4.7 DISCUSSION

In this face to face survey of 3010 South Australians self-reported urinary incontinence was found in 20.3% (n=610), depression in 15.2% (n=459) and both in 4.3% of respondents. Those with urinary incontinence and comorbid depression were more likely to be aged between 15 to 34 years and never married when compared to those with only incontinence.

Multivariate analysis demonstrated that in those with urinary incontinence, an overall health status of Fair or Poor, or the perception that their incontinence was moderately or very serious, increased the risk of having comorbid depression. Depression had a marked effect on QOL for the general population and a significant, additive effect on those with incontinence. Respondents who reported that they experienced urinary incontinence with comorbid depression scored significantly lower than those experiencing incontinence without depression on all dimensions of the SF-36. The interaction between urinary incontinence and depression had a significant effect on the physical functioning dimensions of quality of life.

The quality of life of people who experience urinary incontinence with depression, in both adult females and males of all age groups, has not been assessed previously via population surveys using face to face interviews. Other studies have assessed this qualitatively, or have discussed stigma, and other problems associated with incontinence including depression. But how urinary incontinence and depression interact and affect QOL has not been considered[53,61,232,254].

A lack of population data prompted the retrospective analysis of an existing dataset, already available from the 1998 SAHOS, where questions regarding urinary incontinence, depression and quality of life were asked together. At the time of this study, the questions about urinary incontinence were not validated, however they reflected the definition used by the International Continence Society (ICS)[33]. They have since been validated by other authors[79].

This study has several limitations. Firstly the symptoms of urinary incontinence were not clinically quantified. However, in a population study of this size, it would not be practical to clinically examine cases for this condition, and prevalence rates using self-report have been found to be similar and cost less compared to those found from diagnostic tests[365]. Secondly because recall times differ for urinary incontinence, depression and the quality of life measures, it is possible, that depression and urinary incontinence did not co-exist when the survey was administered. However urinary incontinence and depression are relapsing and remitting conditions and it is difficult to examine the temporality and causality in a cross sectional study. Lastly the use of the PRIME MD in this study to determine depression deviates slightly from the original intentions of its authors[130], as the initial depression screening questions were not used, and the mood module was administered to all in the study. However the prevalences of urinary incontinence (20.3%) [86] and major (6.7%) or other (8.6%) depressive syndrome (15.2%) [135] are comparable with other studies. Circumstances where both these conditions occur together (20.5% of those with urinary incontinence) are also equivalent to international studies[21,366].

Univariate analysis indicates that younger people, and those never married were more likely to experience depression when they had urinary incontinence. This is not unexpected, as incontinence is often considered a disease of older women who have had children, possibly a plausible explanation for their incontinence. In the above group, there may not be an explanation for the condition, leading to a state of low mood and depression.

In the multivariate analysis, self-reported Fair or Poor health, and the perception that one's own urinary incontinence was moderately or very serious were strongly predictive of having incontinence with depression. This may indicate that one's own perceptions of a condition, and their overall health may lead to an increased likelihood of experiencing mental illness. However as this study was cross sectional, we were unable to determine whether the depression was caused by incontinence, or a person's depression increased their perception of symptom severity. This will be explored in future qualitative work.

In the quality of life analysis, we compared respondents with “Incontinence with depression” to those with “Incontinence without depression”. “Incontinence with depression” describes respondents who answered in the positive for any of the incontinence questions, and includes those who also scored positively for depression by the PRIME-MD. “Incontinence without depression” includes respondents with urinary incontinence, not diagnosed with depression by the PRIME-MD in this survey. Respondents with urinary incontinence and depression scored significantly lower on all dimensions of the SF 36, with depression scoring lower than urinary incontinence and those with both conditions together scoring lowest of all. When these conditions occur together, there was a major additive effect particularly in the Mental Health scales, greater than that with either condition alone. It appears that depression increases a person’s negative perceptions of their physical symptoms (incontinence) reducing their QOL scores further than would be expected if either condition occurred independently. This effect is also reflected in the interaction between incontinence and depression and its impact on the QOL dimensions that measure physical functioning.

It may be that identifying and treating depression in a person with urinary incontinence, a patient’s mental health (QOL) will not only improve but also, indirectly their physical QOL.

4.8 CONCLUSIONS

Depression and urinary incontinence both reduce QOL. When they occur together there appears to be an additive effect which affects both physical and mental health. Clinicians should identify and manage comorbid depression when treating patients who have incontinence to improve their overall QOL.

5 URINARY INCONTINENCE: SEVERITY, PERCEPTIONS AND POPULATION PREVALENCE IN AUSTRALIAN WOMEN

PUBLICATION:

Avery JC, Stocks N, Taylor AW. Gill TK. Perceptions and prevalence of urinary incontinence in the Australian population. *Australian and New Zealand Continence Journal*. Autumn 2014; **20**(1): 7-13.1

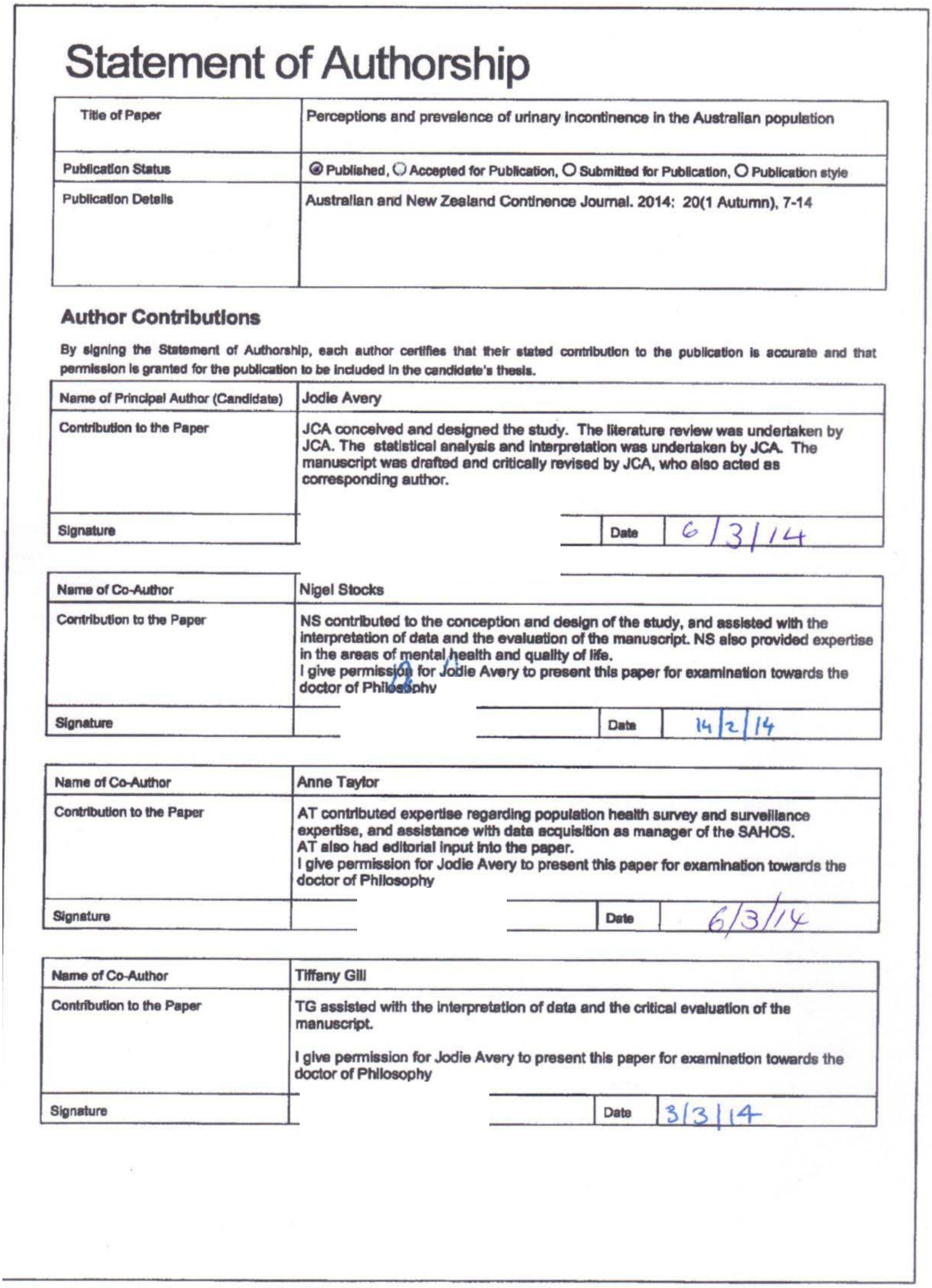
5.1 CONTEXTUAL STATEMENT

This paper addresses the aim of this thesis to explore the subjective experience of the burden of urinary incontinence in relation to mental health. Another objective was to investigate how variables such as gender, age, socioeconomic status and other demographic factors, as well as type and severity of urinary incontinence, affect the mental health and psychosocial factors of those with urinary incontinence. The paper examines perceptions of seriousness of incontinence and compares this with the behaviours exhibited by women with incontinence to manage their condition. The scope of this paper was limited to women only, as the sample did not provide a very large group of men – especially when broken down by type of incontinence. An updated prevalence of overall incontinence has been provided as well as prevalence broken down by type and severity.

Many barriers to help-seeking have been reported in the literature; however the psychosocial aspects have been neglected when identifying why women approach health professionals when they have a problem with incontinence.

This paper describes how the severity and limitations to lifestyle were predictors of women perceiving that their incontinence was moderate to very serious. This is important because help-seeking for incontinence may improve if education and information target women who perceive they have a serious condition, already use continence management aids, have difficulty being involved in activities or use other management strategies for their incontinence. The published version of this paper is available in Appendix for Section 1, at the end of this thesis. A statement of authorship also follows.

5.2 STATEMENT OF AUTHORSHIP



Statement of Authorship

Title of Paper	Perceptions and prevalence of urinary incontinence in the Australian population
Publication Status	● Published, ○ Accepted for Publication, ○ Submitted for Publication, ○ Publication style
Publication Details	Australian and New Zealand Continence Journal. 2014: 20(1 Autumn), 7-14

Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Jodie Avery		
Contribution to the Paper	JCA conceived and designed the study. The literature review was undertaken by JCA. The statistical analysis and interpretation was undertaken by JCA. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author.		
Signature		Date	6/3/14

Name of Co-Author	Nigel Stocks		
Contribution to the Paper	NS contributed to the conception and design of the study, and assisted with the interpretation of data and the evaluation of the manuscript. NS also provided expertise in the areas of mental health and quality of life. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	14/2/14

Name of Co-Author	Anne Taylor		
Contribution to the Paper	AT contributed expertise regarding population health survey and surveillance expertise, and assistance with data acquisition as manager of the SAHOS. AT also had editorial input into the paper. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	6/3/14

Name of Co-Author	Tiffany Gill		
Contribution to the Paper	TG assisted with the interpretation of data and the critical evaluation of the manuscript. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
Signature		Date	3/3/14

Avery, J.C., Stocks, N., Taylor, A.W. & Gill, T.K. (2014) Urinary incontinence: severity, perceptions and population prevalence in Australian women.
Australian and New Zealand Continence Journal, v. 20(1), pp. 7-13

NOTE:
This publication is included on pages 131-141 in the print copy of the thesis held in the University of Adelaide Library.

SECTION 2

6 BRIDGE

The next section of this thesis explores the psychosocial experiences of women living with incontinence primarily from the perspective of their mental health status. Once the quantitative components of this study had been completed, it was clear that there were many unanswered questions surrounding the psychological experiences of women with incontinence. The effect of depression on the quality of life of people with incontinence had been observed, as well as the influence one's own perception of the condition had on behaviour, lifestyle and help seeking.

Incorporating a qualitative component to this study allowed the complexity and in-process nature of meanings to be explored. Using in-depth interviews was appropriate for the study questions. Undertaking a mixed methods study to explore concepts such as depression, enabled context to be provided, particularly in the light of demographic information[314]. Although different samples were used for each of the studies, we found similar experiences in each of the groups.

Section 2 of this thesis describes the development of a qualitative study. A systematic search of the qualitative literature was undertaken to explore areas that needed to be addressed when talking to women with incontinence. The methodology for undertaking this task was researched, as was the rationale for the technique of synthesizing the literature. This technique, known as a "Metasynthesis" was undertaken, and used to develop the interview schedule for the qualitative study. A description of the methodology used in this study, as well as a reflection on the journey to the development of the study is provided. Finally, the analysis and findings from the interview study itself are detailed.

Using both quantitative and qualitative data in this thesis enabled a more complete view of the research questions to be developed. It enabled an examination of these questions from a number of different perspectives, including participants, other researchers and myself.

7 SYNTHESIZING THE MEANINGS: THE RATIONALE FOR UNDERTAKING A METASYNTHESIS

7.1 INTRODUCTION

The following discussion explores the methodology and reasoning behind undertaking a metasynthesis. I embarked upon this task because I wanted to explore the best methodology for deciding how to develop an interview schedule to discover the experiences of women with incontinence and depression, particularly from the qualitative literature. The following chapter provides a description of this type of review, the reasons for undertaking a metasynthesis, the different types, the procedures, as well as a discussion of critiques of the process.

7.2 WHAT IS A METASYNTHESIS?

In empirical quantitative research, reviews that combine the findings of studies concerning similar hypotheses and methodologies have been developed. This methodology, known as meta-analysis or systematic review, combines evidence from multiple studies, thereby increasing the statistically power, to answer defined questions[374]. These types of analyses produce evidence of the highest standard.

In qualitative research, where research is concerned more with context, methodologies are diverse. Using a prescriptive method of aggregating and combining studies is not appropriate, and can lead to a loss of information[375]. A parallel way to bring together various forms of qualitative research is metasynthesis, sometimes known as meta-ethnography or qualitative meta-analysis. The key distinction between an quantitative amalgamation of studies and a qualitative synthesis, is that the qualitative examination yields results that are interpretive, rather than the aggregative findings from quantitative studies[376]. Put another way, understanding and explaining phenomena, rather than increasing the certainty of conclusions, is a key difference between the quantitative and qualitative methodologies[377].

7.3 WHY UNDERTAKE A METASYNTHESIS?

Metasynthesis enables us to become more confident about using qualitative literature to fill evidence gaps, as findings from a number of studies may become more conclusive after a synthesis is performed[378]. An advantage of this to the individual researcher is that, in undertaking a metasynthesis, an investigation can be further progressed rather than continuing to undertake smaller pieces of work which may elicit very similar findings[376] and broader perspectives maybe achieved that that found by the individual researcher[379]. Theories and hypotheses may then evolve which are able to be tested by other researchers within their own area, and these theories may have greater explanatory power than those derived from a literature review[375,380]. The value added nature of a meta synthesis is that the result is greater than the sum of all its parts[381].

7.4 WHAT TYPES OF METASYNTHESIS ARE THERE?

The field of metasynthesis is not new, but neither has it been in existence long enough for a preferred methodology to be defined. The diversity of theoretical persuasions and methodological techniques of qualitative researchers means that such a solution may never be found. Methods are evolving but need to be tried and tested before the most preferred techniques can be established[377]. A number of similar methods have evolved including *Cross Case Analysis*[382], *Case Survey Method*[383], and *Multiple Exemplar Strategy*[384]. Other methods include *Theory Building,* where the level of theory is extrapolated beyond the theory of a single investigation; *Grounded Formal Theory* which uses grounded theory to develop a more comprehensive model; and *Meta-study* which includes Meta-data Analysis, Meta-method and Meta-theory techniques. Additionally, there is *Theory Explication*, where abstract concepts are fleshed out to reconceptualise original phenomenon, and the *Descriptive Meta-synthesis*, where findings are generally not deconstructed[376]. Many of these methods overlap and are not mutually exclusive entities[376].

One approach seems to be favoured by many researchers, possibly because its method is grounded in the originating paradigm of qualitative research[369,381-384]. This method, known as *Meta-ethnography*[375], is one of the most developed, and originated in educational research. It has often been applied across studies with diverse theoretical foundations[385]. The techniques of meta-ethnography has much evolved since first introduced by Noblit and Hare[381].

The structure of a meta-ethnography resembles the qualitative methods of the studies it aims to synthesise. Its main aim is to translate studies into one another, with studies relating to each other in one of three ways[386]. They may be directly comparable as reciprocal translations, they may stand in opposition to each other as refutational translations or they can be taken together to represent a line of argument. In outlining methodological approaches of metasynthesis, an number of publications have discussed Noblit and Hare's method, and proposed it as the best example of the methodology[376-378,387,388].

7.5 HOW DO YOU UNDERTAKE A METASYNTHESIS?

The various methods of metasynthesis follow a similar structure[376]. Study focus, such as the topic, aims and objectives are determined first, then a sampling strategy formulated, with data analysis undertaken as the final step, not unlike the standard scientific method.

Noblit and Hare describe a step by step method for undertaking such an analysis within the technique known as a meta ethnography[386]. This method involves seven distinct steps[375]. Obviously, once the decision has been made that research in one's area need to be brought together, perhaps to discover gaps in the literature, reinforce hypotheses before embarking on new study, or just to make sure research will not be replicated unnecessarily, the first step is to embark on metasynthesis.

Next, determining the focus of the study or deciding what is relevant to the initial interest. This may be guided by the researcher's own field[376]. This crucial part includes defining the scope of the study as well as sampling, however it is not advisable to have too firm selection criteria as loss of valuable data may result from being too restrictive[376]. The sample is a purposive sample, not necessarily an exhaustive one, as the results will be interpreted not predicted. A researcher may benefit by becoming comfortable with particular methods of literature searching, taking advice from expert librarians familiar with databases and search terms.

Thirdly, the studies should be examined, perhaps more than once, particularly to verify whether they enter into the scope of the analysis in question, and to appreciate the detail[386]. Then, a determination of how the studies are related is undertaken, including the identification of themes, perhaps using a grid method, or a qualitative analysis software package[376].

The studies are then translated into one another, such that overarching similar themes and metaphors are derived from each study[381,386].

Penultimately, these translations are synthesised, determining whether results are similar and directly comparable (reciprocal), whether they contradict each other, such that they are in opposition or difference (refutational), or whether they represent a line of argument, agreement or higher level similarity, which can build up a description of the complete nature of the argument[381].

Finally the synthesis is expressed, through reporting and publication[386], or more practically through policy development, so that findings from individual researchers can be disseminated in the public realm.

7.6 CRITIQUES OF METASYNTHESIS METHODOLOGY

Reviews of Noblit and Hare's meta-ethnographic method highlight a number of issues. If qualitative synthesis is something that must be done and developed then, according to Olmsted, this method should achieve this purpose, and also reduce the redundancy found in the repetition of qualitative studies[389]. However, Olmsted rightly highlights that meta-ethnography seems to remove interpretations of a phenomenon further away from the initial experience, introducing a "distance level of interpretation". The method may also not appease audiences more familiar with conventional methods of summary, such as tables and executive summaries. It can also contribute toward reducing potential studies in particular areas, if they are deigned to be less efficient, which may disconcert potential researchers[389].

Another review by Agar found that the contribution of metasynthesis helps reframe how we think about ethnographic comparisons, conducive with interpretive ethnography's new developments. However, this method seems to be just another potential solution to the problem that ethnographies (qualitative studies) can be difficult to compare[381,390].

More positively, Noblit himself reviewed his own technique sixteen years later, and concluded that meta ethnography could move a synthesis from the level of data to a level of interpretation, that social explanation is translation, and that there are multiple forms of a meta synthesis[378].

There are emerging criticisms and lack of consensus regarding the metasynthesis technique and these can be described as theoretical, epistemological, heuristic and practical[377]. One major problem is developing usable and communicable systematic approaches that maintain the integrity of individual studies[387]. In addition, because qualitative analysis is grounded in context, particular studies are only relevant in a particular situation, and arguably cannot be generalised to similar situations[375]. We can only interpret other's metaphors from our own worldview[378].

More general critiques of metasynthesis include the differences in the perspectives of the original researchers with each study, and of course a function of this, the perspectives of the participants. They become interpretations of interpretations[379]. How can these be amalgamated with other stories, when they have been moved another level away[385,391]? Metasynthesis is a useful tool for bringing together general information regarding a topic of enquiry. It does not offer specific conclusions; rather, it can generate broader theories that may encompass a number of situations. Metasynthesis can answer questions about what might happen in a general context but will never give a definitive answer about specific hypotheses.

8 PSYCHOLOGICAL PERSPECTIVES IN URINARY INCONTINENCE: A METASYNTHESIS

PUBLICATION:

Avery J, Braunack-Mayer A, Stocks N, Taylor A, Duggan P. Psychological perspectives in urinary incontinence: a metasynthesis. *OA Women's Health* 2013 **1**(1):9

8.1 CONTEXTUAL STATEMENT

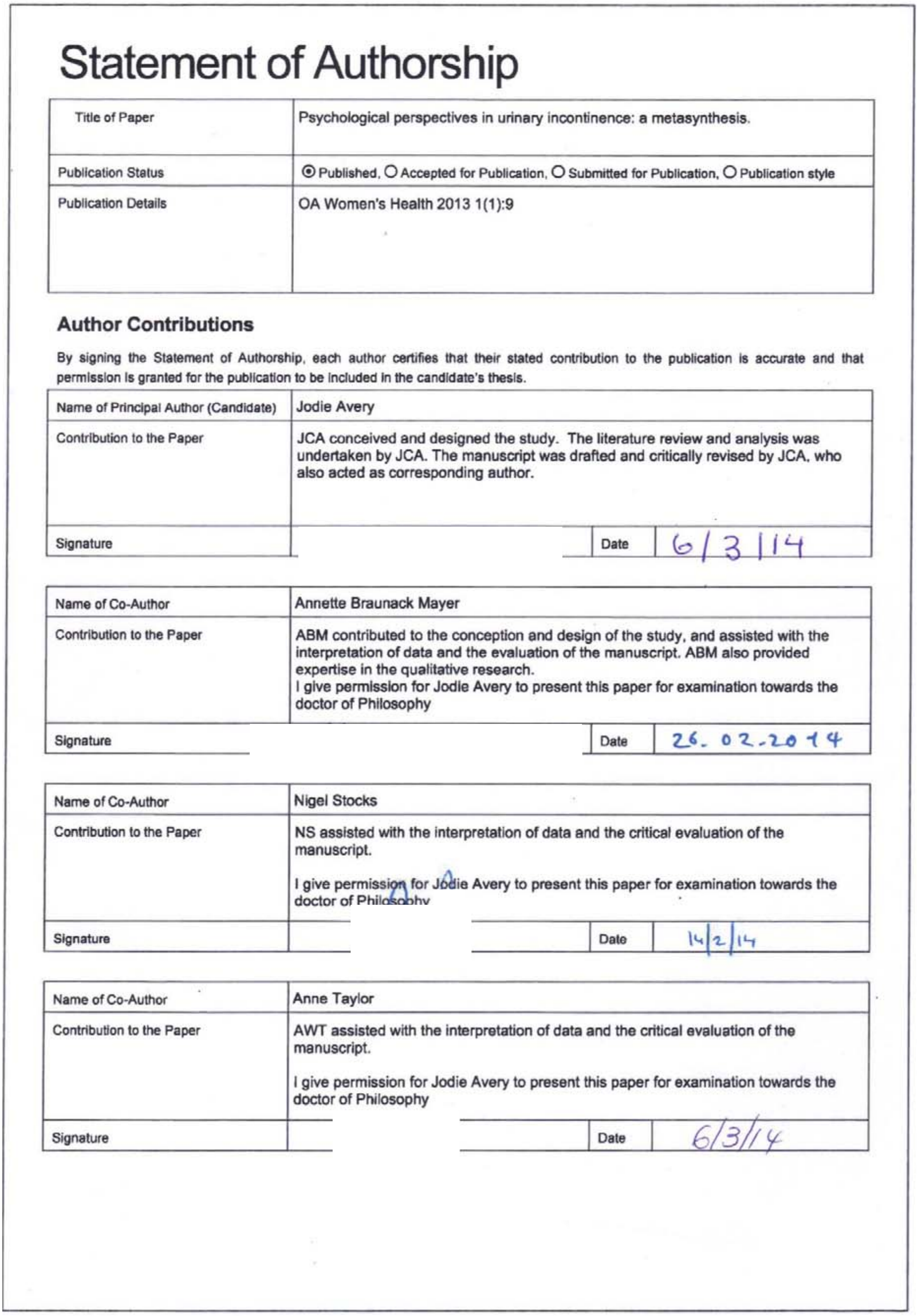
The following review paper primarily addressed the aim concerning how people understand the relationship between incontinence and depression, and its objectives were to explore the relationships between urinary incontinence and depression, as well as to analyse how mental health and urinary incontinence interact through a review of the literature.

The rationale for undertaking metasynthesis is explained in the preceding chapter (Chapter 7). The review looked at a number of qualitative studies concerning women with incontinence and depression. Ten studies from around the world were included and they encompassed several different qualitative techniques. Metasynthesis allowed us to determine how studies were related as well as identifying major themes. Three main themes ran through the studies: Living with incontinence; management of incontinence; and attitudes about incontinence. Other smaller component themes included control, seeking help and personal beliefs, and these provided a basis for the analysis of our own qualitative study.

Our main findings were that incontinence and psychological wellbeing are intertwined. Enquiring about the mental health status of those with incontinence should include an assessment of psychosocial factors to help reduce the burden of incontinence.

The published version of this paper is available in Appendix for Section 2 at the end of this thesis and a statement of authorship follows.

8.2 STATEMENT OF AUTHORSHIP



Statement of Authorship

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Author Contributions

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Name of Principal Author (Candidate)	Jodie Avery		
Contribution to the Paper	JCA conceived and designed the study. The literature review and analysis was undertaken by JCA. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author.		
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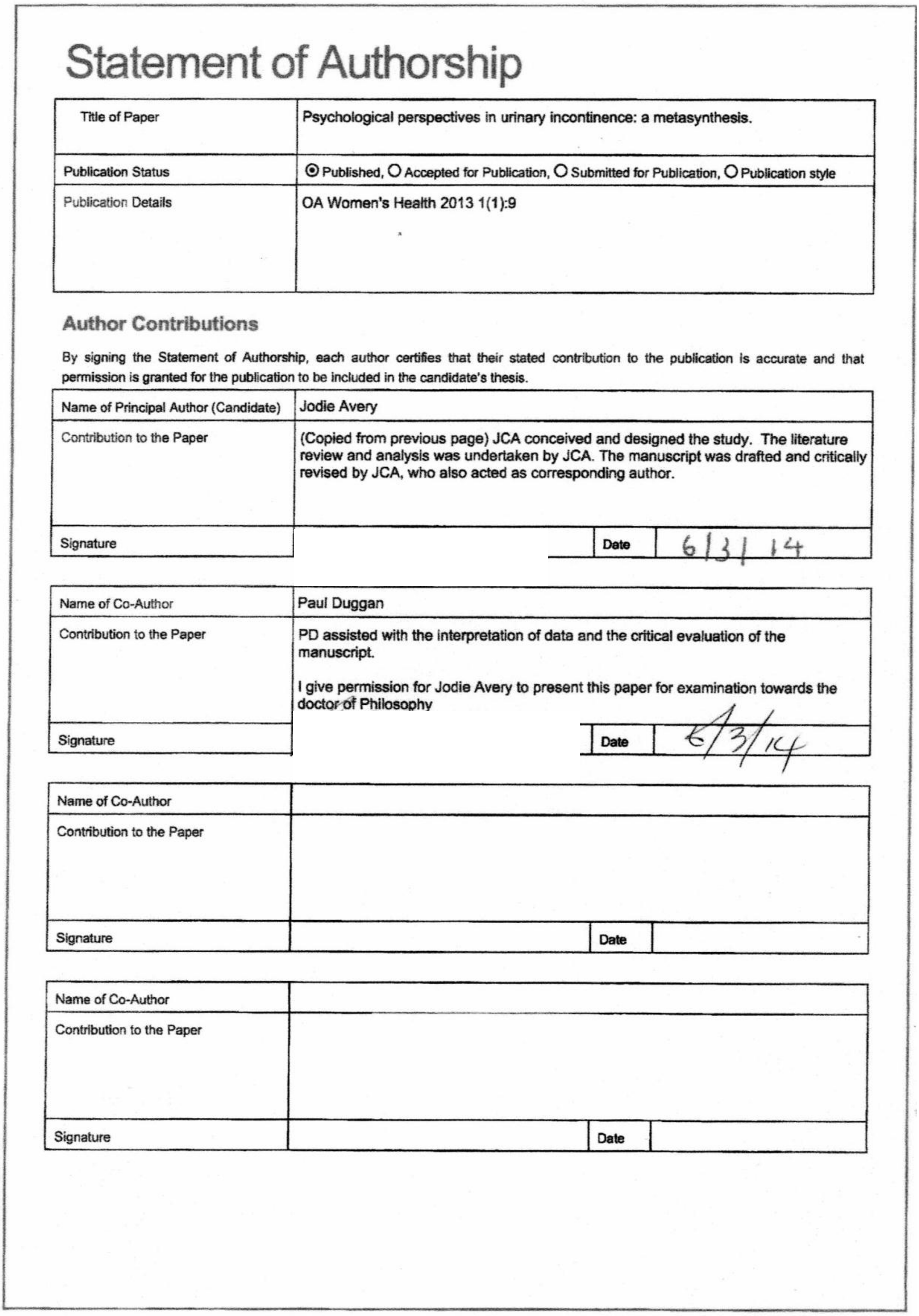
Signature		Date	6/3/14



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Name of Principal Author (Candidate)	Jodie Avery		
Contribution to the Paper	(Copied from previous page) JCA conceived and designed the study. The literature review and analysis was undertaken by JCA. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author.		
Signature		Date	6/3/14

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8.3 ABSTRACT:

8.3.1 Aims

To explore the relationship between mental health status and urinary incontinence, focusing on the role of psychosocial factors.

8.3.2 Introduction

Urinary incontinence with comorbid depression has been found to have a significant effect on quality of life. Examining the associations between the psychosocial factors related to urinary incontinence and mental health may enhance care for patients with these conditions.

8.3.3 Materials and Methods

A search of Medline, CINAHL and SCOPUS databases yielded 15 studies on the topic, and ten studies were found to be in scope. A metasynthesis using Noblit and Hare's approach of Meta-ethnography was undertaken. This involved a number of steps including determining how studies are related and identifying major themes.

8.3.4 Results

Three psychosocial aspects of urinary incontinence appear to influence mental health status: living with, management of and attitudes about incontinence. Other smaller component themes included control, seeking help and personal beliefs.

8.3.5 Discussion

Psychosocial factors appear to mediate the relationship between urinary incontinence and mental health status. An increased awareness of the major psychosocial issues that can influence both incontinence and mental health may contribute to a better management of the condition as well as reduce the burden of the condition on individuals.

8.3.6 Keywords

Urinary incontinence, depression, quality of life, help-seeking, perceptions, literature review, metasynthesis, psychosocial.

8.4 INTRODUCTION

Urinary incontinence is not often considered without mentioning the associated psychological effects, such as psychological distress, depression and anxiety[15,329]. The International Continence Society (ICS) takes great care, in its definition of urinary incontinence (hereon referred to as incontinence), to embrace its association with psychological and psychosocial factors[33]. An examination of mental health in combination with the psychosocial aspects of incontinence, has generally been neglected[19,21,34-37,39].

Many psychosocial factors associated with incontinence may be adversely impacted by depression. Incontinent people experiencing comorbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[15,16,27-30,327]. We do not understand clearly how being depressed interacts with these psychosocial factors[371].

Qualitative studies present one fruitful avenue to gain a better understanding of the relationships between incontinence, depression and psychosocial factors. Although a number of individual qualitative studies of these relationships have been undertaken, there has been no attempt yet to conduct a metasynthesis of the qualitative literature in this area.

Metasynthesis enables us to become more confident about using qualitative literature to fill evidence gaps, as findings from a number of studies may become more conclusive after a synthesis is performed[378]. An advantage of this to the individual researcher is that an investigation can be further progressed rather than continuing to undertake smaller pieces of work which may elicit very similar findings[376] and broader perspectives maybe achieved than that found by the individual researcher[379].

One approach favoured by many researchers, possibly because its method is grounded in the originating paradigm of qualitative research[375], is *Meta-ethnography*[386], which has its origins in educational research. It has often been applied across studies with diverse theoretical foundations[385].

8.5 MATERIALS AND METHODS

8.5.1 Aim

To explore the relationship between mental health status and incontinence in women, focusing on the role of psychosocial factors.

8.5.2 Search Methods

Qualitative studies were sought that addressed incontinence and mental health, in either their aims or their findings. To maximise appropriate studies, broad search terms were used to encompass the full range of studies in this area. An electronic search of the Medline, CINAHL and Scopus databases was undertaken combining the terms 1. “Urinary incontinence” as a MESH heading, and “urinary incontinence”, “overactive bladder” or “urethral syndrome” in the title or abstract, and 2. “Depression”, “depressive disorder”, “mental health”, “social stigma”, “anxiety disorders”, “mood disorders” as a MESH heading, and “depression”, “depressive”, “phobic”, “phobia*”, “mental health”, “stigma”, “stigmati*”, “fear”, “psychol*” or “affective” in the title or abstract. In order to be included in the metasynthesis, studies need to be: concerned with some type of urinary incontinence, overactive bladder, or lower urinary tract symptoms; observed from the respondent’s own perspective; concerned with adult humans. Only articles written in English were chosen. Studies that included both women and men were included when particular themes concerning women were outlined. When searching for studies to include in this metasynthesis, we included those that concerned different types of incontinence, overactive bladder, or lower urinary tract symptoms.

8.5.3 Search Outcome

Fifteen studies from 1993 until 2011 were identified. After reading through the articles five were found to be out of scope; that is they did not provide discussions of incontinence and mental health status from the point of view of the person themselves (sometimes it was carer or health professional perceptions), they concentrated on service use, stigma or quality of life or they were not predominantly a qualitative study.

No previous studies were found that looked at experiences of living with incontinence primarily from the perspective of mental health status. The studies focused on incontinence, and mental health issues arose as part of the examination. Table 1 summarises each article with regard to the sample, methodology, aims and finding of the study.

The quality of each of the included studies was scrutinised using the Critical Appraisal Skills Program (CASP) tool[392]. All included studies were found to sufficiently address all of the criteria.

Using thematic analysis, each study included in the metasynthesis was initially read a number of times to identify overarching themes[393]. Once the major themes were determined, the studies were coded using Nvivo 9[394]. The results from the studies themselves were coded as themes and subthemes using a constant comparative method[395]. Then the emerging themes from each of the studies were compared against each other, in order to examine important psychosocial aspects that mediated incontinence and mental health.

8.6 RESULTS

Incontinence is associated with a number of psychological issues. Some of these issues are primarily defined as major mental health issues, such as depression and anxiety; there are also other psychological issues connected with incontinence such as embarrassment, fear, self-esteem issues, worry, vulnerability, shame, paranoia and uncleanliness[61,118,396-402].

Three main psychosocial themes became evident from the literature as potential influences on the association between incontinence and mental health: day to day living with incontinence; the management of incontinence; and attitudes about incontinence (Box 8.1).

Table 8.1: Analyses of Qualitative Studies concerning Incontinence and Depression

Author	Date	Country	Condition, Sample, Survey Setting / Methods	Aim	Questions	Findings / Main Themes
Ashworth, P. D., Hagan, M. T[398]	1993	United Kingdom,	UI 28 women 25 to 55 years in-depth interviews phenomenological	To discover the meaning of their condition for the sufferers themselves	Concerned the subject's experience of incontinence these include her attitude to her body, her perceptions of other people and their reactions to her, her attitude to herself, and the impact of incontinence on her daily activities	Incontinence is taboo socially unacceptable topic of conversation (inhibiting the approach to health professionals). Reactions of apathy, or may perpetually teeter on the edge of taking ameliorative action: rational ways of tackling the problem are often not followed. The problem is seen as one of personal control.
Mason, L. Glenn, S. Walton, I. Appleton, C.[396]	1999	United Kingdom	SUI 42 postpartum women 21 to 45 years Part of larger study, interviews discourse analysis	To examine the effects of SUI on women in their childbearing years	Please describe how having stress incontinence affects your life?	Many experience physical and psychological symptoms of SUI after delivery, few sought professional care or advice for their symptoms.
Horrocks, S. Somerset, M. Stoddart, H. Peters, T.[118]	2004	United Kingdom,	UI 9 men, 2 women, over 65 Semi-structured interviews grounded theory	Explore reasons why older people living in the community do not present for help with problems of UI and to identify was in which they may be assisted to access continence services	*13 questions:* “How would you describe your general health at the moment?” I noticed from your questionnaire that you experienced some urine leakage. When did you first become aware that this was happening? How did you feel about it?” etc.	Personal attitudes and practical; barriers prevent older people for seeking help for UI.

Author	Date	Country	Condition, Sample, Survey Setting / Methods	Aim	Questions	Findings / Main Themes
Teunissen, D. Van Den Bosch, W. Van Weel, C. Lagro-Janssen, T.[403]	2006	The Netherlands	UI 56 men and 314 women. Independently living aged 60 and over. In-depth interviews, grounded theory.	To determine the impact of uncomplicated ui incontinence on quality of life in elderly men and women in the general population and to identify factors with the greatest effect	Does UI impact your daily life and if so what are the most troubling aspects?	UI in the elderly affects mostly emotional well-being. Men report "being out of control as most important. Women consider "being impelled to take precautions" to be most important.
Hägglund D, Ahlström G.[402]	2007	Sweden	UI 14 women 34-52 years Had sought professional help Interviews, Phenomenological hermeneutic	Illuminate the meanings of women's experiences with UI	"Could you tell me about your experiences with urine leakage, please?" "Can you tell me more about this situation when you leak urine?" "What did you feel?" "How did you experience the situation?" "What happened?" "How do you deal with the situation?"	Being in a vulnerable position means that women had no control over UI and experience powerlessness. Striving for adjustment means that women tried to handle their UI in different ways to regains power and continue to live as normal. *Subthemes*: living in readiness, making urine leakage comprehensible, accepting living with UI, being familiar with the situation.

Author	**Date**	**Country**	**Condition, Sample, Survey Setting / Methods**	**Aim**	**Questions**	**Findings / Main Themes**
Doshani, A. Pitchforth, E. Mayne, C. J. Tincello, D. G.[400]	2007	United Kingdom	UI South Asian Indian Women 30 – 85 years Focus Groups Grounded Theory / Constant comparative method.	To explore views and experiences of UI and perceptions of care among South Asian Indian women.	1. Have you heard about anyone having UI? 2. How did you or they (relatives or friends who suffer from UI) cope with it? 3. Why do you think UI occurs? 4. Do you know of any treatment available for UI? 5. Would you be willing to try alternative therapies? 6. Who would you like to see if you developed this condition and why? 7. Why do you think most women don't seek help for this problem? 8. How do you think we can increase awareness within the community about UI? 9. How do you think we can improve the services provided in the NHS for managing women with UI? 10. If any of the participants answered that they or a family or friend suffered from UI, they would be asked if they would be willing to share the experience with the group, including issues around access to care, treatment and how satisfied they were with the received care.	Normalization / management of symptoms Help-seeking / access to health care Suggestion for improved service.

Author	Date	Country	Condition, Sample, Survey Setting / Methods	Aim	Questions	Findings / Main Themes
Hagglund, D. Wadensten, B.[401]	2007	Sweden	UI 13 women 37-52 years had not sought professional help Interviews, Phenomenological hermeneutic	To illuminate the meaning of women's lived experiences of their behaviour when seeking care for long term UI.	Please tell me what you feel would lead you to seek professional help for UI. When do you need professional help, what treatment do you need, and how do you deal with the UI?	Being in an affected situation; Having personal beliefs about seeking care; Having desired expectations about care
Nicolson, P. Kopp, Z. Chapple, C. R. Kelleher, C.[397]	2008	United Kingdom	OAB Men and women 51-85 years 8 / 10 In-depth semi structured interviews and group interviews Thematic and interpretive analysis	Report the perceptions of patients with OAB about their health-related quality of life and psychological consequences	Explored issues around health-related quality of life	Experience of urgency Fear and coping strategies Anxiety about everyday living Depression and hopelessness Embarrassment Self-esteem sexuality and embodiment Many sufferers avoid admitting to the condition and / or seeking treatment, the psychological costs to them are even greater than with a diagnosed illness because the disruption remains unacknowledged and therefore unresolved.
Hemachandra, N.N. Rajapaksa, L. C. Manderson, L.[399]	2009	Sri Lanka	SUI married women, aged 15-49 6 focus group discussions, 8 key informant interviews, 5 case studies, Phenomenological	To discuss how SUI affects women's lives and how they manage the problem	Detailed information on perceptions, decision making around seeking medical advice, actual help-seeking and management strategies and the mental, emotional, physical and sexual consequences of SUI	Although UI affected outdoor activities, sexual life, and sense of wellbeing, women did not consider it a health problem, rarely discussed it with others, and rarely sought treatment.

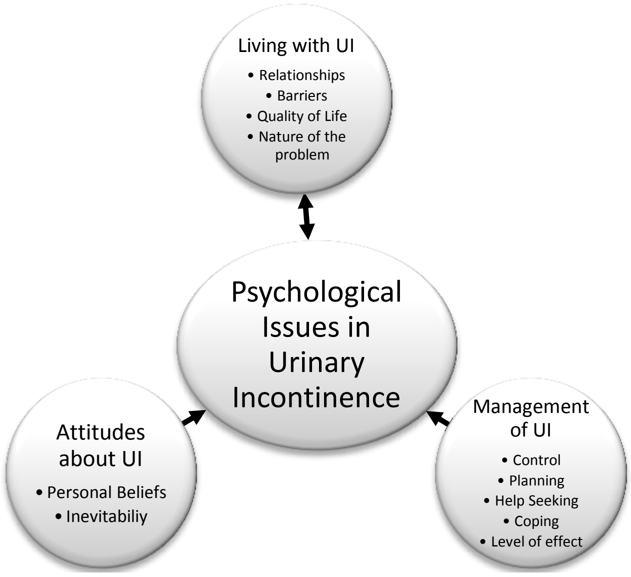
Author	Date	Country	Condition, Sample, Survey Setting / Methods	Aim	Questions	Findings / Main Themes
Elstad, E. A. Taubenberger, S.P. Botelho, E. M. Tennstedt, S. L.[61]	2010	USA	LUTS 151 black, white and Hispanic men and women In-depth interviews Grounded theory	Characterise the stigma of daytime frequency and urgency and differentiate it from the stigma of UI Describe race/ethnic and gender differences in the experience of stigma among a diverse sample of individuals with LUTS	Questions related to own experiences of having LUTS, as well as their impression on what other people think of individuals with LUTS and 1. Speculate on how they might feel in certain situations; 2. Provide their perception of how others view them; and 3. Discuss their own opinions about others who experience LUTS.	Stigma associated with frequency and urgency – not just UI Stigma of frequency/urgency is rooted in social interruption, Loss of control of the body, and speculation as to the nature of a non-specific 'problem'. Stigma of LUTS goes beyond UI to include behaviours associated with frequency and urgency

UI: Urinary Incontinence SUI: Stress Urinary Incontinence LUTS: Lower Urinary Tract Symptoms OAB: Overactive Bladder

8.6.1 Living with urinary incontinence

A first major theme emerged from the literature related to living with incontinence. This theme concerned relationships, particularly those of an intimate nature with a partner or spouse, but also with friends, family; restrictions on activities; as well as overall quality of life. The nature of incontinence, with its complex issues in many different areas, means that, particularly when seeking help, those with incontinence do not know where to start discussing their problem[398]. Some papers described the problem in terms of its practical effects, but others concentrated on how the condition affected them emotionally. The greatest effect on quality of life appeared to result from coping with urgency[397]. The mental health of those with incontinence was affected on a day to day basis, and included depression, hopelessness, as well as anxiety. The exhaustion from broken sleep could compound such feelings. Some incontinent women also felt that their depression was making them ill in other ways[397].

Box 8.1: Psychological factors influencing psychosocial issues in urinary incontinence



The effect incontinence had on relationships, both intimate and social, was a major issue. Avoiding any kind of sexual relationship, even with a longstanding partner was common.

> *"You can't be physically attractive if you are not clean"*[397].

> *"Aye it is terrible. Good job I don't have a man, my husband is dead. I am by myself. But it is really embarrassing"*[397].

It seemed, for those with incontinence, that not having an intimate relationship could be best for all concerned, particularly if partners commented on the smell or leakage during sexual relations[396,397,401]. However, lack of intimacy seemed to also increase tension in the household as well as negative feelings.

> *"My husband says that I stink (muthra gadai) because of it. Sometimes he does not like to be near me. He no longer has sex with me. I am always worrying whether he sees other women. Then I feel sorry for myself. But who can help me with this?" (Renuka, 40 years)*[399].

As a result of the condition, a woman's body became irrelevant, that is she may no longer feel attractive, resulting in further self-esteem issues[398]. These themes illustrate the pressure for satisfactory relationships and intimacy, and this may contribute to poorer mental health in those with incontinence.

Major restrictions in many life activities also occurred because of incontinence, including the inability to exercise, especially aerobics or swimming. Running for the bus or playing with children was also restricted. The role as mother was interrupted because of incontinence.

> *''My little girl's eight now, and I can't run around and play with her. If she says 'race you,' I say 'no - you'll have to race your dad.'''*[396].

Even coughing, sneezing or raising one's voice could cause an accident, and this was quite a problem in the public setting[396,398,403]. Social roles were greatly restricted: working; going to visit friends; going to the cinema; or shopping[399] were all activities that were found to be problematic. Physical activity, appropriate social roles and social inclusion are important factors for good mental health, and it is evident that these were affected by incontinence.

A range of other feelings were also associated with incontinence, which in turn affected day to day living. These included embarrassment in discussing their condition with family, friends and care providers, which affected help-seeking behaviour[396,397,399-401]. The women experienced embarrassment when having to make frequent trips to the bathroom[61].

Experiences of associated shame with a problem of such a private nature contributed towards such feelings[118].

Constantly aware, stressed and worried about having an accident and others finding out, or not being able to find a bathroom in time, weighed heavily on these people[396,397,399]. Fear also pervaded any sense of wellbeing that could occur, as there was always the chance of an accident or leakage[396,397,399]. For those with incontinence, the psychosocial aspects of day to day living adversely affected psychological wellbeing.

8.6.2 Management of urinary incontinence

Another consistent theme in the literature was the need for people with incontinence to 'manage' their condition. Managing incontinence had both practical and psychological components. The practical management themes included planning, constant awareness, specific behaviours, avoidance of activities, barriers to adequate management and help-seeking. Psychological management themes included those of coping, disclosure, explanations of causes, and control.

Management of incontinence was most commonly undertaken by planning. People with incontinence discussed "designing their life around it"[397], using protection, taking precautions or preventing accidents in a number of different ways[61,396-399,403].

> *"I think to myself, when I get to the hill with the birch trees I'm not going to have to urinate, and when I get to the boulder, I can't hold myself any longer. But just quitting thinking about it, having someone along with me on the walk, then the thought doesn't enter my mind and I manage the walk, it is psychological"*[401]

Not disclosing their condition was one way that life could be made more bearable. Some people kept their condition hidden, even from their partners and family[396]. Others were worried that if they revealed their condition, even by using others' toilets, they would become stigmatized[61,398,399,401]. Further, incontinence was particularly hidden for men, as it was seen as a woman's problem and as a private thing, not to be disclosed[118].

> *"Because as long as nobody knew - so in a way it was a problem. Didn't want my husband to find out."*[396]

Control of one's incontinence could be construed either positively or negatively. Some women had only a minor problem that they had "control over"; however, others saw their problem as something they could not control, leading to desperation, powerlessness and anger[396,402,403]. Some of those experiencing incontinence felt that it reflected a lack of control in their life more generally[398], as they were not able to control their own bodily functions[118].

A number of other issues surrounded the management of incontinence. Coping referred to the management of urgency and preventing accidents[397], but it also concerned the ability to just get on with life, by having various strategies to get through each day, including denial of the situation[398]. Having to be constantly aware of the situation was necessary but tiresome[396]. Avoiding activities which would lead those with incontinence into dangerous situations seemed to be a much used tactic, as well as the use of camouflaging clothing[118,397].

> *"Well I am going out tonight and I am sick [with worry]. I don't go out normally – I don't. Not even like say going to the doctor's, because if I have an 'accident' I will die." (female patient)*[397]

Finally, behaviours that could lead to the person with incontinence to be seen as different were undertaken. These included the constant use of toilets at functions, frequent use of toilets at private residences when visiting, trying to avoid having accidents, avoiding intimate activities such as sex, or flying on planes, going for long walks and other activities, which led sufferers to become socially undesirable[61]. Not being in control contributed towards the level of anxiety.

One important component of managing incontinence is help-seeking, specifically addressed in seven of the studies, and a major focus in five. Hagglund and Ahlstrom report that women felt "wounded by health care staff"; they were not followed up in the provision of protective pads, particularly if they were younger[402]. In all studies the theme of embarrassment with regard to help-seeking emerged[396,399,401]. Confidentiality and privacy were other barriers. A number of papers suggested that certain characteristics of the health practitioner could assist in encouraging help-seeking, such as the gender of the practitioner[399,400], ethnicity[400], or the type of health professional, for example general practitioner[399,400], nurse[400,401] or allied health professional[400].

> *''You know, in our area, all the doctors are men. Then how can I discuss 'woman's stuff' with them. I feel embarrassed''*[399]

The women in the studies found that they were treated differently by different practitioners; however, overall they were not satisfied with the information and care that they had received. Problems such as these were regarded as barriers to help-seeking[118].

8.6.3 Attitudes about urinary incontinence

People experiencing incontinence held a number of different attitudes along a continuum; from those who completely normalised their symptoms, to those that found the whole experience taboo.

At one end of the continuum, some women saw incontinence as a sequel to pregnancy and birth and accepted that it was inevitable[396,399]. Ageing was also cited as a reason for the problem, along with associated weakness of the body, previous surgery and medication use, as well as compounding chronic conditions[118,400]. Rationalising incontinence in this way made it a little easier to cope with[401].

If the symptoms of incontinence could be normalised in ways such as above, associated problems could be minimised[396]. Incontinence was not often mentioned as a disease or a health problem, and arguments were made that it was a normal state:

> *‘‘I think it is a usual occurrence in women. It is not a disease. Child bearing, aging, heavy work may aggravate it’’ (Malini, 34 yrs, focus group discussion)*[399]

It was taken for granted that incontinence was just a normal part of ageing or having children [118,400], and it was also seen as a “natural thing”[401].

> *‘‘I didn’t bring this injury on myself, I’ve ended up with a bladder control problem, I associate it with giving birth and having children since it didn’t happen before that, it’s a natural thing, it’s nothing I could of done something about’’*[401]

Many people with incontinence did not consider that it was actually a medical condition [398]. These attitudes affected their help-seeking behaviour, as well as perceptions about the condition [118]. Some of those with incontinence were very clear in the attribution of cause they gave to their condition so that they blamed themselves, believing they could have prevented it through pelvic exercise[396,402].

At the other end of the continuum, the shame and embarrassment of incontinence meant for some that it was a taboo subject with stigma attached. It could not be discussed with friends and family. Those who were incontinent worried about the smell, having accidents and the frequency with which they visited the bathroom. They were often very concerned by what other people thought, and many spent much time concealing their condition[61,396,399]. The attitudes these women attributed to other people were often unfounded.

> *"If I go to someone's house and I have to go to the bathroom a lot, maybe it might not be the right time to go to the bathroom to pee, but since I have this weakness in my bladder, I have to go right away... I worry because I think other people are going to think 'what's wrong with her? Why is she going to the bathroom so much?'...It's truly not normal for someone to need to go to the bathroom so much!" (Hispanic woman)*[61]

The age of the affected person affected their attitudes, with younger people more likely to conceal their problem at all costs[402]. The taboo about incontinence also affected help-seeking behaviour[118,397,401]. Some women experienced stigma as a result of the relationship of incontinence to the genital area, as it was "bad" or "dirty", and needed to be concealed[398,399]. Others thought that it would be less of a problem if it was talked about more publically, perhaps if there were a "champion" with incontinence who wanted to share their experiences[400].

If people with incontinence believed they were not in control if their own bodies, they could experience a kind of disembodiment, which led to low self-esteem, resulting in other problems either physical or psychological. Feelings of vulnerability developed from a lack of control in one's life[402].

> *"But making light of it does not always work: I try to make a joke of it, but sometimes you've really got to feel down. You know, you get awful down."*[397]

The impact of the condition had much to do with how those with incontinence perceived it. Did they accept the condition, or deny it? Did they think that their personality was such that they wouldn't let it become a problem? Did they feel that it would get better, thus showing signs of hope? Positive perceptions such as these meant a reduced impact on life.

> *"Won't let it become a problem; it's not in my personality, will always find ways round it.''*[396]

The opposite was also the case, where those who worried about incontinence, more likely to be impacted[396]. It was also evident that, once people got older and experienced other conditions, the impact of incontinence, in the scheme of things, was lessened[118,400]. Further, with women, as the role of women included both family and career duties, the problems of incontinence, and things that affected the women themselves, were less of a priority[401].

8.7 DISCUSSION

Incontinence is associated with poorer mental health[238], and there are many psychosocial factors that mediate this relationship. Qualitative studies investigating incontinence are often concerned with particular aspects of the condition, such as quality of life or help-seeking. However, the impact incontinence has on mental health is part of a bigger story. The synthesis of studies in this area demonstrates that psychological factors mediate a number of other issues, such as help-seeking, related to incontinence.

Three main psychosocial themes: living with; management of; and attitudes about incontinence, were identified from the nine studies analysed, with a number of subthemes falling under each of these areas. When the three main themes were examined in each study, key components emerged: how living with incontinence affected relationships and quality of life, the restrictions that occurred and the actual nature of the problem; how the management of incontinence included control, planning, coping and seeking help, and that the level of effect on one's life could be due to their own feelings about the condition; and attitudes about incontinence that included personal beliefs about aspects of the condition, such as the inevitability of it, and anxiety about, what other people thought.

The studies included in this metasynthesis also covered different population groups of people with incontinence, with variation by gender, age, ethnicity, and whether or not help had been sought. Although some differences between groups, such as gender and ethnic groups, could be found, the similarities between such groups may enable more directed assistance for the management of incontinence and similar conditions, as these findings show that many of the practical problems of incontinence can have an impact on emotional problems, and taking care of the psychological wellbeing may reduce the burden of managing the condition and increase overall quality of life.

As no previous studies have been found that addressed women's experiences of living with incontinence primarily from the perspective of their mental health status, the strength of this synthesis is it combines the evidence from a number of studies, enabling us to draw wider conclusions about our research questions. This metasynthesis indicates the importance of alleviating the psychological issues associated with incontinence, via a consideration of the major psychosocial aspects. If the condition is treated, taking into account the aspects of management, day to day living and attitudes, there may be reduced psychological burden and better outcomes for those with the condition.

Incontinent people experiencing comorbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[15,16,27-30,327]. Clearly, for the 30% of those with incontinence who also suffer from depression, an opportunity to reduce the burden of incontinence is presented, as treating depression may be more successful than treating incontinence[21-24].

8.8 CONCLUSION

Previous studies have described the relationship between incontinence and mental health, and poorer mental health is associated with a reduced help-seeking. There have been no studies exploring the interaction of incontinence, depression and help-seeking, a combination which we would expect to be common. Additionally, few recent investigations have concentrated on the impact of mental health problems upon psychosocial issues that relate to incontinence such as on quality of life, management and coping behaviours, social connectedness, and beliefs and knowledge of the condition, focussing more upon risk factors such as gender, age, cognitive impairment and physical health.

Here an opportunity for further investigations into these interactions is presented. When managing a condition such as incontinence, especially when treatment is not successful, it is imperative to take into account lifestyle, coping and management strategies, as well as attitudes surrounding the condition. Routine questions could be asked of patients attending general practices regarding symptoms to identify those with incontinence who may not be aware of available treatments. Referral should be encouraged to specialist services, because, for instance, continence advisors can provide detailed information and advice about day to day living. In turn, those with the condition may be able to assist in breaking down the taboos surrounding the condition by sharing their stories.

Incontinence and psychological wellbeing are intertwined and this adversely affects a number of aspects of life. Enquiring about the mental health status of those with incontinence should include an assessment of psychosocial factors to help reduce the burden of incontinence. To improve the management of these conditions, further research should investigate whether psychological issues precede incontinence or vice versa.

9 EXPLORING EXPERIENCES AND MEANINGS: METHODS FOR UNDERTAKING A QUALITATIVE STUDY OF WOMEN WITH INCONTINENCE AND DEPRESSION

9.1 INTRODUCTION

In the next two chapters, I focus on how I investigated the psychosocial experiences of women I interviewed in my study, how I explored their strategies for coping and the influences on their psychosocial well-being. This chapter provides the background, context and methodology for the findings described in Chapter 10. As Chapter 10 is written as a stand-alone publication, I have included appropriate methodology in that chapter as well. I also refer to some of the tables in the next chapter and the appendix to avoid repetition.

I have written this chapter as a reflexive temporal narrative in order to provide context on why I chose to undertake a qualitative investigation. It is important also to consider the role of reflexivity in the process of my research because it can clarify the impact of my own position and perspective[404].

Reflexivity is a process which is present from the pre-research stage through to the final writing up of the analysis. It enables us to critically inspect everything in our research and thus is one way to increase the integrity of qualitative research[404]. It considers that research is not a one way street and that the researcher and those who are being researched constantly interact with each other[361]. The researcher is a “positioned subject” in that their own pre-existing understandings, experiences and theoretical traditions come into play in all stages of the research[361]. I feel through my own experience of chronic illness similar to that studied here that I bring my own history and perceptions into play, from the design of the study through to the final analysis and discussion of the results.

9.1.1 Rational for undertaking the qualitative study

My original research question concerned whether depression experienced by people with urinary incontinence is associated with psychosocial factors. My thesis was to be based on a number of cross sectional population studies, looking at incontinence, depression and quality of life, as well as a number of other psychosocial factors, particularly help-seeking for incontinence when depression was also being experienced. My methodology at this point reflected my research question.

The initial results from the population surveys found that depression and incontinence both reduce quality of life. When they occur together there appears to be an additive effect which affects both physical and mental health, perhaps by increasing a person's negative perceptions of their illness[371]. Analysis of a second population survey found that women with any urinary incontinence, who considered their condition to be very or moderately serious, were more likely to report severe incontinence. Women whose lifestyle was limited by incontinence were more likely to perceive their condition to be very serious. Together, severity and limitations to lifestyle were predictors of women perceiving that their incontinence was moderate to very serious[3].

However, there were a number of questions that could not be answered with cross sectional population studies. One main question was "Did incontinence cause depression?" or "Which came first?" Also "What were the influences of mental health on the experience of incontinence?" The nature of my candidature meant that a longitudinal study examining causality such as this was not possible. I used an alternative way to examine these questions through a qualitative synthesis of the literature around women's experiences of urinary incontinence and psychological wellbeing (see Chapter 8). Here I found that these two concepts were intertwined and this adversely affected a number of aspects of women's life. I found that enquiring about the mental health status of those with incontinence should include an assessment of psychosocial factors that could help reduce the burden of incontinence. I concluded that, to improve the management of these conditions, further research should investigate how psychological issues interact with incontinence[372].

My final study was qualitative. This involved recruiting and undertaking in-depth interviews with women with urinary incontinence, regarding their experiences, their mental health and psychosocial outcomes, including burden and help-seeking. As part of the overall larger study around the psychosocial associations of incontinence and depression, this qualitative component would explore the complexity and in-process nature of meanings for participants[76,361].

9.2 RIGOUR AND ETHICS

In order to ensure meaningful and useful research, it is imperative to follow rigorous methodological procedures[361]. Rigour can be defined as the thoroughness and appropriateness of the use of research methods[405], and it is used to protect against bias and enhance the reliability of findings[406]. There are a number of approaches available to enhance study rigour including theoretical rigour, methodological rigour, interpretive rigour, evaluative rigour, and rigorous reflexivity[361]. Most of these strategies have been employed in this research project and their use and justification is described below.

9.2.1 Theoretical Rigour

Theoretical rigour is achieved when the appropriate theories and concepts are chosen to undertake a study so that the research strategy is consistent with the research goals[361]. The main way this was undertaken in the present study was through the completion of a metasynthesis of the relevant literature to inform the interview schedule. The metasynthesis was also undertaken to ensure the study was addressing meaningful concepts[361]. This also ensured that many of the recurrent themes had a scholarly basis. I also used a questionnaire to assess depression which had previously been validated in a similar population of women[159].

9.2.2 Methodological Rigour

Methodological or procedural rigour concerns the transparency or "explicitness" of the description of the way the research was conducted[405]. In order to achieve methodological rigour in this study, a number of strategies were employed including keeping a research journal which described every step of the research process, problems encountered, notes about interviews and any other relevant information. Other ways to ensure rigour here included establishing a rapport with the women to be interviewed, firstly through an introduction letter and a telephone discussion, and then also at the time of interview. Interviews were immediately transcribed after interview to ensure that the management of data followed the same procedure for each interview. The methods for this study are described in detail in both this chapter and as part of the findings described in Chapter 10.

9.2.3 Interpretive Rigour

This type of rigour has been defined as the way the research accurately represents the understandings of events and actions within the framework and worldview of people engaged in them[361]. The data analysis undertaken here was within the phenomenological tradition[407], and an iterative process was undertaken in conjunction with my supervisor (ABM), to derive a framework that adequately described the final themes and concept that came out of the analysis (as described in section 9.4.5). This made sure that the interpretation of the data was completed not only by myself as a novice researcher, but with the assistance of an experienced qualitative researcher.

9.2.4 Evaluative Rigour and Ethical Considerations

In this section, I discuss the procedures that ensured evaluative rigour was addressed. Evaluative rigour is concerned with the ethical and political aspects of this research[405].

The Human Research Ethics Committees of the University of Adelaide and the Royal Adelaide Hospital provided ethics approval for this study. Documentation of approval for this study from the University of Adelaide HREC, as well as the invitation letter and study information sent to eligible participants in the Study are included Appendix 2.

9.2.4.1 *Privacy and Confidentiality*

In order to maintain the privacy of eligible women, initial contact was be made by their consulting clinician. An information sheet describing the study, as well as a consent form was posted to potential participants. Then, if interested, the women were able to contact me directly by telephone.

As there was the potential for intimate personal details to be disclosed during the interview with participants from potentially vulnerable groups, such as frail and elderly women, this could raise concerns about confidentiality and informed consent. The women were assured of their anonymity, including that they would be given pseudonyms and that their personal or identifying details would be kept separately from their interview data. The women were also made aware that they were free to withdraw from the study at any time, and that their treatment would not be affected by any decision they make about their involvement in the study.

9.2.4.2 *Duty of Care*

If the women or I felt that the woman had suffered any harm or distress from the interview, they were referred back to the consulting clinician. If psychological issues were uncovered during the interview, I encouraged the woman to return to their clinician to discuss any such issues. As an interviewer, and not a practitioner, I was not in a position to provide psychological counselling and we did not think that this would be appropriate. However I could provide information about websites about depression, and indicate other resources (e.g. counselling) that the participant could to access, such as Beyond Blue or the Lifeline telephone helpline and the Continence Foundation.

Additionally, as these participants were visited at home, it was important to provide an adequate introduction and referral of my credentials by the recruiting practitioner, Professor Duggan. This included providing information about my professional background as a health professional to assure participants of the confidentiality of the research and help allay fears of talking about the personal and sensitive topic of UI. As I was entering interviewees' homes, a record of appointment times and addresses was also supplied to a responsible party at the University, in case of any problems that may be encountered.

9.2.5 Reflexive Context

Trying to understand how my own values and views may influence the findings of this study can, as well as reflecting on the process of this research, may add credibility and it is suggested that this should be part of any method of qualitative enquiry[408].

My research interests have always centred upon women's health and I spent some time as a clinical trial coordinator assisting with studies concerning pregnancy and women's nutrition. When it came time to undertake my Master's dissertation, although my public health training was predominately epidemiologically and biostatistically based, I decided to undertake a small qualitative study with women with Polycystic Ovarian syndrome. I was looking at the information needs of these women[409] and the financial and time constraints of conducting a more quantitative study were not feasible.

It was here that I first expanded my knowledge into the qualitative area, and I found that I enjoyed the contrast between larger clinical trials, smaller pieces of related information, and the more complex long interviews with individuals.

Just prior to this time, I had been diagnosed with Ulcerative Colitis, an inflammatory bowel disease, in which the symptoms alternated between constipation and diarrhoea. This meant almost constant pain, general illness and fatigue, and that I could not be too far away from the bathroom. Usually a "flare" lasts for about three months and then the disease goes into remission, but this is not always the case. So the similarities between this illness and incontinence are very similar, so much so that a contemporary PhD Candidate was studying the psychological factors involved in inflammatory bowel disease.

More recently, I had been employed as an epidemiologist with the SA Department of Health, primarily dealing with large cross sectional population studies. It was here that I became involved in researching incontinence, using data from Professor Alastair McLennan derived from the Health Omnibus Survey, and I was able to originally publish on this in 2004[410]. After attending the International Continence Society Conference in Florence in 2003, I heard a speaker talk about the link between incontinence and depression, and I decided that this would make an excellent PhD topic.

9.2.5.1 *Voice*

As this is a mixed methods study, I felt it was important to distinguish the two sections of the thesis from each other, even thought I was concerned with interrelated research questions. The first part of my study, using pre-collected quantitative data, meant that I did not have ownership of the data. I had not been involved in the collection of the data, although in my work I am involved in managing the survey that collects these data. I came to the data down the track, after others had collected it, and I knew it could assist me in my research.

However, in the second section of this thesis, I had been intimately involved in all aspects of the qualitative study, from inception to analysis and writing up. Accordingly, being this involved, I needed to speak from experience in my methods and analysis. Writing in the first person shows that both the researcher and informants (of which the researcher is also one) are part of the research[411].

However, in the next chapter (Chapter 10), as a publication including other authors, I have written using “we”. This is inclusive of my other authors. However, some of the tasks may have only included myself, or myself and another, not all of the authors. In the statements of authorship the contribution of each author is clarified.

9.3 THEORETICAL PERSPECTIVE

I chose to undertake this study using a research methodology within the interpretivist paradigm, which, in opposition to a positivist approach, *“looks for culturally derived and historically situated interpretations of the social life world”*[412].

As one of the original objectives of my thesis was to ease the burden, including depression, and increase the quality of life in women experiencing incontinence, it was important to choose a methodology that could create an understanding of human nature, human development, intimate relationships, and helping relationships, and that could be seen to empower health workers in their work with this group of women[413]. Phenomenological studies may be able to achieve this because they seek to understand individual lived experience, focus in-depth on the meaning of a particular aspect of experience and assume that through dialogue and reflection the quintessential meaning will be revealed [414]. Phenomenologists study situations in the everyday world from the viewpoint of the experiencing person[413].

The main purposes of a phenomenological enquiry are description, interpretation and critical self-reflection, and throughout the researcher engages in critical self-reflection about the topic and the process[414]. The researcher begins their research with the data of their own experience, their own reflecting intuiting and thinking are used as primary evidence towards their interpretation of the phenomenon[404].

Each person will perceive the same phenomenon in a different way; each person brings to bear his lived experience specific understandings and historical background[404]. The researcher is able to identify common themes by dwelling on many manifestations of the phenomenon. The essential structure of the phenomenon is revealed by articulating the interrelationship of these themes[413]. Structurally understanding what something is for the people experiencing it can provide crucial information in theoretical, empirical and intervention realms[413].

9.4 METHOD

I undertook in-depth interviews with women with urinary incontinence recruited from a women's health clinic, regarding their experiences with various psychosocial outcomes. A Framework approach[11] was used to condense and systematically analyse the data collected in the interviews.

9.4.1 Aim

This collection of interviews aimed to explain how mental health and urinary incontinence interact, by exploring the subjective experience of the burden of urinary incontinence in relation to mental health.

9.4.2 Recruitment

Recruitment was commenced at a women's health clinic at a large public hospital, general practices and private specialist practices. However despite initial enthusiasm from the specialist doctor and the general practitioners recruitment in these centres did not proceed.

Using maximum variation sampling[415], which captures and describes the central themes or principal outcomes that cut across a great deal of participant variation, I recruited a number of women from the women's health clinic. The clinic assisted in the identification of women with incontinence, and once identified, the Head of the clinic, who was also one of my supervisors, Associate Professor Paul Duggan, invited the women by letter to participate in the study. The letter explained what the interviews would entail, and invited them to contact me if they had any questions or wished to arrange an interview time.

After giving information to 179 women, I was contacted by 19 who agreed to be interviewed. Another three eligible women had heard about the study during the recruitment process also agreed to be interviewed. The interviews were undertaken between March and June 2012.

9.4.3 Selection and Exclusion Criteria

The following criteria were used to select the participants for the interviews:

9.4.3.1 ***Selection criteria:***

- Women aged 18 years and over
- Women who lived in the community
- Women who experience urinary incontinence, with and without depression
- Women who are able to provide informed consent.

9.4.3.2 ***Exclusion criteria***

- Women who are Non-English speaking
- Women who had dementia, or a severe or acute neurological disease (e.g. epilepsy, acute CVE, severe Parkinson's disease, acute confusion) or a severe psychiatric disorder such as bipolar disorder, schizophrenia).

A result of these criteria meant that one interview was removed from analysis as it was deemed that the participant's depression at the time was extremely severe and I did not believe that she could give informed consent. Another two planned interviews were not undertaken. One was due to the woman inquiring after the initial recruitment process and, with the other, I felt very unsafe when I arrived at the woman's house.

9.4.4 Data Collection

9.4.4.1 ***Interview schedule***

In order to develop the interview schedule, a metasynthesis of the literature surrounding incontinence and depression was undertaken (Chapter 8)[372]. I also considered the results of my initial quantitative studies (Box 10.1), and used the first interview as a pilot to develop the interview schedule. The metasynthesis found that many of the issues associated with depression and incontinence had not been addressed, including the intersection with other psychosocial factors. However, three psychosocial aspects of urinary incontinence did appear to influence mental health status: living with; management of; and attitudes about incontinence. Other smaller component themes included control, seeking help and personal beliefs. The themes appear throughout the literature.

The themes and subthemes were also verified by Professor Annette Braunack-Mayer, my supervisor and an experienced qualitative researcher. These themes guided the final interview schedule, which is available in Appendix 2.

9.4.4.2 ***In-depth interview s***

The method to collect data that was chosen for this study was in-depth interviewing. This is a focused technique that aims to explore the complexity and in-process nature of meanings, similar to a conversation[361]. All interviews were carried out with participants in either their own homes or another location convenient to the participant.

All participants provided informed consent, I asked permission of the women to tape the interviews, and I also took notes particularly concerning demographics, and who else was present. Often their husbands or other family members were present; in some cases this may have made the women feel more at ease, particularly having a strange person entering their home at night. In one case, the "carer" of the woman decided to take it upon himself to answer the questions for the women herself. In this case, the woman could barely communicate anyway; she suffered from very severe depression (which I did not know from the initial recruitment information). I ended up excluding this interview from the analysis.

Basic demographic information was also collected from each participant and I had collected some other information about their condition from the clinic. Depression status was assessed using the mood module of the Primary Care Evaluation of Mental Disorders Questionnaire Patient Health Questionnaire (PRIME MD PHQ)[130]. I had previously used the PRIME MD PHQ in the initial quantitative part of this study to screen for depression. The questionnaire has been validated against structured and longer diagnostic schedules which are able to detect a number of mental disorders.

Again, in this study, the various mental disorders that can be identified with this questionnaire were collapsed to indicate other or major depressive syndrome, or no depressive syndrome. For the purposes of this study, women were considered to be depressed if they self-reported depression or scored positively for other or major depressive syndrome on the PRIME-MD PHQ.

9.4.5 Analytical Process

The interviews were recorded digitally and transcribed by a specialist research transcription service. After reading through the transcriptions of the interviews, I undertook initial naive coding, using the qualitative data management software Nvivo9[394], in order to identify the key themes in the interviews.

Before I decided on the final analytical approach, a number of processes were undertaken. There is no real or starting point or "recipe" to follow when undertaking analysis in the phenomenological tradition[407]. So, initially, a grounded theory[416] approach was taken, which is an iterative process developing in response to the data obtained and ongoing analysis.

The experiences described in each interview were compared with themes derived from the metasynthesis: living with incontinence; managing incontinence; and attitudes about incontinence. Each interview was summarised in terms of these three major themes. I initially used the Framework approach[360], described below, to analyse the interview data, but this did not offer an adequate description of how mental health and urinary incontinence interact for this group of women. In the later stages of my analysis I turned to the concept of resilience to organise my analysis and this proved much more fruitful. The next two sections provide a more detailed account of these analytical approaches.

9.4.5.1 *Framework Approach*

I approached the analysis of the interview data using a method known as the Framework approach[360]. Originally designed for large-scale social policy research, this technique provides a systematic approach to analysis through a number of interconnected stages which guide the analysis[417]. The key characteristics of this method are that: it is a case and theme based approach; there is a hierarchy of themes and subthemes and each key theme forms one "matrix" or grid in the analytical framework; it reduces the data through summarising and synthesis; and it retains links to the original data[360]. There are a number of stages in this analytical process and these are described in Table 9.1[417,418].

The framework approach allows data to be both managed and analysed simultaneously. This is advantageous when there are a lot of data available, as it reduces the quantity of data through summarising and synthesis. It also allows tracking of the analytical process in a systematic way[360].

In order for an interrogation of the data and an identification of patterns between specific demographics, such as depression status and incontinence status, and emerging codes, I imported a socio-demographic profile of all the participant women into the N*Vivo9 casebook and developed an attribute table.

Table 9.1: The Stages of the Framework Approach

Stage	Description of the process
1. Transcription	Word for word, verbatim. Become immersed in the data
2. Familiarisation with the interviews	Reading transcription and listening to recording in order to become familiar
3. Coding	Read transcript line by line and apply codes
4. Developing a working analytical framework	Codes can be grouped together into categories, which are then clearly defined. Identification of a thematic framework
5. Applying the analytical framework	Indexing or coding the data to this framework
6. Charting the data into the framework matrix	Explaining variation and finding patterns
7. Interpreting the data	Mapping and interpretation, which explores and interprets the data in the context of the original objectives of the study

Table adapted from Gale et al 2013[417]

Emergent themes from the interviews were considered in the context of the themes that arose from this metasynthesis; however, as noted above, I was unable to come up with any solid conclusions about why some women with incontinence became depressed and why some did not. The one standout theme related to whether the women felt in control of their lives whilst they had incontinence.

In order to explore the data further I started to use a more phenomenological approach, in part because I noticed that “being in control” was a dominant theme in most of the interviews. I also decided to ask some questions of the data by using an approach looking at the basic units of social life[419]. My modified questions included type, structure, frequency, causes, processes, consequences, and strategies. Each interview was described in terms of these questions.

I also used Giorgi's approach to phenomenological analysis in my analysis. I read through the transcripts again one by one, and noted the themes, and units of meaning. I looked at the phenomenon of "control" from within a particular woman's life experiences and asked what stood out about this phenomenon, what was the most important aspect, what was the next most important, how did the themes fit together, and I went through the data and put everything each woman had said about it in one place. Then I summarize and edited the meanings and manifestations of each of the themes and wrote an overall portrait of the "control" phenomenon for each woman[420].

I also considered other theories (such as Oliver's Theory of disability[210]), exploring the symptomology of depression. Simultaneously with this analytical process, I investigated issues of personal control. However, these seemed not to adequately describe the process, particularly the sense of control that still seemed to emerge as a dominant difference between the sub groups.

Then, each interview was summarised in terms of being in control, and also by depression status. After producing a number of tables of these findings, I looked for systematic differences between the groups and commonalities within the groups, to identify more significant themes.

9.4.5.2 ***Connecting with the data***

At this point in my analysis, I felt as though I was retracing my steps, going over things many times and discovering new pieces of information from the data. I just needed a connection to appear. My analysis was becoming stagnant. I continued to read other theorists and learn about how people talked about depression. It was frustrating coming from a quantitative background, when following some continuous steps usually elicited some kind of outcome.

Only after a point where I had created a clearer picture about my interpretations did I come across some information which would give more sense to the process. It was my "Eureka" moment! Below I include some quotes from a paper by Smythe in 2008[421], as I feel they describe exactly the process which I was undertaking and through which I was being guided by my supervisor Annette Braunack-Mayer:

> *"A research supervisor has the challenge of helping the student stay immersed in their data, to courageously persist in thinking and struggling to understand, yet to let the text (experiences) speak (to offer new understandings). Students must learn to trust that understanding will come, but not without the circling discipline of reading, writing, talking, mulling, rereading, rewriting and keeping new insights in play" (Smythe 2008)*[421]
>
> *"Then it also opened up what other kinds of writing we could look at. We found we were connecting with the data. The process itself is unutterable but we know it takes concentrated periods of time. You cannot think like this in little spurts. Since there are n steps you cannot return to them, you don't know where you are in the line. It's like being in a circle of writing. When you are in that phenomenological mode the writing becomes poetic, like it's coming from some different place. I look at that writing now and can't believe we wrote it." (Smythe 2008)*[421]
>
> *The secret to achieving such writing is the gift of large spaces of undistracted time and the willingness to trust that the emergence will come. (Smythe 2008)*[421]

These quotes describe the process of phenomenological analysis which I was struggling to understand, even though I knew it was an analytical process I needed to undertake.

Fortunately, a chance attendance at a seminar concerning health, disability and lifespan development, introduced me to the construct of resilience. The literature in this area deals predominantly with children who have survived stressful experiences, such as child abuse, bullying or wars. When I explored this construct further, it concisely explained many of the concepts I had identified through my initial analysis of the interactions of mental health and incontinence in women, such as support structures, self-esteem, physical and mental health, coping style, resourcefulness, and self-discipline (Chapter 8)[372].

At this stage I reviewed the literature around resilience, particularly in terms of qualitative studies about chronic conditions in adults. I have represented the analysis trail diagrammatically in Box 9.1 below. This represents my journey with the data up until my interpretation.

9.4.5.3 ***Resilience***

There has been much discussion about what actually defines resilience; it has been described as a composite of a number of different factors. This makes measuring resilience difficult because it has been both described as a continuum and an aggregate of a number of different resources[422].

Resilience has been defined as the mechanisms that protect people against the psychological risks associated with adversity[423]. It has also been seen as the outcome of the successful adaptation and swift recovery after experiencing severe adversity[424]. There have been many studies looking at the associations between resilience and depression[339,424-429]. The main way resilience is thought to interact with psychological factors is that it has been reported to mediate reduced depression and anxiety[342,430], and researchers have proposed that patients with psychological problems such as depression may benefit from treatments that enhance resilience[431].

This concept has been studied both qualitatively and quantitatively. Previously, when examining resilience quantitatively, a single questionnaire had not been available. This meant that measures of the individual concepts of resilience, such as control, self-esteem, or mastery have been combined and used to estimate overall resilience[89]. More recently, a validated questionnaire has emerged, the Connor-Davidson Resilience Scale (CD-RISC), which has been able to show that resilience is modifiable, can improve with treatment, and greater resilience corresponds to higher levels of global improvement[432].

Resilience has occasionally been studied in the context of women with incontinence and depression, but not using qualitative interviews. One study interviewed women aged 25 to 74 years about chronic conditions, physical functioning and psychological health using a number of different short questionnaires. Resilience was measured here using a weighted sum of the constructs derived from these questionnaires including: Control over one’s life; Satisfaction with self; Contribution to others; and Ability to solve life’s problems. The most important finding from this study was that the association of reduced resilience with urinary incontinence in women of all age groups, and also control over one’s life was significant for women with incontinence under 50 years when compared to those without incontinence[89]. The belief that one had solutions to life problems was also found to be a very important factor in resilience in this study.

Other chronic conditions have been studied quantitatively in the context of resilience and its association with depression. These conditions included cardiac disease, peripheral atherosclerosis, stroke, diabetes mellitus, lung disease, arthritis, cancer, spinal cord injury, pre-eclampsia, and HIV. One study of chronic conditions examined whether psychosocial resources such as resilience have the same effect across patients with different diseases, and found that the ‘buffer effect’ of psychosocial resources were different across various chronic diseases. It recommended that different interventions should be designed for different conditions to prevent depression[429].

One study looking at 150 consecutively treated cancer patients found that psychological resilience may independently contribute to low emotional distress in these patients[433].

Sixty patients with a spinal cord injury (SCI) were surveyed to examine factors that contribute to the process of positive adjustment, or resilience, and it was found that resilience is an important psychological process in the longer-term management of SCI, and interventions should be designed that promote the cognitive and behavioural characteristics of resilient coping, and introduced in the early stages of SCI rehabilitation so as to prevent future emotional distress[434].

In a group of 67 surveyed women who had previously experienced pre-eclampsia, those with high resilience showed significantly less depression and better mental quality of life compared to women with low resilience[435]. It was concluded that resilience was a factor that protected patients after preeclampsia and suggested that screening for resilience should take place to identify women in need of psychological support.

When studying resilience, the constructs that have been measured or described for this psychosocial resource have been diverse. They have also evolved over time as our understanding of what contributes to resilience grows. Table 9.2 examines some of the different constructs studies have used to measure resilience in relation to depression.

I have grouped these constructs into the patterns that were described by Polk in a concept synthesis of overarching resilience patterns[422]. These patterns include: the Dispositional pattern, which described physical and ego related psychosocial attributes such as constitutional and genetic factors, intelligence, health and temperament; the Relational pattern, which refers to the characteristics of roles and relationships and social interests; the Situational pattern, which examine the approach to situations or stressors, such as cognitive appraisal and problem solving; and finally the Philosophical belief pattern, which encompasses personal beliefs and meaning and the actions that accompany these such as altruism and positive meanings in experiences.

Polk’s concept synthesis provides a neat summary of all the constructs that have evolved from the literature to describe what we are measuring when we discuss resilience. Having four defined patterns provided a basis for the theoretical framework used to analyse the present study, and reiterates the findings from my metasynthesis[372]. I continued to use the Framework approach as the basis for my analysis using Polk’s resilience patterns as the conceptual framework.

Box 9.1: Analytical Trail

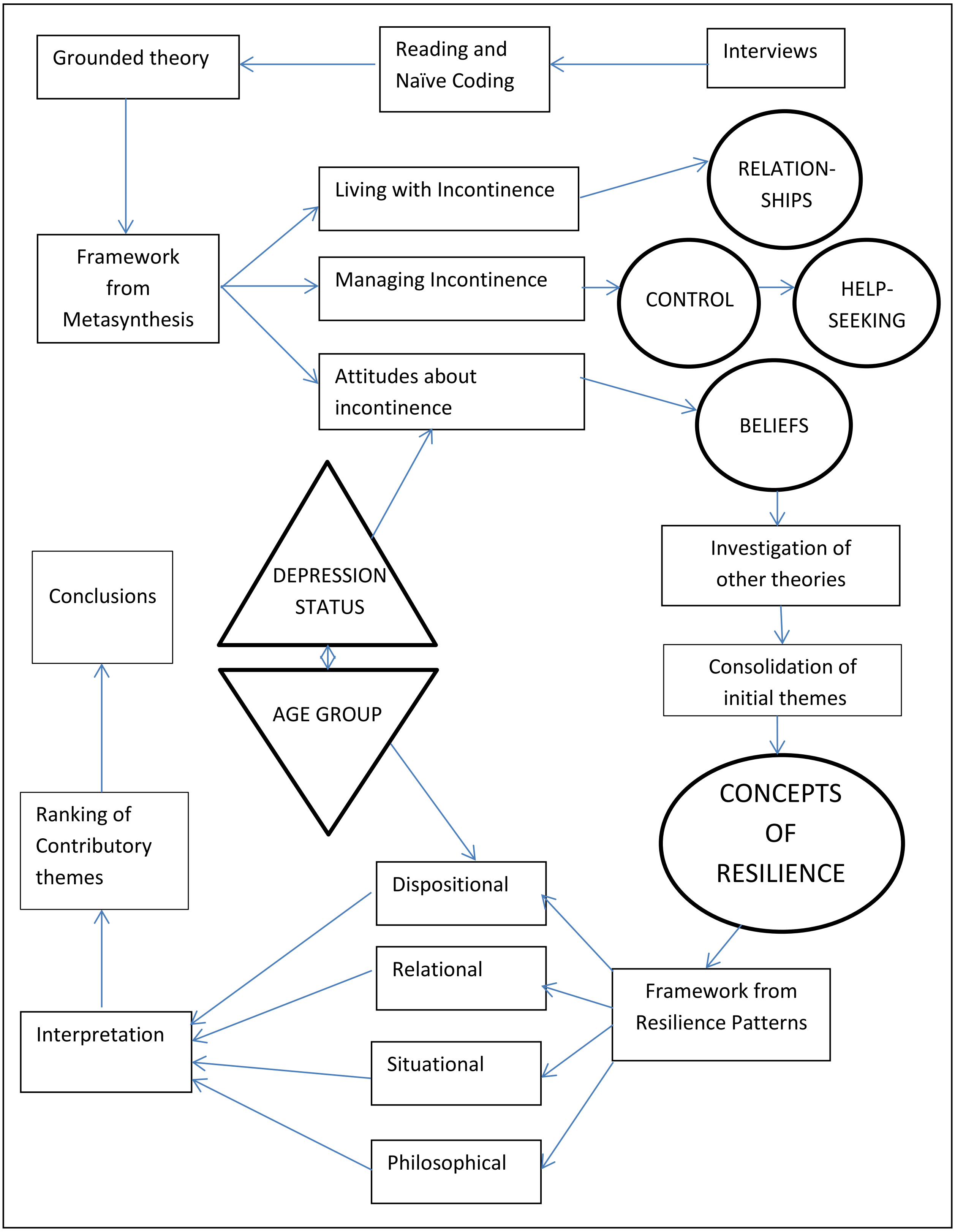


Table 9.2: Resilience constructs from the literature compared with Polk's Mid Range Theory Patterns[422]

	Dispositional	Relational	Situational	Philosophical Beliefs
Rutter 1987[423] *Psychosocial resilience and protective mechanisms*	• Personality features such as self esteem	• Family cohesion and absence of discord • Availability of external support systems that encourage or reinforce coping behaviours		
Beardslee 1989[436] *The role of self-understanding in resilient individuals: the development of a perspective*			• Adequate cognitive reappraisal • Realistic appraisal for the consequences of actions • The individuals assessment of personal capacity for action • The individuals assessment of the effects of personal actions • Action • Developmental perspective • Changes over time, growing older • Understanding as a protective factor	
Bisschop et al 2004[429] *Chronic diseases and depression: the modifying role of psychosocial resources*	• Self esteem • Self-efficacy • Mastery	• Social support • Partner status • Social network size • Instrumental and emotional support • Perceived support – loneliness	• Personal coping resources	

	Dispositional	**Relational**	**Situational**	**Philosophical Beliefs**
Tusaie & Dyer 2004[437] *Resilience: a historical review of the construct*	Physical health	Work or school performance	Behaviour adjustment Psychosocial adjustment	
Southwick et al 2005[438] *The psychobiology of depression and resilience to stress: implications for prevention and treatment*		Social support (role models)	Cognitive flexibility (positive explanatory style, positive reappraisal, acceptance) Active Coping Style (exercise and training) Positive emotions (optimism and humour)	Meaning (religion, spirituality and religion)
Kilic et al 2013[434] *Examining factors that contribute to the process of resilience following spinal cord injury*	Self-efficacy Psychological distress		Locus of control	
Diehl & Hay 2013[428] *Personality-Related Risk and Resilience Factors in Coping With Daily Stress Among Adult Cancer Patients*	Self-concept Incoherence		Personal control	
Rutten et al 2013[427] *Resilience in mental health: linking psychological and neurobiological perspectives*	Positive emotions	Secure attachment		Purpose of life
Wu et al 2013[439] *Understanding Resilience*	Optimism Physical exercise	Social support	Cognitive reappraisal Active coping Humour	Prosocial behaviour (altruism) Trait mindfulness Moral compass

9.4.5.4 *Conceptual Framework*

Once a number of definitions or frameworks of resilience had been considered, I found that the concept synthesis proposed by Polk[422], using the overarching resilience patterns of Dispositional, Relational, Situational and Philosophical Beliefs, reflected and summarised the emergent themes from my initial coding of the transcripts of the interviews. Using Polk's concept synthesis, I recoded the interviews using a resilience lens looking at components of these patterns. Table 9.3 describes the themes used for this framework. Other themes were expected; however the women did not discuss these, or they could not be adequately determined through the interviews. The themes omitted included academic achievement, intelligence, mastery, and cognition.

Table 9.3: Themes used in the Framework

Dispositional	Relational	Situational	Philosophical
• Physical Health • Physical Appearance • Wellbeing • Athleticism • Temperament • Self Esteem • Mental Health • Competence • Self-Discipline • Self-Efficacy • Helplessness	• Commitment to Relationships • Social Support Network • Varied Activities • Job Competence	• Coping Style • Cognitive Appraisal • Goal Setting • Locus of Control • Problem solving • Adaptability • Resourcefulness • Novelty Seeking	• Reflective • Belief that Life is Worthwhile • Belief in Self Help • Altruism • Faith

9.4.5.5 *Contributory Theme Ranking*

Once I had identified four overall depression status categories, (ND, SRD, OMD, SRD & OMD) I grouped the interview responses and produced framework matrices for each resilience pattern by depression group using N*Vivo9[394]. Within each of these groups I also ranked the women according to the size of the difference between their positive and negative themes within each of the resilience patterns. A table of the scoring for the Contributory Theme Ranking is provided in Appendix 2.

If there were more positive responses, the number of negative responses was subtracted from the number of positive responses, with a positive result. If there were more negative responses, the positive responses were subtracted from the negative and the result was made into a negative number. Each woman was then given a rank and put into a continuum in their depression category. A continuum describing where each of the women sat is described in Table 10.1 in the next chapter.

I had also created a framework matrix for each of the resilience patterns described by Polk - the Dispositional, Relational, Situational and Philosophical Patterns[422]. As each of the contributor towards each resilience pattern could be construed as positive and negative (i.e. athletic, not athletic; good physical health, bad physical health), these were tallied to determine the overall level of resilience of each of the women, being either high or low.

In order to summarize the overall results, for each individual resilience pattern, the positive and negative scores were related to whether the majority of women for each depression status group had a greater number of positive or negative themes for each pattern. When the majority of responses were negative and there were also equal responses, then that category scored negative overall. If there were equal negative and positive scores, then that category scored equal overall. A table summarizing the ranking of each resilience pattern compared with depression status is described in Table 10.2.

9.4.6 Summary

This chapter describes the investigative journey I followed in order to examine the psychosocial experiences of the women interviewed in my study, as well as how I explored the influences on their psychosocial well-being and their coping strategies. My exploration started with a description of the rationale for undertaking this qualitative study after starting with a quantitative population approach, and then I described my role and background as a reflexive researcher. I discussed my theoretical perspective based around an interpretivist phenomenological approach.

Once I had discussed the background, I describe the methodology I used for this study. I described the process of designing a study using in-depth interviews, as well as the ethical implications of this project.

Then I described my analytical process. This included using the Framework approach, which I applied to a number of different conceptual frameworks including that derived from the metasynthesis undertaken in the previous chapter (Chapter 8), and then one derived from Polk's concept synthesis of resilience. I described how, throughout the analysis, I was striving to connect with the data, which I achieved through reading theories and examining and summarizing the data in different ways. Finally I described how I came to interpret the data using a technique I called Contributory Theme Ranking, which came out of the analysis of the themes that influenced depression in these women with incontinence. This technique enabled me to rank the women in this study in relation to their depression status, as well as highlight which concept of resilience was most likely to affect how they experienced depression.

The various tools described above enabled a thorough interrogation and summary of the data, in order to elicit the findings described in Chapter 10.

10 "IT'S OUR LOT": RESILIENCE AND ITS INFLUENCE ON THE EXPERIENCE OF DEPRESSION IN WOMEN WITH URINARY INCONTINENCE

SUBMITTED PUBLICATION (26 March 2014):

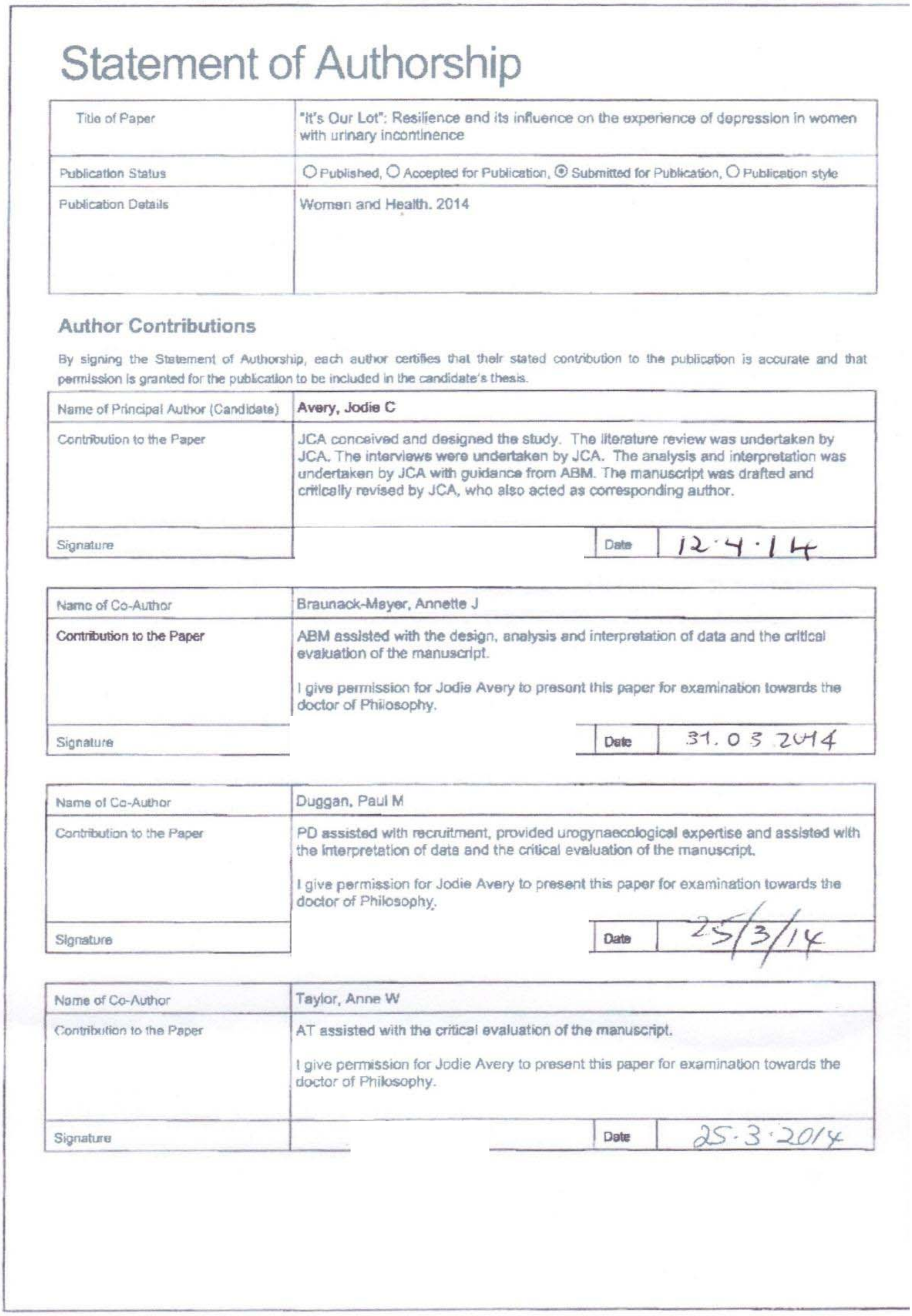
Avery JC, Braunack Mayer AJ, Duggan PM, Taylor AW, Stocks NP. "It's our lot"; how depression influences the experience of incontinence. *Women and Health* 2014 **1(**X):X

10.1 CONTEXTUAL STATEMENT

The following chapter written and submitted as a publication describes a study addressing one of the main aims of this thesis: To explore the subjective experience of the burden of urinary incontinence in relation to mental health. The objectives addressed in this chapter include: To examine whether depression, experienced by those with urinary incontinence, is associated with other psychosocial factors, such help seeking behaviour, quality of life and social networks; to investigate how variables such as gender, age, socioeconomic status and other demographic factors, as well as type and severity of urinary incontinence, affect the mental health and psychosocial factors of those with urinary incontinence; and to analyse how mental health and urinary incontinence interact.

This chapter brings together many of the concepts described in Section 1 of the thesis, as well as the progression through the rationale, methodology and analysis of the qualitative data. The techniques of metasynthesis, qualitative interview and framework analysis have all contributed to the results presented in this chapter. By exploring the subjective experience of the burden of urinary incontinence, in relation to mental health, we have been able to explain how these conditions may interact. We found that women with incontinence who were highly resilient experienced less depression, such that resilience-focused interventions in women newly diagnosed with incontinence may lessen the impact of depression. This part of the thesis is written using "we". This is due to the chapter being written as a publication. The contributions of each individual author are presented in the following statement of authorship. The published version of this paper is available in Appendix 2 at the end of this thesis.

10.2 STATEMENT OF AUTHORSHIP



Statement of Authorship

Title of Paper	"It's Our Lot": Resilience and its influence on the experience of depression in women with urinary incontinence
Publication Status	○ Published, ○ Accepted for Publication, ● Submitted for Publication, ○ Publication style
Publication Details	Women and Health. 2014

Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	**Avery, Jodie C**		
Contribution to the Paper	JCA conceived and designed the study. The literature review was undertaken by JCA. The interviews were undertaken by JCA. The analysis and interpretation was undertaken by JCA with guidance from ABM. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author.		
Signature		Date	12·4·14

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Contribution to the Paper	ABM assisted with the design, analysis and interpretation of data and the critical evaluation of the manuscript. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy.		
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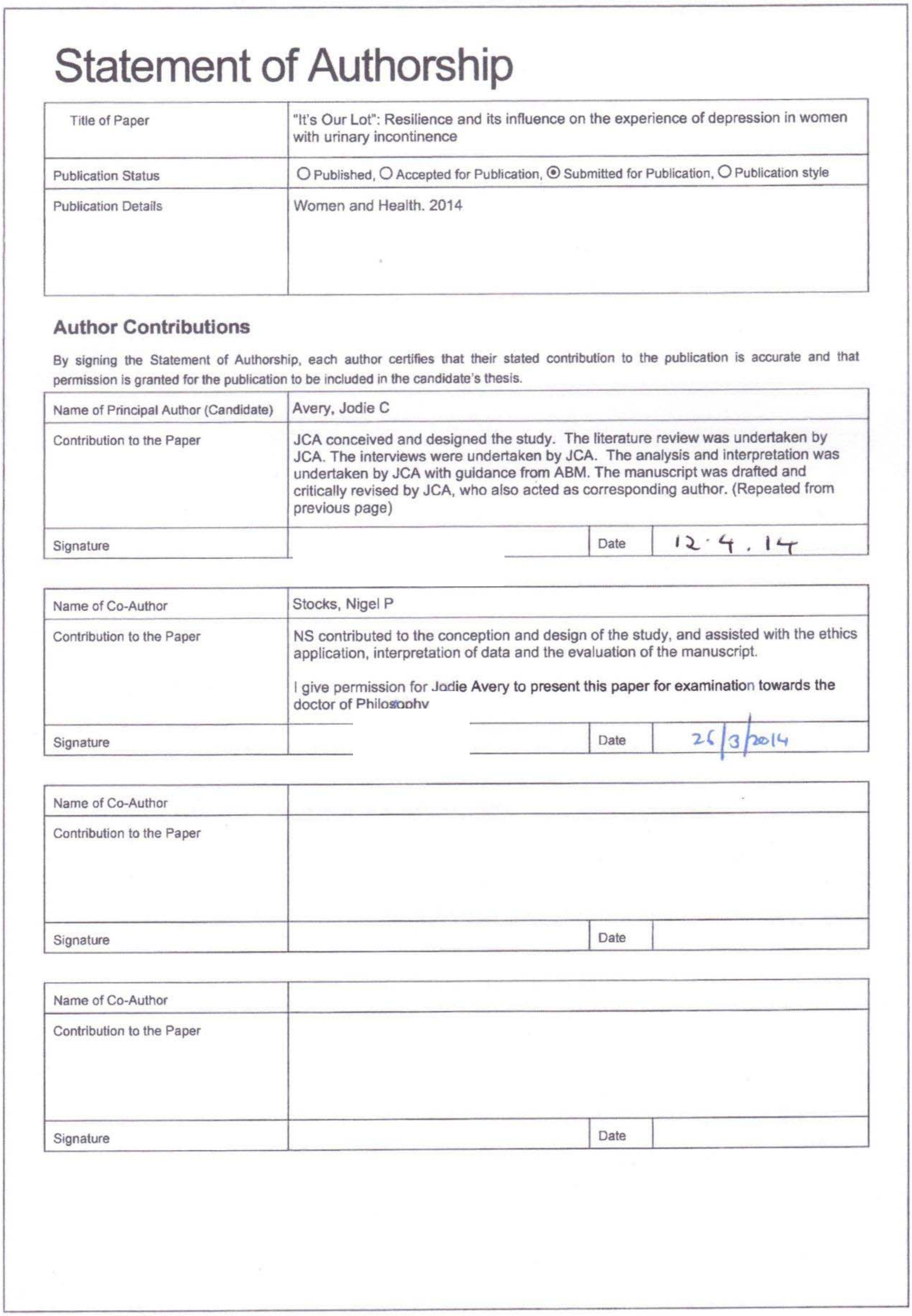
Signature		Date	25·3·2014



Statement of Authorship

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Name of Principal Author (Candidate)	Avery, Jodie C		
Contribution to the Paper	JCA conceived and designed the study. The literature review was undertaken by JCA. The interviews were undertaken by JCA. The analysis and interpretation was undertaken by JCA with guidance from ABM. The manuscript was drafted and critically revised by JCA, who also acted as corresponding author. (Repeated from previous page)		
Signature		Date	12·4.14

Name of Co-Author	Stocks, Nigel P		
Contribution to the Paper	NS contributed to the conception and design of the study, and assisted with the ethics application, interpretation of data and the evaluation of the manuscript. I give permission for Jodie Avery to present this paper for examination towards the doctor of Philosophy		
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Contribution to the Paper			
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10.3 ABSTRACT

10.3.1 Background

Urinary incontinence has been associated with psychological effects such as depression. By exploring the subjective experience of the burden of urinary incontinence, in relation to mental health, we may be able to explain how these conditions interact.

10.3.2 Method

A qualitative study was undertaken using the Framework approach. In-depth interviews were analysed from nineteen women regarding their experiences with psychosocial outcomes, for those with urinary incontinence with and without depression.

10.3.3 Findings

Older women across all severities of incontinence and categories of depression tended to cope better than younger women. Within our resilience framework, two patterns of resilience - relational and situational – appear to contribute most to the experiences of women with incontinence and the particular way they respond to depression. These aspects of resilience seem to contribute to less depression and greater wellbeing and equip women with incontinence with skills to better cope with their situation.

10.3.4 Conclusion

Women who are highly resilient experience less depression and can manage their depression better. Women who do not exhibit resilience are more likely to experience depression, and their incontinence has a greater impact on their lives. Resilience-focused interventions in women newly diagnosed with incontinence may lessen the impact of depression on these women.

10.4 INTRODUCTION

Urinary incontinence is not often considered without some mention of the associated psychological effects, such as psychological distress, depression and anxiety[15]. The International Continence Society (ICS) in its definition of urinary incontinence, incorporates an association with psychological and psychosocial factors[33]. However, despite this recognised link, an examination of mental health in combination with the psychosocial aspects of incontinence has generally been neglected[19,21,30,34,37].

The empirical literature demonstrates a relationship between urinary incontinence and mental health[15,371], and that impaired mental health is associated with a reduction in help seeking[215,308,440]. However, research which explicitly focuses on the psychological implications of incontinence has been minimal, mostly concentrating on older people, women and/or samples of convenience[16-18]. There have been no studies concerning the interaction of incontinence, depression and help seeking, although we might expect such interactions to occur. Few recent investigations have concentrated on the impact of mental health on psychosocial issues relating to incontinence such as quality of life, management and coping behaviours, social connectedness, and beliefs and knowledge of the condition, focussing more upon risk factors such as gender, age, cognitive impairment and physical health[15,19,20]. This study investigates these interactions.

Many psychosocial factors associated with incontinence may be adversely affected by depression[21,31,65,441]. Incontinent people experiencing co-morbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[15,16,27-30,371]. One of the reasons why these interactions are important is because, when an opportunity to reduce the burden of incontinence is presented, treating depression may be as successful as treating incontinence[21-24], increasing overall quality of life[371].

One concept which stands out when describing this relationship is resilience, particularly in relation to psychosocial aspects such as support structures, self-esteem, physical and mental health, coping style, resourcefulness, and self-discipline which are all constructs of this concept. There has been much discussion about what actually defines resilience; it has been described as a composite of a number of different factors. This makes measuring resilience difficult because it has been described both as a continuum and an aggregate of a number of different resources[422].

Resilience has been defined as the mechanisms that protect people against the psychological risks associated with adversity[423]. It has also been seen as the outcome of the successful adaptation and swift recovery after experiencing severe adversity[424]. There have been many studies looking at the associations between resilience and depression[339,424-429]. The main way resilience is thought to interact with psychological factors is that it has been reported to reduce depression and anxiety[342,430], and researchers have proposed that patients with psychological problems such as depression may benefit from treatments that enhance resilience[431].

Resilience has not often been studied in the context of women with incontinence and depression, particularly not qualitatively. One study interviewed women aged 25 to 74 years about chronic conditions, including incontinence, physical functioning and psychological health using a number of different short questionnaires. Resilience was measured using a weighted sum of the constructs derived from these questionnaires including: Control over one's life; Satisfaction with self; Contribution to others; and Ability to solve life's problems. The most important finding from this study was the association of lack of resilience with urinary incontinence in women of all age groups. In addition, control over one's life was significant for women with incontinence under 50 years when compared to those without incontinence[89]. The belief that one had solutions to life problems was also found to be a very important factor in resilience in this study.

The constructs of resilience have been grouped into overarching patterns, using a concept synthesis, by Polk[422]. These patterns are the Dispositional pattern, which describes physical and ego related psychosocial attributes such as constitutional and genetic factors, intelligence, health and temperament; the Relational pattern, which refers to the characteristics of roles and relationships and social interests; the Situational pattern, which examines the approach to situations or stressors, such as cognitive appraisal and problem solving; and finally the Philosophical belief pattern, which encompasses personal beliefs and meaning and the actions that accompany these such as altruism and positive meanings in experiences.

In this study we aimed to analyse how mental health, urinary incontinence and resilience interact, by exploring the subjective experience of the burden of urinary incontinence in relation to mental health. Using a Framework approach[360], we explored how resilience affects the experience of depression in women with urinary incontinence, including what is distinctive about resilience in women with urinary incontinence.

10.5 Method

A qualitative study was undertaken using the Framework approach[360] to analyse in-depth interviews with individuals who had experienced urinary incontinence regarding their experiences with psychosocial outcomes.

10.5.1 Ethics

Ethics approval was obtained from the Human Research Ethics Committees of the University of Adelaide and the Royal Adelaide Hospital. All participants were provided with an information sheet about the study and signed a consent form.

10.5.2 Recruitment

Maximum variation sampling[415] was utilized to target women attending a women's health centre, who had previously or were still experiencing urinary incontinence, with or without depression. This sampling technique captures and describes the central themes or principal outcomes that cut across a great deal of participant variation. Once identified, the women were invited by the Head of the Centre to participate in the study. The women were informed about what the interviews would be about and asked to contact the first author (JCA) if they wished to proceed. Of the 179 women contacted, 19 women agreed to be interviewed. During the recruitment process, three other eligible women had heard about the study and also agreed to be interviewed. Recruitment took place over a period of three months and the interviews were undertaken between March and June 2012.

The criteria used to select the participants for the interviews were that: they were 18 years and over; female; they were community-dwelling; they experienced urinary incontinence, with and without depression; and they were able to provide informed consent. Participants were excluded from interview if they were non-English speaking; had dementia, or a severe or acute neurological disease or a severe psychiatric disorder. Two possible interviews were not undertaken, one due to a woman contacting us after the initial recruitment process and the other due to the interviewer feeling unsafe when visiting the woman's house. A third interview was removed from analysis as it was deemed that the woman's depression at the time was extremely severe, thus meeting one exclusion criterion.

10.5.3 Data Collection

The interview schedule was developed from a metasynthesis of the qualitative literature surrounding incontinence and depression[372], as well as from the results of the initial previous quantitative studies[371,442]. The first interview was also used as a pilot to develop the interview schedule. All participants provided informed consent and permission was sought from participants to record their interview for further analysis. Basic demographic information was also collected from each participant.

In-depth interviewing is a focused technique that aims to explore the complexity and in-process nature of meanings, in a way that is similar to a conversation[361]. All interviews were carried out with participants by the first author (JCA) in either their own homes or another location convenient to the participant, allowing for the greatest information flow between the first author and the participants. The women were asked about the history of their urinary incontinence; did they still experience it, what type were they diagnosed with, what procedures and treatments had they undergone and did they consider themselves cured or were they better than prior to their treatment (Box 10.1). Limited other information from clinic records was available to cross check these responses.

Box 10.1: Interview schedule:

Does urinary incontinence impact your daily life and if so what are the most troubling aspects?

When did you first become aware that the incontinence was happening? How did you feel about it then?

Why did you think there was a problem / seek help in the first place?

Who did you see about your problem? What did they tell you? How did you feel about what you found out? What happened next?

Could you describe how urinary incontinence affects how you feel now? Which parts of your life does it affect the most? Would you say it makes you Depressed? Anxious? Stressed? Did you have these types of feelings before you became incontinent?

How serious do you think your condition is? How does this make you feel?

What kinds of things would you like to be able to do but because of your incontinence you are unable?

Do you think you are in control of your incontinence or do you think it controls your life? Which aspects of your life does it control?

What do you think other people think about your situation? Do they know about it? If they don't know, why not? How did you explain it to your family?

Is there anything else you would like to tell me or add about your experiences?

An assessment of depression was also made using the mood module of the Primary Care Evaluation of Mental Disorders Questionnaire Patient Health Questionnaire (PRIME MD PHQ)[130]. The PRIME-MD is a two part evaluation developed to diagnose some of the most common mental disorders seen in primary care. The first part of the questionnaire, the Patient Questionnaire (PQ), was designed to be completed by the patient or subject alone, and answers from this trigger five different follow-up modules in the Clinical Evaluation Guide (CEG). The modules, which reflect the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R)[155], include Mood, Anxiety, Alcohol, Eating Disorder and Somatoform. However, it was found that the time required for a clinician to administer the instrument was too long, so the development of the PRIME MD Patient Health Questionnaire (PHQ) was developed for self-administration[156]. This questionnaire has been validated against structured and longer diagnostic schedules which are able to detect a number of mental disorders.

In this study, the various mental disorders that can be identified with this questionnaire have been collapsed to indicate other or major depressive syndrome, or no depressive syndrome. For the purposes of this study, women who neither self-reported depression, nor scored for other or major depressive syndrome on the PRIME-MD PHQ, were considered to have No Depression (ND). Women were considered to be depressed if they self-reported depression (SRD) or scored positively for other or major depressive syndrome on the PRIME-MD PHQ (OMD). Additionally some women both self-reported depression and scored on the PRIME MD (and these women were classified as SRD & OMD). In addition, women were classified as "younger" or "older" women. We have used a cut off of 60 years of age to delineate between these two groups (younger: 43 to 59 years and older: 60 to 89 years).

10.5.4 Data Analysis

The interviews were recorded digitally and transcribed by a specialist research transcription service. Initial coding of the interviews was undertaken by the first author using N*Vivo 9[394]. The themes and subthemes were verified by another author (ABM).

The analytical technique used for this study was the Framework approach[360]. This technique provides a systematic approach to analysis through a number of interconnected stages which guide the analysis.

There are a number of stages in this analytical process including: Familiarisation with the data, through listening to interviews and reading transcripts; Identification of a thematic framework; Indexing or coding the data to this framework; Charting, or explaining variation and finding patterns; and Mapping and interpretation, which explores and interprets the data in the context of the original objectives of the study[418].

A socio-demographic profile of all the participant women was imported into the N*Vivo 9 casebook and an attribute table was developed. This enabled interrogation of the data and the identification of patterns between specific demographics, such as depression status, incontinence status, and emerging codes.

10.5.4.1 *Overall Resilience Patterns*

Once we had identified the overall depression status categories we grouped the interview responses and produced framework matrices for each resilience pattern by depression group using N*Vivo9. A framework matrix for each of the resilience patterns described by Polk - the Dispositional, Relational, Situational and Philosophical Patterns[422] - was created. Every positive and negative contributor towards each resilience pattern was considered, and tallied to determine the overall level of resilience of each of the women, being either high or low. Within each of these groups, we also ranked the women according to the size of the difference between their positive and negative themes within each of the resilience patterns. If there were more positive responses, the number of negative responses was subtracted from the number of positive responses, with a positive result. If there were more negative responses, the positive responses were subtracted from the negative and the result was made into a negative number. Each woman was then given a rank and put into a continuum in their depression category.

For example, "Heather" did not self-report depression; however she did score for other or major depressive syndrome on the PRIME-MD. In her interview, she was coded positively for four Dispositional themes, and negatively for one Dispositional theme; positively for two Relational themes, with no negative Relational themes; positively for four Situational themes, with no negative themes; and one positive Philosophical theme, with no negative Philosophical themes. Overall "Heather" was coded for eleven positive themes and one negative theme, so her overall rank was "ten", meaning she had the highest resilience of all the women.

Thus, for each individual resilience pattern, the positive and negative scores related to whether the majority of women for each depression status group had a greater number of positive or negative themes for each pattern. If the majority of responses were negative and there were also equal responses, then that category scored negative overall. If there were equal negative and positive scores, then that category scored equal overall. (In the case of "Heather" again, as she was in the high resilience "OMD" group, the other women in this group had all scored positively for each depression category, which allowed generalisations to be made about this group in relation to their resilience patterns.)

10.6 FINDINGS

This section explores a number of questions that were posed when analysing the experiences of women with incontinence. The answers to the questions revealed the patterns of resilience experienced by women within each depression status group. Particular women talked about different resilience patterns. Some refer to each of them.

Initially, we discuss the experiences that contribute to a lessening of the burden of incontinence and depression in women. Then we describe how resilience affects the experience of depression in women with incontinence, and describe the distinctive characteristics of resilience in women with incontinence.

10.6.1 Experiences that contribute to a lessening of the burden of incontinence and depression

Our analysis suggests that, for this study population, some aspects of resilience may contribute to less depression, higher wellbeing and equip women with incontinence with skills to better cope with their overall situation. In this section, we outline the three most important themes in our findings. Firstly, older women across all severities of incontinence and categories of depression tended to cope better than the younger women. Secondly and thirdly, within our resilience framework, two concepts – the Relational pattern and the Situational pattern – seem to contribute most significantly to the experiences of women with incontinence, and the particular way they respond to depression.

10.6.1.1 *Older women tend to cope better with incontinence and depression*

Many older women have life experiences that may enable to them to cope with adversity and stressful situations such as chronic illness[443,444]. Regardless of the severity of their incontinence, or whether they self-reported depression or scored for other or major depression on the PRIME-MD PHQ, in general the older women appeared to exhibit high resilience, whereby on the resilience continuum they demonstrated a higher positive difference between talking about positive and negative themes of resilience. Whether these women were cured of their incontinence, whether it was better than before, or if they still experienced incontinence, they felt that they were in control. Fewer older women self-reported that they had experienced depression; it was more likely that they did not mention depression at all or had scored for other or major depression, but did not perceive themselves to be depressed.

Table 10.1 shows where each woman sat, within each of the depression categories, as defined by self-report or scoring for other or major depression on the PRIME MD PHQ, and along the resilience continuum.

Table 10.1: Continuum of Resilience for Depression Status

	No Depression	RR	OMD	RR	SRD	RR	SRD and OMD	RR
High Resilience			**Heather 65-69**	10				
			Julia 65-69	7				
	Teresa 85-89	6						
					Matilda 65-69	5		
					Winona 40-44	5		
	Janice 70-74	4			**Naomi 75-79**	4		
	Samara 70-74	3			Hannah 40-44	3		
			Sarah 60-64	2	Rhonda 50-54	2		
	Karina 80-84	1			**Kaliope 60-64**	1		
					Delia 45-49	0		
Low Resilience					Ruth 55-59	-3	Anna 45-49	-3
					Penelope 70-74	-3		
							Selena 50-54	-5
					Martha 70-74	-9		

SRD: Self-Reported Depression. OMD: Other or Major Depressive Syndrome.
RR: Resilience Rank
Note. Each case has be de- identified with a pseudonym and an indication of their age group: Jane 50-55
The older age group women are in BOLD

The way the older women conveyed their experiences of incontinence was with a no-nonsense attitude of acceptance. Incontinence did not appear to matter much in the scheme of things. This is how their life was and they just had to cope with it:

> *"Well I don't let it affect me……Oh I think I can manage it, yeah."* (Karina 80-84 ND)

> *"I've sort of got so used to it that it's just a daily – it's just something in my day…….Yeah, I've sort of gone, 'Well this is life', I've got other things to think about now, yeah…….Well it's life, you know, what can you do?........Well that's it, no, that's it, yeah, yeah, and it's really horrible to think like that, but you know, as I say, that's life, it's our lot."* (Sarah 60-64 OMD)

They were able to rationalise their situation, and often they would use their age and compare themselves to others in order to help them do this:

> *"I don't think it's serious at all. I mean at my age I'm lucky that I've got as few as problems that I've got. This is so minor compared to what a lot of other people have got. I don't even think about it. As I say; it's part of my daily routine; it's part of life and I just do it."* (Heather 65-69 OMD)

These older non depressed women consistently described positive relationships and social support. They were able to rely on adequate social support if needed. Their spouses were very important to them, shared in their struggles, and the women demonstrated commitment to their relationships:

> *"The point is that we're at home and we're together and so we just get on with it."* (Teresa 85-89 ND)

These women also enjoyed a sense of positive wellbeing, even when still experiencing incontinence. They rationalised their situation and thought it better to be happy, transforming adversity into something meaningful:

> *"That's the way I consider it. Why spend your later years being miserable? It's not worth it. Get on with it, enjoy yourself."* (Heather 65-69 OMD)

Some of the older women had developed a good coping style and a realistic appraisal of their situation:

> *"No, it's just there, I just cope with it and get on with it………I guess it's not so serious because I know how to cope with it but there have been times when I haven't been able to get home quick enough or do whatever quick enough and that's a nuisance value, more so than getting you upset. ...It doesn't really change anything very much because I've just got to cope with what happens and I always take a spare pad with me if I'm going out at all, because there's always toilets about the place that you can change the pads when you've used them up." (Naomi 75-79 SRD)*

Overall, this group of older women seemed to have a very even temperament. They just got on with their life despite their difficulties:

> *"Oh yes, I still live life, yes, I still live life, yes." (Julia 65-69 OMD)*

Compared with the younger women with incontinence in this study, incontinence did not take on a majorly intrusive role in the lives of the older women. Incontinence was more likely to feature prominently in the lives of the younger women:

> *"I think it was starting to get worse and it was starting to, not take over, but it was starting to play a really big part in what I was doing, I guess. It was just always there." (Winona 40-44 SRD)*

The analysis presented in Table 10.2 suggests that overall, older women with incontinence, who were highly resilient particularly for the Relational, Situational and Philosophical patterns of resilience, were not experiencing depression. However, younger women who were resilient for these patterns did self-report depression.

Breaking this down by depression categories, older women who were highly resilient, rating highly in all resilience patterns, tended to score for other or major depression. Older women, who were highly resilient for the Situational pattern and the Philosophical pattern and rated equally for the Relational pattern, were inclined to self-report depression.

Women with incontinence who had low resilience, rating equally for the Situational pattern and lower for all other patterns except the Philosophical pattern, self-reported depression. Women who rated equally for the Relational and Philosophical pattern, and low for the Dispositional and the Situational pattern, scored for both other and major depression, and self-reported depression.

Table 10.2: Resilience Patterns and Depression status

Depression Status	Dispositional	Relational	Situational	Philosophical
High Resilience				
ND HR	–	+	+	+
OMD HR	+	+	+	+
SRD HR old	–	=	+	+
SRD HR young	–	+	+	+
Low Resilience				
SR LR	–	–	=	+
SRD & OMD LR	–	=	–	=

ND: No Depression, SRD: Self-reported depression, OMD: Other or Major Depression
HR: High resilience, LR: Low resilience

10.6.1.2 *Relational pattern of resilience influences the associations between incontinence and depression*

Resilience constructs which are classified under the Relational pattern include characteristics of roles, work and school performance[437], relationships[429,438] and social support and interests[429,439]. The main differences noted in women who have experienced incontinence were the effects that incontinence had on their relationships, family and their social support, which then seemed to influence their depression.

The older women with higher resilience who did not perceive themselves to be depressed were mostly in committed supportive relationships. Their partners were very involved in their lives and the women spent time caring for them as well:

> *"We've always been like that. I've got a very good marriage. We are each other's best friends. We don't need anybody else. We moved to Australia with nobody here. All our family's in [another county] and we moved over with our children because we knew as a family unit we were strong. [My husband] and I are quite happy with each other's company. People say, "How are you going to retire together?" Not a problem because we are each other's best friends and we support each other absolutely. I haven't got an issue". (Heather 65-69 OMD)*

Those who were not in these sorts of relationships actually saw it as a positive thing, and they had other forms of support such as family:

> *"Yeah, the only time I worried was when I was left by myself with four children……..And that wasn't a very pleasant thing. It took a few years to get over that but, once I got over it, it was 'oh well, tough, I'm better off anyway'……. "Oh yeah, [I have support from] all my kids, all my kids."" (Sarah 60-64 OMD)*

The older women who self-reported depression described a similar situation to the other older women. They were also committed to relationships, even though intimate relationships could be a problem:

> *"Yeah it just became everywhere we went we know where the toilets are, don't we? He's a good toilet finder…….I can't have sex now because I wet him, you know." (Kaliope 60-64 SRD)*

They also had adequate social support, and were involved in a number of varied activities in their communities, even volunteering, which kept their social networks flourishing:

> *"Well I do most things, I'm involved at the church, I go to the football and as soon as I get to the football – my girlfriend is in the same position so she was talking to me tonight and she's under [my doctor] too, but she meets me out the front of the football and as soon as we get there, we go to the toilet." (Matilda 65-69 SRD)*

The younger women with self-reported depression had a similar story to tell for this pattern. They were also involved in varied activities and their social support was reasonably sufficient, although it could be better:

> *"Friends, I lost my mum to breast cancer six years ago, so that was pretty bad, I lost a good friend that I used to speak to every night and we could speak about anything and everything, she died, it will be two years in September, so Dad has now moved up to [the country], my brother lives up there, so yeah I've got one friend, she's actually just gone through, diagnosed as Manic Depressive, so we've gone through that whole thing in the last few months so she's, I guess, she's there to talk to about stuff but, yeah, she's got I suppose her own things, but our girls are the same age, so they've known each other since the girls were at childcare together, so yeah, friends I suppose." (Winona 40-44 SRD)*

A major difference between the above groups, and both older and younger women with self-reported depression and lower resilience, was that they had fewer and weaker supportive relationships. The older women with self-reported depression who demonstrated lower resilience did not appear to be in as strongly committed relationships. This was a major difference from the women with higher resilience. One woman broke off her relationship due to the incontinence:

> *"Socially. I had a very dear friend and I just sort of said to [my friend], 'Look, I'm very sorry but I feel - ', he said, 'Don't worry about', I said, 'I feel very embarrassed about it and I'd rather just sort of', there was nothing sexually – I looked after his mother for 12 years and we became very close and he's sort of always been there if anything is wrong, and he didn't want to break the relationship, but I did. I don't know, I just got so embarrassed about it………He wants us to get back together but it's just most probably me and it's just so embarrassing and when my granddaughter came down for the wedding in March at [the seaside], she said, 'Why are you so embarrassed about it?' and I said, 'Because I am' and I am embarrassed about it because it's awful." (Martha 70-74 SRD)*

The younger women in this group with a higher degree of depression also had a history of unsuccessful relationships:

> *"I don't think so, I didn't have a very good relationship anyway, but no, besides that, no, I don't really think it did impact, besides, yeah, it just wasn't nice feeling like I did with that area, but I mean, there wasn't any like soreness, there wasn't anything like that, it was just the yucky feeling about it". (Anna 45-49 SRD and OMD)*

10.6.1.3 ***Situational pattern of resilience guides the experience of incontinence and depression***

The Situational pattern of resilience includes those constructs of resilience which concern personal coping resources[429], behavioural and psychosocial adjustment[437], positive emotions, cognitive appraisal[438], problem solving and control[428,434]. The women who had a more positive experience of incontinence, with and without depression, had developed a positive coping style, not only when managing their incontinence but also in most aspects of their life. They were flexible and just got on with what they were doing. Their incontinence was just another aspect of their lives.

As well as maintaining a realistic appraisal of their situation, rationalising it and accepting it as part of life, these women sought out positives in their situation. For example, they said they were better off than other people, or that it was expected at their age. They had reasonable expectations of their life, positive attitudes and they knew their limits, particularly if they had other factors which may influence their situation, such as other chronic conditions:

> *"I think I do most things that I want to do. I've just got to allow for it." (Karina 80-84 ND)*

These women usually thought that they were in control of their incontinence. They were also very resourceful in managing their situation and were also very adaptable. They knew exactly what they needed to do:

> *"No, because I used to pad up well….Well you know, I mean I bought really good pads, big pads, eventually I was wearing the actual pants, you know…..And then, not just them, I used to pad that as well so that when I went out, if I did cough, nobody knew and, no, it didn't affect me that way because I made sure that it didn't." (Janice 70-74 ND)*

> *"No, it doesn't control me. I'm in control of it absolutely…but generally it does not rule our lives. I don't stay home because of it. I don't not do things because of it." (Heather 65-69 OMD)*

Other women who did not have a positive experience with incontinence, particularly where their mental health was concerned, had not developed a positive coping style, and sometimes exhibiting avoidance behaviours, particularly in social situations:

> *"Everyone would say, 'Sit down after the game' and I'd go, 'I'll see you later'. It's embarrassing but it used to run down your legs, I mean, it's disgusting, and then I'd like have to sit on a plastic bag in my car to drive home and then get in the shower and wash everything and it was just, no, it wasn't fun…….Yeah, I mean, it got to the point that I thought, this is going to be smelly and it's just, yeah, and it was making like, I'd get a few migraines because I think I was probably worried about that happening and then like trying to get home and get cleaned up, it wasn't fun." (Anna 45-49 SRD and OMD)*

Further, their appraisal of the situation could be a little unrealistic:

> *"No, no I'm not, but I do get paranoid about like, I don't know, say I don't think how much I might have had to drink and I might go a few times and then I'll get like worried like, 'Is something wrong' but then I'll go, 'Just don't be stupid, there's nothing wrong' but it's something that's not daily on my mind I suppose but I do often – it's an area that I have of concern if something doesn't feel right." (Anna 45-49 SRD and OMD)*

Some even felt completely controlled by their incontinence:

> *"I hated it. It just stopped me from doing so much. If I – if I bent down I would wet myself, and if I stood up, I wet myself. It controls my life." (Ruth 55-59 SRD)*

In summary, this examination of how women with incontinence talk about their experiences, particularly in relation to depression, suggests that the experiences of women with incontinence, with respect to depression and resilience, are quite variable. We have found older women with no depression who were highly resilient and older women who scored for other or major depression, who were also highly resilient. Then we have older and younger women who were resilient, who self-reported depression. We also identified a group of less resilient women who all self-reported depression with or without scoring for other or major depression.

A number of themes from the analysis of women's experiences of depression and incontinence have emerged. Firstly, the experience of depression in women who have had incontinence varies with age. Secondly, some constructs of resilience, such as those found within the Relational pattern of resilience, may buffer, or reduce the effects of depression on women with incontinence. Thirdly, women with incontinence have different perceptions of depression depending on a number of factors, such as those that contribute toward the Situational pattern of resilience. These three key outcomes enable us to describe the diverse experiences of depression in women with incontinence and are explored in the next section.

10.7 DISCUSSION

This study shows that a number of factors come into play when describing the experiences of women who have incontinence that may be associated with depression. Factors such as age, relationships and appraisal all seem to influence the extent to which depression may affect the lives of these women, for a number of different reasons.

10.7.1 Age related lessening of the burden of incontinence and depression

The older women in this study appeared to cope better with their incontinence and either experience depression less or manifest it in a different way to many of the younger women. Younger women with incontinence, at a different stage of life to the older women, may still be raising children, looking after their partners, maintaining household duties, as well as still undertaking work outside the home. It has been previously found that there is an association between illness intrusiveness and younger age and greater disease severity, less internal locus of control, and avoidant/emotion-focused coping[445]. So many responsibilities at the same time as dealing with a chronic illness may contribute to incontinence being more intrusive in their lives, resulting in increased depression[446].

Additionally, younger women may perceive that their health status should be better than it is and that they should not be experiencing an "old women's" disease. As mentioned previously, the older one gets, the more life experience one has, and this may assist coping with adversity and stressful situations[443,444]. Older people also experience less depression resulting from the impact of stressful life events, such as chronic illness[447].

Further, older women seem to be able to manage their incontinence more effectively than working aged women, by using strategies such as using protection and increasing hygiene practices; by contrast the younger, working age women are more likely to avoid some of their normal activities such as sexual activity[448], social situations[449] or playing sport[450].

These reasons point to a need for support and counselling for women which will provide more personalised coping strategies for urinary incontinence and take into account the life stages of women with incontinence to minimise the occurrence or burden of depression.

10.7.2 Aspects of life that buffer against depression associated with incontinence:

As we have seen in this study, some of the women scored for other or major depression, but did not indicate they were depressed. Although they may have mental health challenges, some of the components of resilience may be contributing towards a buffering effect against depression[429]. The Relational pattern of resilience seems to have aspects to it which "buffer" or lessen the impact of depression, and these include social support and relationships. One of the best examples of this is the social support construct which has been studied in cancer patients, where having social support can reduce emotional distress[429,433]. Having relationships with others can boost positive self-concepts and self-worth, thus increasing mental health.

10.7.3 Appraisal and Perceptions of Incontinence and Depression:

Many of the women who had experienced incontinence in this study were categorised as self-reporting depression, or scoring for other or major depression on the PRIME-MD PHQ, or a combination of both of these. These women also elicited differing patterns of resilience, particularly for the Situational pattern of resilience.

One group of women neither self-reported depression, nor scored on the PRIME-MD PHQ. These women were not depressed and were highly resilient. Other women who did score for other or major depression, but did not perceive themselves to be depressed, seemed to be even more resilient than the women with no depression. Is there a link between perceiving that one is depressed and being less resilient? It seems that this may be the case here. Are there factors at play when one considers that they are depressed that contribute towards overall resilience?

It has been suggested that multimorbidity and depressive symptoms are partially mediated by health-related quality of life, functional limitations and self-rated health[451]. Older women in this study may have been more likely to experience multimorbidity, which may have impacted on their perceptions of depression. We have also found that women with any urinary incontinence, who considered their condition to be very or moderately serious, were more likely to report severe incontinence. Women whose lifestyles were limited by incontinence were more likely to perceive their condition to be very serious. Together, severity and limitations to lifestyle were predictors of women perceiving that their incontinence was moderate to very serious[442].

Thus, are women who experience incontinence and other conditions, more likely to perceive that they are depressed and report this? Other women who have not experienced other chronic conditions may be less likely to perceive they are depressed, even though they may still be experiencing depressive symptoms.

Other factors which have been found to be important in increasing resilience, particularly in women with incontinence, include having a belief that one had solutions to life's problems[89]. Additionally, when people feel that they are in control of their situation, this may also act as a buffer against stress and its effects including depression[428]. Further, positive appraisal of situations, positive life events and an enhanced cognitive style also contributed toward a lessening of depressive symptoms[344,436]. These constructs have all been found to occur within the Situational Pattern of resilience.

10.7.4 Strengths and limitations of this study

This study had participants from a broad age range, with differing types of incontinence, differing levels of depression, and focused on the psychological implications of incontinence. A qualitative method was chosen for this study, allowing women's own experiences, thoughts, and feelings about living with incontinence to be studied. This approach allowed us to explore the experience of incontinence more comprehensively than we would have been able to do in a population survey. Similar qualitative investigations have not been undertaken in such a diverse population to date, focussing more often on the elderly or particular types on incontinence.

Our recruitment methods were not as representative as we would have liked. We used a convenience sample from one local hospital clinic; however we were able to select women across a broad age group. Therefore, a further limitation in this study was that, bar their age, this group was quite homogenous. Women in this study were all recruited from the same public hospital setting, which this may have meant that they were from a similar socio economic group, although from visiting their homes, there seemed to be diversity. If the women had been seen in private specialist clinics, they would have incurred out of pocket expenses, but would not have had endured treatment delays due to long waiting lists. The women also seemed to be similar in their educational level, all were no more than high school educated, and their occupations were non-professional. However, we have previously found these characteristics of women with incontinence to be typical[371]. Many of the women also lived in a close geographic proximity, which may have been associated with the location of the clinic.

The original intention was to interview some patients from other settings such as general practice and private specialist, but we were unable to carry this out because the private specialist contacted decided not to burden his patients with a study, and the general practice contacted did not reply to our requests. We then decided that we had enough women available to interview from the clinic, so did not pursue other options. The women interviewed had all sought specialist help for their condition, and many had been treated, so we could not represent women with incontinence who had not received any help for their condition from health professionals.

We also made a date error in our first mail out, which may have led some women to think it was an old study, thereby not replying to our offer. This was rectified in subsequent mail outs. Additionally, as the setting for the interview was usually the women's home, many occasions their partners were present, which may have limited the women's disclosure of information. However, most of the time this did not seem to be a problem, with the partners actually joining in and providing additional information.

A limitation of this study was that we did not have a clinical diagnosis of depression in this study, only self-report or a diagnosis made using the PRIME MD PHQ. We only had information as to whether the women were incontinent, and no information as to whether they had undergone any psychiatric assessment or treatment for mental illness, unless they told us.

One of our original objectives for this study was to understand the temporality of depression, resilience and/or incontinence. However, in a study of this type, we cannot really untangle what came first. While we do have a nuanced picture of the experience of these issues, we would need to undertake a cohort study (either qualitative or quantitative) over time to establish this. This study gives us an insight into how the women experienced their lives at the present time with reference to some past experiences.

The design of this study could have been greatly enhanced if questions exploring aspects of resilience had been part of the interviews. Resilience was not identified as a major influence until after the interview data had been analysed. There may have been scope to investigate the constructs of resilience further through additional questions.

10.7.5 Implications

The women with incontinence in this study described a diversity of experiences with regard to incontinence, how they coped and managed it and whether they experienced co-morbid depression. Some aspects of resilience seem to have a greater impact on the mental health of these women, including their age, their social support structures, their relationships, their beliefs about control, and their ability to realistically appraise their life.

Using the findings presented here we may be able to design programs to enhance resilience, thereby decreasing depression and increasing quality of life. Tailoring different approaches that can be effectively targeted both by age and different aspects of resilience may aid in the overall management of incontinence. Aspects such as coping and appraisal style could be identified and targeted in newly diagnosed patients which limit the development of depression. Many women do not seek help for their incontinence; however, practitioners who are approached by women for help may be able to screen for both depression and resilience using any of the available questionnaires designed for this purpose[157,432]. Building resilience may be helpful in encouraging mental wellbeing in those with incontinence.

10.8 CONCLUSION

In conclusion, results from this study suggest the women who are highly resilient experience less depression and can manage their depression better. Women who do not exhibit resilience are more likely to experience depression, and their incontinence has a greater impact on their lives. Women with resilience are more likely to be older, have greater social support, experience control in their lives and realistically appraise their situations. These women experience less depression or do not perceive themselves to be depressed. Resilience-focused interventions in women newly diagnosed with incontinence, may lessen the impact of depression on them.

11OVERALL CONCLUSIONS

11.1 INTRODUCTION

This thesis, through its component chapters, has addressed the main research question:

> *How is depression associated with psychosocial factors such as quality of life, help-seeking and social networks in people with incontinence, and what are the consequences of these associations in people with incontinence and co-morbid depression?*

The first part of the research question - the associations between incontinence and depression - were addressed in Section 1, the quantitative part of the thesis. The qualitative research presented in Section 2 delved more deeply into the meanings these associations had for the individual experiencing incontinence and depression. Supporting chapters reviewed the literature and described the methodologies used. This chapter summarises the findings and implications of the studies that were undertaken. It describes the significance, contribution to the knowledge base, limitations, implications and future directions in this research field.

11.2 SUMMARY OF FINDINGS

Each hypothesis presented in this thesis came with associated aims and objectives. Under each of the four hypotheses described below, the following objectives were addressed:

- *To explore the relationships between urinary incontinence and depression;*
- *To identify the psychosocial factors that are associated with chronic conditions, particularly urinary incontinence;*

- *To investigate how variables such as gender, age, socioeconomic status and other demographic factors, as well as type and severity of urinary incontinence, affect the mental health and psychosocial factors of those with urinary incontinence; and*
- *To analyse how mental health and urinary incontinence interact.*

11.2.1 Hypothesis 1

The first hypothesis:

> *The help-seeking behaviour of people with incontinence is adversely affected by comorbid depression;*

encompassed the aims:

> *To explore the relationship between depression and urinary incontinence, and demonstrate the effects of this association on psychosocial factors associated with incontinence, including help-seeking, quality of life, perceptions of symptom severity, and social networks;*

as well as:

> *To explore the subjective experience of the burden of urinary incontinence in relation to mental health.*

This hypothesis is primarily addressed in Chapter 2, the literature review of population studies using help-seeking as the primary psychosocial factor of interest and example. Help-seeking was selected as it represented an important outcome when incontinence and depression are found together, with its effect on everyday life, self-esteem, management of incontinence and quality of life. Much research has been undertaken concerning help-seeking in both incontinence and depression. Interestingly, one of the main reasons for not seeking help for incontinence was that, often, it was only seen as a minor inconvenience for people, not serious or severe enough to worry about, or not seen as something abnormal.

These beliefs, however, can be subjective and other factors may influence such perceptions. Factors found to predict help-seeking for incontinence included social networks, functional status, cognitive function and depression. Similarly, barriers to help-seeking for depression included stigma, cognitive appraisal, and not really needing help, a lack of control and social support, and mental health literacy. Predictably, when incontinence and depression present together, it is often an impetus to seek help.

The above hypothesis was also addressed in Chapter 5 and the accompanying paper:

> **Avery JC**, Stocks N, Taylor AW. Gill TK. Perceptions and prevalence of urinary incontinence in the Australian population. *Australian and New Zealand Continence Journal.* Autumn 2014; **20**(1): 7-13.1

This published paper investigated the seriousness and severity as experienced by women with urinary incontinence, and found that 31.0% of women with incontinence had sought help from a health professional. Although mental health was not considered in this paper, the exploration of seriousness and severity provide an example of the psychosocial factors at play when women experience incontinence. These factors may also be precursors to women experiencing co-morbid depression because such perceptions, as a subjective experience, can feature as one of the constructs of being resilient, which may affect the development of depression.

Finally, a discussion of this aim is presented in Chapter 8, the published metasynthesis which discusses the psychological perspectives of urinary incontinence. This paper reviewed a number of studies, and found several themes that ran through the studies: living with incontinence; management of incontinence; and attitudes about incontinence. Other smaller component themes included control, seeking help and personal beliefs. These themes provided a perspective on how incontinence affects many parts of life, including psychological aspects.

These results support evidence that co-morbid depression adversely affects the help-seeking behaviour of people with incontinence. Depression in those with incontinence is one factor that can affect help seeking, but others that may also contribute include control, social networks and quality of life. An important conclusion was that managing depression in those with incontinence may contribute towards better treatment outcomes.

11.2.2 Hypothesis 2

The second hypothesis presented is:

> *The quality of life of people with incontinence is adversely affected by comorbid depression;*

This was explored with the aims:

> *To explore the relationship between depression and urinary incontinence, and demonstrate the effects of this association on psychosocial factors associated with incontinence, including help-seeking, quality of life, perceptions of symptom severity, and social networks;*

as well as:

> *To explore the subjective experience of the burden of urinary incontinence in relation to mental health.*

Again this is first examined in the literature review of Chapter 2. Quality of life was discussed for both incontinence and depression and it was found that those experiencing these conditions did have lower quality of life than the general population. Additionally it was found that depression, when associated with other chronic medical conditions, had unique and compounding negative effects on patient functioning.

The work that provides support for this hypothesis was Chapter 4 and its accompanying paper:

> **Avery J**, Stocks N, Duggan P, Braunack-Mayer A, Taylor A, Goldney R, MacLennan A. Identifying the quality of life effects of urinary incontinence with depression in an Australian population. *BMC Urology.* 2013; 13(11)

Multivariate analysis in this study demonstrated that in people with incontinence, the risk of having comorbid depression was increased by an overall health status of "Fair" or "Poor", or the perception that their incontinence was moderately or very serious.

The major finding from this study was that depression and incontinence both reduce health-related quality of life. Occurring together they produce an effect that is greater than just the sum of the individual effects on both physical and mental health. These results reinforce the conclusions from the literature review, as well as demonstrating the effects of the association between incontinence and depression on psychosocial factors.

Chapter 8 and accompanying paper also support this hypothesis:

> **Avery J**, Braunack-Mayer A, Stocks N, Taylor A, Duggan P. Psychological perspectives in urinary incontinence: a metasynthesis. *OA Women's Health* 2013 **1**(1):9

The subjective experiences of the women included in the metasynthesis, who come from many different countries and situations, all display the effects that combined incontinence and depression have on their quality of their life. Increasing quality of life will reduce the burden experienced by many of these women.

In conclusion the relationship between quality of life in people with incontinence and co-morbid depression was explored through the literature and quantitative analysis. Reduction in the quality of life of people with both incontinence and depression combined was greater than that found when the effects of each individual condition were added together.

11.2.3 Hypothesis 3

The third hypothesis proposed was:

> *Perceptions of symptom severity of people with incontinence are adversely affected by comorbid depression.*

Associated with this hypothesis were the aims:

> *To explore the relationship between depression and urinary incontinence, and demonstrate the effects of this association on psychosocial factors associated with incontinence, including help-seeking, quality of life, perceptions of symptom severity, and social networks,*
>
> *To explore the subjective experience of the burden of urinary incontinence in relation to mental health;*
>
> and
>
> *To explore how people understand the relationship between urinary incontinence and depression.*

Chapter 2 again provided a context for this hypothesis and aims, particularly whether incontinence is a subjective problem, which can make diagnosis and measurement a problem. It also considered how ‘severity’ is perceived and the impact it had on individuals lives.

The limitations experienced by women with incontinence included not being able to leave the house, not being able to socialise, and not being able work as much as they did before they developed incontinence. These limitations as well as the perceptions women have about the severity and seriousness of their condition, point to the constructs of resilience, which have been found to influence the effect of comorbid depression.

The main focus of the published paper in Chapter 5 concerned both the severity and associated perceptions of incontinence in women. In this paper, the severity of incontinence and the subsequent limitations to lifestyle were found to be predictors of women perceiving their incontinence to be moderate or very serious.

The literature analysed in Chapter 8 also considered the perceptions of severity by women with incontinence. The qualitative literature dealt with the meanings the women in this study attributed to their situation, and how the women understood the relationship between incontinence and depression. The perceptions women had around their incontinence included that it was something they could not control, leading to desperation, powerlessness and anger; however those who only had a minor problem thought they were able to control it. This reflected the amount of control they had in their lives[3]. There were also perceptions around coping, avoidance strategies, and rationally appraising their situation[,] , and these contributed towards the impact on one’s life.

Chapter 10 presented a qualitative interview study in which the experience of depression in women with incontinence was explored.

> **Avery JC**, Braunack Mayer AJ, Duggan PM, Taylor AW, Stocks NP. “It’s our lot”; how depression influences the experience of incontinence. *Women and Health* 2014 (submitted publication: 26 March 2014)

This study found that constructs of resilience, such as cognitive appraisal of one’s situation, or the perceptions about the condition one has, can be detrimental or beneficial to the experience of depression.

Women who were classified as highly resilient in this study experienced less depression and managed their depression better. Women who were less resilient were more likely to experience depression, and their incontinence had a greater impact on their lives. Furthermore, the women with high levels of resilience were more likely to be older, have greater social support, experience greater control in their lives and more realistically appraised their situations, such as having to manage their incontinence and associated challenges. These women experienced less depression or did not perceive themselves to be depressed.

The perceptions of how severe and how serious one's incontinence symptoms are to the women that experience them are very much linked to aspects of resilience. Of particular importance are those described by Polk's Situational pattern, which considers cognitive appraisal - how they think and rationalize a situation - as well as problem solving – how they manage a situation. As resilience has been associated with reduced depression, it is important to consider these constructs and the influence they have on psychological wellbeing.

11.2.4 Hypothesis 4

The fourth hypothesis was

> *The social networks and support of people with incontinence are adversely affected by comorbid depression;*

and this was supported by the aims*:*

> *To explore the relationship between depression and urinary incontinence, and demonstrate the effects of this association on psychosocial factors associated with incontinence, including help-seeking, quality of life, perceptions of symptom severity, and social networks;*
>
> *To explore the subjective experience of the burden of urinary incontinence in relation to mental health; and*
>
> *To explore how people understand the relationship between urinary incontinence and depression.*

Once again, evidence from the literature was examined in Chapter 2 and Chapter 8. The importance of social networks and relations as influential psychosocial factors were discussed in depth. Notably, the International Continence Society considers the importance of the social impact of incontinence. Limitations in activities can contribute to perceptions of the severity of incontinence, and there are many other psychosocial impacts of incontinence. The qualitative literature has reiterated this, where both intimate and social relationships were affected.

The study described in Chapter 10 considered women's social networks and how these influence the experience of depression in women with incontinence. Involvements in positive social networks, as well as the quality of ones relationships, were linked to aspects of resilience, particularly those described by Polk's Relational pattern, which refers to the characteristics of roles and relationships and social interests.

The Relational pattern of resilience seems to have aspects which "buffer" or lessen the impact of depression, and these include social support and relationships. Mental health can be improved by having relationships with others, as this can boost positive self-concepts and self-worth.

11.3 LIMITATIONS

As three of the chapters from this thesis have already been published, and one submitted for publication, the limitations of the individual studies have already been discussed in depth. However, a brief outline is provided here. This section also discusses he limitations of the thesis as a whole.

The first published study described in Chapter 4 was a secondary analysis of population data. The limitations reflected those found in cross sectional surveys generally. The symptoms of urinary incontinence and depression were not clinically quantified; however, it was impractical to clinically examine the total population that was included in the survey. Recall times may not have been accurate for depression, incontinence and quality of life measures, and they may not have coexisted.

Additionally, being a face to face survey, some respondents may have been embarrassed to talk about their incontinence or depression to the interviewer, as there was some loss of anonymity. This could have introduced a response bias. Because of the length of some parts on the interview such as the quality of life measurement and the depression measurement, some respondents may have reverted to answering neutrally, which could have affected the results of the survey.

In Chapter 5, the severity and perceptions of incontinence were discussed. Although this study did not consider depression, the main focus was the perceptions of the women. The main limitation was that severity was defined as a dichotomous variable rather than a continuous severity scale. Again the symptoms of urinary incontinence were not clinically quantified, and the measures of "seriousness" and "limitations" were subjective.

Answers to these questions may have elicited more information if they had been derived from a number of questions or a scale, so that they could be comparable across the board. However, for this secondary population study analysis, they were sufficient.

The major limitation of the quantitative studies was the reliance on ‘old’ data. However, using previously collected data is an efficient method to undertake population research and undertaking a contemporary survey would have been time consuming and very expensive. Although prevalences may have changed, the effect of incontinence and depression on quality of life, perceptions and limitations described in this thesis present themes that are consistent with current literature.

Finally, Chapter 10 was a qualitative interview study conceived and designed to investigate women’s experiences with incontinence and depression. The recruitment methods in this study were not as representative as we would have liked. A convenience sample from one local hospital clinic was used; however the sample comprised of women across a broad age group. Therefore, a further limitation in this study was that, other than their age, this group was quite homogenous. By recruiting from the public hospital setting the women may have had similar socio economic status, although from visiting their homes, there seemed to be some diversity.

Administratively, a date error was made in our first mail out, which may have led some women to think it was an old study, thereby not replying to the offer, and reducing the response rate. However this was mitigated by having a second mail out directed at older women. The sample ended up being made up of an equal number of older (60 years and over) and younger (59 or less years) with an even spread of ages across both groups.

Although the clinical status of the women’s incontinence was known, there was no clinical diagnosis of depression in this study, only self-report or a diagnosis made using the PRIME MD PHQ. There was no information as to whether the women had undergone any psychiatric assessment or treatment for mental illness, unless they reported this. The women interviewed had all sought specialist help for their condition, and many had been treated, so women with incontinence who had not received any help for their condition from health professionals were not interviewed.

The design of the studies included in this thesis could have been greatly enhanced if questions exploring aspects of resilience had been part of their methodologies. Resilience was not identified as a major influence until after the qualitative data had been analysed. There may have been scope to investigate the constructs of resilience further through additional qualitative interview and quantitative survey questions. However, time did not permit this work to be undertaken.

11.4 FUTURE DIRECTIONS

This research has provided evidence regarding the link between urinary incontinence and depression. Opportunistic investigation regarding incontinence symptoms is important because spontaneous help-seeking for incontinence is limited. Women who present to health care professionals could be routinely asked about any incontinence symptoms. Women with these symptoms may also be at risk for depression, and this should be considered in the overall management of their condition. If incontinence is identified, resilience focused interventions in women could lessen the impact of any coexisting depression. This type of intervention has been successful in conditions such as diabetes where one type of intervention to boost resilience used specific educational sessions promoting resilience concepts, and another intervention was to increase psychological and social supports.

How also can we improve help-seeking and quality of life of women with incontinence and comorbid depression? Firstly women, who use continence management aids, those who have difficulty being involved in activities or those who use other incontinence management strategies, could be targeted with information and education. An evaluation surrounding the information about causes, treatments, as well as education provision and the further needs of women who are managing their incontinence, could be undertaken to identify deficits in this area. From this, educational material could be produced specifically addressing the deficits in this area.

Secondly, the mental health status of those with incontinence should include an assessment of psychosocial factors, which, if addressed, can reduce the burden of incontinence. In order to further verify the link between incontinence and depression, as well as confirm the role that resilience plays in influencing the manifestation of depression in women with incontinence, a population study which could include questions regarding incontinence, depression, severity of these conditions, as well as a resilience questionnaire could be undertaken.

Thirdly identification and management of any comorbid depression may improve quality of life. Incorporating age and resilience-focused interventions particularly in younger women newly diagnosed with incontinence may lessen the impact of depression in these women. Here, a randomised controlled trial with women with incontinence could be considered, including resilience focused interventions, and measuring outcomes concerning depression could answer the new questions that have been generated by this research. Additionally, a qualitative study could be undertaken to further examine resilience concepts in this context.

11.5 CONCLUDING REMARKS

This thesis has demonstrated that incontinence and psychological wellbeing are intertwined. When depression and incontinence occur together there appears to be an additive effect, greater than the sum of the individual parts, which affects both physical and mental health. Additionally, perceptions of severity and limitations to lifestyle can predict that women perceive that their incontinence is moderate to very serious.

The resilience interventions described above are simple activities, but the contribution to the quality of life of women experiencing incontinence and co-morbid depression can be profound. Increasing resilience in those with incontinence and reducing comorbid depression may increase the ability of women to take control of their health, and improve their health and psychosocial outcomes. The lessons learnt here may also translate to the management of other chronic conditions where mental health plays a role in the care provided and outcomes achieved.

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13 APPENDICES FOR SECTION 1

13.1 SAHOS LETTER AUTUMN 1998

Dear Sir/Madam

I am writing to seek your assistance in an important health survey being conducted on behalf of a range of organisations which are involved in the delivery of health services to South Australians.

This survey is essential for us who plan health services to keep in touch with the thinking of the community. The survey is about a number of issues that input upon the quality of life that people have.

If it is not convenient when the interviewer calls, a time will be made any day of the week at virtually any time of the day to fit in with your commitments.

In households where more than one person is aged 15 or over, the interviewer will ask to speak to the person who was the last one to have a birthday. This might seem rather unusual but it is an important procedure to ensure a random sample is obtained.

I want to reassure you than your answers will be used for planning purposes only and your individual responses remain confidential. The answers you give will be entered into a computer for analysis purposes but your name and other details which could identify you are not.

If you have already agreed to take part in the survey thank you very much. If you are still deciding whether you should do so I urge you to make time so that your opinions are heard on the interesting range of subjects which are covered in the survey.

Please contact Mrs Anne Taylor, Centre for Population Studies in Epidemiology, South Australian Health Commission (telephone 82266323) or Mrs Helen Harrison, Harrison Health Research (phone 82237033) if you have any questions about the survey.

Yours faithfully

Dr Ian Calder

Acting Executive Director

PUBLIC & ENVIRONMENTAL HEALTH SERVICE

13.2 SAHOS INCONTINENCE QUESTIONS AUTUMN 1998

J.9 DO YOU EVER LOSE ANY URINE WHEN YOU DON’T MEAN TO, LIKE WHEN YOU COUGH, SNEEZE OR LAUGH?

1. Yes
2. No
9. Refused to answer

J. 10 DO YOU EVER SUDDENLY FEEL THE URGE TO GO TO THE TOILET BUT ACCIDENTALLY WET YOURSELF BEFORE REACHING THE TOILET ?

1. Yes
2. No
9. Refused to answer

Sequence Guide
If respondent has problems with incontinence (box 1 crossed in J.9 or J.10) ~ J.II
If refused to answer W
Otherwise --O W

J. 11 HOW SERIOUS DO YOU THINK THIS PROBLEM IS?

1. VERY SERIOUS
2. MODERATELY SERIOUS
3. NOT VERY SERIOUS
4. NOT AT ALL SERIOUS
9. Refused to answer

J. 12 WHAT DO YOU THINK CAUSED THIS?

1. Injury
2. Childbirth
3. Old age
4. Other (specify)
5. Don't know
9. Refused to answer

J.13 DOES THIS PROBLEM LIMIT YOUR ACTIVITIES IN ANY WAY?

1. Yes 1
2. No --1 J.15 2
9. Refused to answer J. 15

J.14 IN WHAT WAY IS YOUR LIFE LIMITED?

1. Can't leave the house
2. Can't socialise like I used to
3. Can't work as much as I used to
4. Other (specify) ....
9. Refused to answer

J. 15 DO YOU USE AIDS OR PRODUCTS TO HELP WITH THE PROBLEM?

1. Yes
2. No - J .17
9. Refused to answer- J .17

J.16 WHAT WOULDBETHE AVERAGE AMOUNT OF MONEY YOU WOULD SPEND EACH MONTH ON AIDS OR PRODUCTS?

1. Enter dollars per month ....
2. None
9. Refused to answer

J.17 HAVE YOU CONSULTED A HEALTH PROFESSIONAL ABOUT THIS PROBLEM?

1. Yes
2. No - J.20
9. Refused to answer - W9

J. 18 WHO DID YOU CONSULT?

1. General practitioner/GP
2. Specialist
3. Chemist
4. Continence adviser
5. Physiotherapist
6. Other (specify)
9. Refused to answer

J.19 WHAT KIND OF TREATMENT HAVE YOU RECEIVED FOR THIS PROBLEM?

1. Medication
2. Physiotherapy - exercises
3. Physiotherapy - other
4. Other (specify)
5. None
9. Refused to answer

W

J. 20 WHO DO YOU THINK YOU COULD GO TO FOR HELP?

1. Doctor ~ 1
2. Family member ~ 2
3. Continence adviser ~ 3
4. Physiotherapist ~ 4
5. Other (specify) ~ 5

Sequence Guide

13.3 SAHOS LETTER SPRING 2001

September 2001

Dear Sir/Madam

Your household has been chosen to take part in an important health survey being conducted on behalf of a range of organisations which are involved in improving the health of South Australians.

This study is conducted annually at this time of the year and it is essential for us who plan health services to keep in touch with the thinking of the community.

An interviewer will be visiting your home in the next few weeks to conduct the survey. If it is not convenient when the interviewer calls, a time will be made any day of the week at virtually any time of the day to fit in with your commitments.

In households where more than one person is aged 15 or over, the interviewer will ask to speak to the person who was the last one to have a birthday. This might seem rather unusual but it is an important procedure to ensure a random sample is obtained.

I want to reassure you that your answers will be used for health planning purposes only and your individual responses will remain confidential. The answers you give will be entered into a computer for analysis purposes but your name and other details which could identify you are not.

It is important to the success of this study that everyone chosen takes part. We rely on people’s voluntary cooperation to provide information to help everyone understand what is happening in our community. Please contact Ms Anne Taylor, Centre for Population Studies in Epidemiology, South Australian Department of Human Services (telephone 1800 635 352) or Mrs Roxanne Steventon, Harrison Health Research (telephone 82237033) if you have any questions about the survey.

Thank you in advance for your help.

Yours faithfully

Dr David Wilson

Head, Centre for Population Studies in Epidemiology

13.4 HOS INCONTINENCE QUESTIONS SPRING 2001

V **INCONTINENCE**

MANY PEOPLE ARE INCONVENIENCED BY TROUBLESOME URINARY PROBLEMS.

V.1 *Show Prompt Card V1*

DO YOU EXPERIENCE ANY OF THESE PROBLEMS? COULD YOU JUST TELL ME THE NUMBER, IF ANY, WHICH APPLIES.

1. A strong need to urinate (pass water) with little or no warning
2. Needing to go again less than two hours after finishing
3. Wetting underclothes
4. Needing to get up twice or more at night to urinate
5. Stopping and starting several times when urinating
6. Having a weak urinary system
7. Other (specify)………………
8. No problems

V.2 THE NEXT QUESTION IS SHOWN ON THIS CARD. CAN YOU PLEASE TELL ME THE NUMBER WHICH APPLIES TO YOUR ANSWER.

Show Prompt Card V2

Do you ever lose any urine when you don’t mean to, for example when you cough, sneeze or laugh?

1. Yes
2. No
3. Refused

V.3 THE NEXT QUESTION IS SHOWN ON THIS CARD. CAN YOU PLEASE TELL ME THE NUMBER WHICH APPLIES TO YOUR ANSWER.

Show Prompt Card V3

Do you ever suddenly feel the urge to go to the toilet but accidentally wet yourself before reaching the toilet?

1. Yes
2. No
3. Refused

<u>Sequence Guide</u>:

If ‘no’ or ‘refused’ in V.2 AND V.3 go to Section W

V.4 HOW SERIOUS DO YOU THINK THIS PROBLEM IS? WOULD YOU SAY:

1. VERY SERIOUS
2. MODERATELY SERIOUS
3. NOT VERY SERIOUS
4. NOT AT ALL SERIOUS
5. Refused

V.5 WHAT DO YOU THINK CAUSED THIS?

1. Injury
2. Childbirth
3. Old age
4. Pelvic floor muscles
5. Other (specify)
6. Don’t know
7. Refused

V.6 DOES THIS PROBLEM LIMIT YOUR ACTIVITIES IN ANY WAY?

1. Yes
2. No go to V.8
3. Refused go to V.8

V.7 IN WHAT WAY IS YOUR LIFE LIMITED?

1. Can't leave the house for too long
2. Can't socialise like I used to2
3. Can't work as much as I used to
4. Other (specify)…………………
5. Refused

V.8 DO YOU USE AIDS OR PRODUCTS TO HELP WITH THE PROBLEM?

1. Yes
2. No
3. Refused

V.9 HAVE YOU CONSULTED A HEALTH PROFESSIONAL ABOUT THIS PROBLEM?

1. Yes
2. No go to V.13
3. Refused go to V.13

V.10 WHO DID YOU CONSULT?

1. General practitioner/GP
2. Specialist
3. Chemist
4. Continence adviser
5. Physiotherapist
6. Other (specify)…………
7. Refused

V.11 IN THE LAST TWELVE MONTHS, HOW MANY TIMES HAVE YOU SEEN A HEALTH PROFESSIONAL ABOUT THIS PROBLEM?

1. None
2. Once
3. Two or three times
4. Four to six times
5. Seven to twelve times
6. More than twelve times

V.12 WHAT KIND OF TREATMENT HAVE YOU RECEIVED FOR THIS PROBLEM?

1. Surgery
2. Medication
3. Physiotherapy
4. Other (specify)……………
5. None
6. Refused

V.13 HAVE YOU MANAGED THIS PROBLEM IN OTHER WAYS? *If so* HOW?

1. Yes – support of friends/family
2. Yes – lifestyle changes (eg diet/exercise)
3. Yes – other
4. No

13.5 PRIME MD

NOTE:
This appendix is included on pages g-j of the print copy
of the thesis held in the University of Adelaide Library.

13.6 SF36

SF-36 QUESTIONNAIRE, AUTHORISED AUSTRALIAN VERSION

A1 These first questions are about your health now and your current daily activities. Please try to answer every question as accurately as you can.

In general, would you say your health is:

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor

A2 Compared to one year ago, how would you rate your health in general now? Would you say it is:

1. Much better than one year ago
2. Somewhat better than one year ago
3. About the same as one year ago
4. Somewhat worse now than one year ago
5. Much worse now than one year ago

A3 The following questions are about activities that you might do during a typical day. As I read each item, please tell me if your health now limits you a lot, limits you a little, or does not limit you at all, in these activities.

First, vigorous activities, such as running, lifting heavy objects, participating in strenuous sports. Does your health limit now limit you a lot, limit you a little, or not limit you at all?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A4 What about moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf. Does your health limit now limit you a lot, limit you a little, or not limit you at all?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A5 And what about lifting or carrying groceries? *(Interviewer: If necessary, ask does your health now limit you a lot a little, or not at all?)*

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A6 Climbing several flights of stairs?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A7 Climbing one flight of stairs?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A8 Bending, kneeling or stooping?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A9 Walking more than one kilometre?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A10 Walking half a kilometre?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A11 Walking 100 metres?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A12 Bathing or dressing yourself?

1. Yes, limited a lot
2. Yes, limited a little
3. No, not limited at all

A13 The next four questions ask about your physical health and your daily activities. During the past four weeks, have you had to cut down on the amount of time you spent on work or other regular daily activities as a result of your physical health?

1. Yes
2. No

A14 During the past four weeks, have you accomplished less than you would like as a result of your physical health?

1. Yes
2. No

A15 During the past four weeks, were you limited in the kind of work or other activities you do, as a result of your physical health?

1. Yes
2. No

A16 During the past four weeks, have you had any difficulty performing the work or other activities you do, for example, it took extra effort?

1. Yes
2. No

A17 The following three questions ask about your emotions and your daily activities. During the past four weeks, have you cut down the amount of time you spent on work or other regular daily activities as a result of any emotional problems, such as feeling depressed or anxious?

1. Yes
2. No

A18 During the past four weeks, have you accomplished less than you would like as a result of any emotional problems, such as feeling depressed or anxious?

1. Yes
2. No

A19 During the past four weeks, did you not do work or other regular daily activities as carefully as usual as a result of any emotional problems, such as feeling depressed or anxious?

1. Yes
2. No

A20 Again during the past four weeks, to what extent has your physical health or emotional problems interfered with your social activities like visiting friends or relatives? Would you say: *(Interviewer: read out responses)*

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely

A21 During the past four weeks, how much did pain interfere with your normal work, including both work outside the home and housework?

Did it interfere: *(Interviewer: read out responses)*

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely

A22 How much bodily pain have you had during the past four weeks? Have you had: *(Interviewer: read out responses)*

1. None
2. Very mild
3. Mild
4. Moderate
5. Severe
6. Very severe

A23 The following questions are about how you feel and how things have been with you in the past four weeks. As I read each statement, please give me the one answer that comes closest to the way you have been feeling. How much of the time during the past four weeks did you feel full of life? Would you say all of the time, most of the time, a good bit of the time, some of the time, a little of the time or none of the time?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A24 And how much of the time during the past four weeks have you been a very nervous person? Would you say all of the time, most of the time, a good bit of the time, some of the time, a little of the time or none of the time?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A25 And how much of the time during the past four weeks have you felt so down in the dumps that nothing could cheer you up?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A26 How much of the time during the past four weeks have you felt calm and peaceful?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A27 And how much of the time during the past four weeks did you have a lot of energy?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A28 And how much of the time during the past four weeks have you felt down?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A29 How much of the time during the past four weeks did you feel worn out?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A30 How much of the time during the past four weeks have you been a happy person?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A31 How much of the time during the past four weeks did you feel tired?

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

A32 During the past four weeks, how much of the time has your physical health and emotional problems interfered with your social activities like visiting friends and relatives? Would you say: *(Interviewer read out)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

A33 Now I'm going to read you a list of statements. After each one, please tell me if its definitely true, mostly true, mostly false, or definitely false. If you don't know just tell me. Firstly, "I seem to get sick a little easier than other people". Would you say that's definitely true, mostly true, mostly false, or definitely false, or you don't know?

1. Definitely true
2. Mostly true
3. Don't know
4. Mostly false
5. Definitely false

A34 What about the statement, "I am as healthy as anybody I know". Would you say that's definitely true, mostly true, mostly false, or definitely false, or you don't know?

1. Definitely true
2. Mostly true
3. Don't know
4. Mostly false
5. Definitely false

A35 What about the statement "I expect my health to get worse". Would you say that's definitely true, mostly true, mostly false, or definitely false, or you don't know?

1. Definitely true
2. Mostly true
3. Don't know
4. Mostly false
5. Definitely false

A36 And finally, what about the statement "My health is excellent". Would you say that's definitely true, mostly true, mostly false, or definitely false, or you don't know?

1. Definitely true
2. Mostly true
3. Don't know
4. Mostly false
5. Definitely false

13.7 SYNTAX

13.7.1 SPSS Scoring for PRIME MD HOS98A

```
***Created by Jodie Avery, 12/10/07***.

***Source: Spitzer 1999.  This syntax for original version of data using dichotomous answers
HOS1998a*********.

****Updated and checked 29/12/07 using original Laura Fisher Syntax from Bob Goldneys original
paper (phqfidg phqslow replace phqspeed) ***.


*******NOTES.

*******Original Goldney papers - all depression and major depression collapsed categories and its
all the questions will allow for, HOS1998a data originally collected for this paper.

*******Spitzer 1999 Maj Dep Syn if answers to phqnoint or phqdown (phqab) and five or more of all
questions (phqnoint phqdown phqsleep phqenergy phqbad phqconc phqfidg phqslow phqdead) are
yes.

*******Spitzer 1999 Other Dep Syn if answers to phqnoint or phqdown (phqab)and two, three or
four of all questions (phqnoint phqdown phqsleep phqenergy phqbad phqconc phqfidg phqslow
phqdead) are yes.

*******If more than 4 items with missing responses, they were coded as missing for depressive
diagnosis (From Diamond study syntax).


*********************************************************************************************************
*****************.


GET

  FILE='C:\Documents and Settings\Jodie\My Documents\University Studies\PhD'+

 '\Data\PhD datasets\HOS98a PhD.sav'.


WEIGHT BY wt.


FREQUENCIES

  VARIABLES=e29 e30 e26 e27 e28 e31 e32 e33 e34 e35

  /ORDER=  ANALYSIS .
```

```
****DEPRESSIVE SYNDROME DIAGNOSIS (9 items dichotomous).
**** e29  = phqnoint.
**** e30 = phqdown.
**** e26 =  phqsleep.
**** e27 =  phqenergy.
**** e28 = phqeat.
**** e31 =  phqbad.
**** e32 = phqconc.
**** e34 =  phqslow.
**** e33 = phqfidg.
**** e35 = phqdead.

recode e29 (1 = 1) (2 = 0) (9 = 99) into phqnoint.
value label phqnoint 1 "Yes" 0 "No" .
variable label phqnoint  "PHQNOINT  PHQ Little interest/pleasure in doing things e29".
format phqnoint  (f2.0).
variable level phqnoint  (nominal).
freq phqnoint.

recode e30 (1= 1) (2 = 0) (9 = 99) into phqdown.
value label phqdown 1 "Yes" 0 "No" .
variable label phqdown  "PHQDOWN  PHQ Feeling down, depressed, hopeless e30".
format phqdown  (f2.0).
variable level phqdown  (nominal).
freq phqdown.

recode e26 (1= 1) (2 = 0) (9 = 99) into phqsleep.
value label phqsleep 1 "Yes" 0 "No" .
```

```
variable label phqsleep  "PHQSLEEP  PHQ Trouble falling/staying asleep, sleeping too much e26".
format phqsleep  (f2.0).
variable level phqsleep  (nominal).
freq phqsleep.

recode e27 (1= 1) (2 = 0) (9 = 99) into phqenergy.
value label phqenergy 1 "Yes" 0 "No" .
variable label phqenergy  "PHQENERGY  PHQ Feeling tired/having little energy e27".
format phqenergy  (f2.0).
variable level phqenergy  (nominal).
freq phqenergy.

recode e28 (1= 1) (2 = 0) (9 = 99) into phqeat.
value label phqeat 1 "Yes" 0 "No" .
variable label phqeat "PHQEAT  PHQ Poor appetite/overeating e28".
format phqeat  (f2.0).
variable level phqeat  (nominal).
freq phqeat.

recode e31 (1= 1) (2 = 0) (9 = 99) into phqbad.
value label phqbad 1 "Yes" 0 "No" .
variable label phqbad "PHQBAD  PHQ Feeling bad about yourself... e31".
format phqbad  (f2.0).
variable level phqbad  (nominal).
freq phqbad.

recode e32 (1= 1) (2 = 0) (9 = 99) into phqconc.
value label phqconc 1 "Yes" 0 "No" .
variable label phqconc "PHQCONC  PHQ Poor Trouble concentrating on things e32".
```

```
format phqconc (f2.0).
variable level phqconc  (nominal).
freq phqconc.

recode e34 (1= 1) (2= 0) (9 = 99) into phqslow.
value label phqslow 1 "Yes" 0 "No" .
variable label phqslow "PHQSLOW  PHQ Moving/speaking slowly... e34".
format phqslow  (f2.0).
variable level phqslow  (nominal).
freq phqslow.

recode e33 (1= 1) (2= 0) (9 = 99) into phqfidg.
value label phqfidg 1 "Yes" 0 "No" .
variable label phqfidg "PHQFIDG  PHQ being do fidgety or restless... e33".
format phqfidg  (f2.0).
variable level phqfidg  (nominal).
freq phqslow.

recode e35 (1= 1) (2 = 0) (9 = 99) into phqdead.
value label phqdead 1 "Yes" 0 "No" .
variable label phqdead "PHQDEAD  PHQ Thoughts that you would be better off dead... e35".
format phqdead  (f2.0).
variable level phqdead  (nominal).
freq phqdead.

****If more than 4 items with missing responses, they were coded as missing for depressive diagnosis.
****To find cases with four or more missing categories.

compute phqmiss = 0.
```

```
if (phqnoint = 99) phqmiss = phqmiss +1.
if (phqdown = 99) phqmiss = phqmiss +1.
if (phqsleep = 99) phqmiss = phqmiss +1.
if (phqenergy = 99) phqmiss = phqmiss +1.
if (phqeat = 99) phqmiss = phqmiss +1.
if (phqbad = 99) phqmiss = phqmiss +1.
if (phqconc = 99) phqmiss = phqmiss +1.
if (phqslow = 99) phqmiss = phqmiss +1.
if (phqfidg = 99) phqmiss = phqmiss +1.
if (phqdead = 99) phqmiss = phqmiss +1.
freq phqmiss.

*******Add scores to obtain a total.
*******First two questions .

compute phqab = 0.
if (phqnoint = 1 and phqdown = 1) phqab = 1.
if (phqnoint = 1 and phqdown = 0) phqab = 1.
if (phqnoint = 0 and phqdown = 1) phqab = 1.
if (phqnoint = 0 and phqdown = 0) phqab = 0.
if (phqnoint = 9 and phqdown = 0) phqab = 0.
if (phqnoint = 0 and phqdown = 99) phqab = 0.
if (phqnoint = 99 and phqdown = 1) phqab = 1.
if (phqnoint = 1 and phqdown = 99) phqab = 1.
if (phqnoint = 99 and phqdown = 99) phqab = 99.
variable label phqab "PHQAB answer to noint or down are yes".
execute.
fre phqab.
```

```
recode phqnoint  (99 = sysmis).
recode phqdown  (99 = sysmis).
recode phqsleep  (99 = sysmis).
recode phqenergy  (99 = sysmis).
recode phqeat  (99 = sysmis).
recode phqbad   (99 = sysmis).
recode phqconc  (99 = sysmis).
recode phqslow  (99 = sysmis).
recode phqfidg  (99 = sysmis).
recode phqdead (99 = sysmis).

compute phqcnt=phqnoint+phqdown+phqsleep+phqenergy+phqeat +
phqbad+phqconc+phqslow+phqfidg+phqdead.
variable label phqcnt "PHCNT PRIME MD PHQ dichotomous COUNT (HOS98A)".
execute.
fre phqcnt.
compute phqts = 0.
if (phqab  = 1 and phqcnt > 1 and phqcnt < 5) phqts = 1.
if (phqab  = 1 and phqcnt > 4 and phqcnt < 10) phqts = 2.
if (phqab  = 0 and phqcnt > 1 and phqcnt < 5) phqts = 0.
if (phqab  = 0 and phqcnt > 4 and phqcnt < 10) phqts = 0.
value label phqts 0 "No depressive syndrome" 1 "Other Depressive syndrome" 2 "Major
Depressive syndrome" 9 "Not Stated".
variable label phqts "PHQTS PRIME MD PHQ dichotomous TOTAL SCORE (HOS98A)".
variable level phqts (nominal).
format phqts (f2.0).
fre phqts.
if (phqmiss >3) phqts = 99.
recode phqts (99 = sysmis).
fre phqts.
```

```
compute phqdep = 0.

if (phqts  = 0) phqdep = 0.

if (phqts  = 1) phqdep = 1.

if (phqts  = 2) phqdep = 1.

if (phqts  = 9) phqdep = 9.

value label phqdep 0 "No depressive syndrome" 1 "Other or Major Depressive syndrome" 9 "Not Stated".

variable label phqdep "PHQDEP PRIME MD PHQ dichotomous No depression vs Depression (HOS98A)".

variable level phqdep (nominal).

format phqdep (f2.0).

fre phqdep.
```

13.7.2 SF-36 scoring syntax for HOS data

```
**********
*****SECTION A: GENERAL HEALTH AND WELLBEING - SF36.
**recode SF36 variables into dummy variables
   (so that original data is not lost).***

COMPUTE RA1  = A1.
COMPUTE RA2  = A2.
COMPUTE RA3  = A3.
COMPUTE RA4  = A4.
COMPUTE RA5  = A5.
COMPUTE RA6  = zA6.
COMPUTE RA7  = A7.
COMPUTE RA8  = A8.
COMPUTE RA9  = A9.
COMPUTE RA10 = A10.
COMPUTE RA11 = A11.
COMPUTE RA12 = A12.
COMPUTE RA13 = A13.
COMPUTE RA14 = A14.
COMPUTE RA15 = A15.
```

```
COMPUTE RA16 = A16.

COMPUTE RA17 = A17.

COMPUTE RA18 = A18.

COMPUTE RA19 = A19.

COMPUTE RA20 = A20.

COMPUTE RA21 = A21.

COMPUTE RA22 = A22.

COMPUTE RA23 = A23.

COMPUTE RA24 = A24.

COMPUTE RA25 = A25.

COMPUTE RA26 = A26.

COMPUTE RA27 = A27.

COMPUTE RA28 = A28.

COMPUTE RA29 = A29.

COMPUTE RA30 = A30.

COMPUTE RA31 = A31.

COMPUTE RA32 = A32.

COMPUTE RA33 = A33.

COMPUTE RA34 = A34.

COMPUTE RA35 = A35.

COMPUTE RA36 = A36.
```

```
***Label new variables.

variable label RA1  " RA1  In general would you say your health is ".

variable label RA2  "RA2 Compared to one year ago, how would you rate your health in general now".

variable label RA3  "RA3 Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports".

variable label RA4  "RA4 Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf".

variable label RA5  "RA5 Lifting or carrying groceries".

variable label RA6  "RA6 Climbing several flights of stairs?".

variable label RA7  "RA7 Climbing one flight of stairs?".

variable label RA8  "RA8 Bending, kneeling or stooping?".

variable label RA9  "RA9 Walking more than one kilometre?".

variable label RA10  "RA10 Walking half a kilometre?".

variable label RA11  "RA11 Walking 100 metres?".

variable label RA12  "RA12 Bathing or dressing yourself?".

 variable label RA13  "RA13 During the last four weeks have you had to cut down on the amount of time you spent on work or other activities as a result of your physical health?".

variable label RA14  "RA14 Accomplished less than you would like as a result of your physical health?".

variable label RA15  "RA15 Been limited in the kind of work or other activities as a result of your physical health?".

variable label RA16  "RA16 Had difficulty performing the work or other activities as a result of your physical health (for example, it took extra effort)?".
```

variable label RA17 "RA17 During the past four weeks have you had to cut down on the amount of time you spent on work or other activities as a result of any emotional problems such as feeling depressed or anxious?".

variable label RA18 "RA18 Accomplished less than you would like as a result of any emotional problems?".

variable label RA19 "RA19 Had to not do work or other activities as carefully as usual as a result of any emotional problems?".

variable label RA20 "RA20 During the past four weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups? Has it interfered:".

variable label RA21 "RA21 How much bodily pain have you had during the past four weeks?".

variable label RA22 "RA22 During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?".

variable label RA23 "RA23 During the past four weeks, did you feel full of life?".

variable label RA24 "RA24 Have you been a very nervous person?".

variable label RA25 "RA25 Have you felt so down in the dumps that nothing could cheer you up?\n(St2 QuB)".

variable label RA26 "RA26 Have you felt calm and peaceful?”.

variable label RA27 "RA27 Did you have a lot of energy?".

variable label RA28 "RA28 Have you felt down?".

variable label RA29 "RA29 Did you feel worn out?".

variable label RA30 "RA30 Have you been a happy person?".

variable label RA31 "RA31 Did you feel tired?".

variable label RA32 "RA32 During the past four weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?".

variable label RA33 "RA33 How true or false is the following statement for you ... I seem to get sick a little easier than other people.".

variable label RA34 "RA34 How true or false is the following statement for you ... I am as healthy as anybody I know.".

variable label RA35 "RA35 How true or false is the following statement for you ... I expect my health to get worse.".

variable label RA36 "RA36 How true or false is the following statement for you ... My health is excellent.".

value label RA1 1 "Excellent" 2 "Very good" 3 "Good" 4 "Fair" 5 "Poor".

value label RA2 1 "Much better now than one year ago" 2 "Somewhat better now than one year ago" 3 "About the same as one year ago" 4 "Somewhat worse now than one year ago" 5 "Much worse now than one year ago".

value label RA3 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA4 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA5 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA6 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all ".

value label RA7 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA8 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA9 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all ".

value label RA10 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all ".

value label RA11 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA12 1 "Yes, limited a lot" 2 "Yes, limited a little" 3 "No, not limited at all".

value label RA13 1 "Yes" 2 "No" .

```
value label RA14  1  "Yes" 2  "No".

value label RA15  1  "Yes " 2  "No".

value label RA16  1  "Yes" 2  "No".

value label RA17  1  "Yes" 2  "No".

value label RA18  1  "Yes" 2  "No".

value label RA19  1  "Yes" 2  "No".

value label RA20  1  "Not at all" 2  "Slightly" 3  "Moderately" 4  "Quite a bit" 5  "Extremely".

value label RA21  1  "None " 2  "Very mild" 3  "Mild" 4  "Moderate" 5  "Severe" 6  "Very severe".

value label RA22  1  "Not at all" 2  "A little bit" 3  "Moderately" 4  "Quite a bit" 5  "Extremely".

value label RA23  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA24  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA25  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA26  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA27  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA28  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA29  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA30  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".
```

```
value label RA31  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA32  1  "All the time" 2  "Most of the time" 3  "A good bit of the time" 4  "Some of the time" 5  "A little of the time" 6  "None of the time".

value label RA33  1  "Definitely true" 2  "Mostly true" 3  "Don't know" 4  "Mostly false" 5  "Definitely false".

value label RA34  1  "Definitely true" 2  "Mostly true" 3  "Don't know" 4  "Mostly false" 5  "Definitely false".

value label RA35  1  "Definitely true" 2  "Mostly true" 3  "Don't know" 4  "Mostly false" 5  "Definitely false".

value label RA36  1  "Definitely true" 2  "Mostly true" 3  "Don't know" 4  "Mostly false" 5  "Definitely false".



***recode out of range values as missing.

freq z2_A1 z2_A2 z2_A3 z2_A4 z2_A5 z2_A6 z2_A7 z2_A8 z2_A9 z2_A10 z2_A11 z2_A12 z2_A13 z2_A14 z2_A15 z2_A16 z2_A17 z2_A18 z2_A19

z2_A20 z2_A21 z2_A22 z2_A23 z2_A24 z2_A25 z2_A26 z2_A27 z2_A28 z2_A29 z2_A30 z2_A31 z2_A32 z2_A33 z2_A34 z2_A35 z2_A36.



if (Ra1 > 5 or Ra1 = 0) Ra1 = 9.

if (Ra2 > 5 or Ra2 = 0) Ra2 = 9.

if (Ra3 > 3 or Ra3 = 0) Ra3 = 9.

if (Ra4 > 3 or Ra4 = 0) Ra4 = 9.

if (Ra5 > 3 or Ra5 = 0) Ra5 = 9.

if (Ra6 > 3 or Ra6 = 0) Ra6 = 9.
```

```
if (Ra7 > 3 or Ra7 = 0) Ra7 = 9.

if (Ra8 > 3 or Ra8 = 0) Ra8 = 9.

if (Ra9 > 3 or Ra9 = 0) Ra9 = 9.

if (Ra10 > 3 or Ra10 = 0) Ra10 = 9.

if (Ra11 > 3 or Ra11 = 0) Ra11 = 9.

if (Ra12 > 3 or RA12 = 0) Ra12 = 9.

if (Ra13 > 2 or Ra13 = 0) Ra13 = 9.

if (Ra14 > 2 or Ra14 = 0) Ra14 = 9.

if (Ra15 > 2 or Ra15 = 0) Ra15 = 9.

if (Ra16 > 2 or Ra16 = 0) Ra16 = 9.

if (Ra17 > 2 or Ra17 = 0) Ra17 = 9.

if (Ra18 > 2 or Ra18 = 0) Ra18 = 9.

if (Ra19 > 2 or Ra19 = 0) Ra19 = 9.

if (Ra20 > 5 or Ra20 = 0) Ra20 = 9.

if (Ra21 > 6 or Ra21 = 0) Ra21 = 9.

if (Ra22 > 5 or Ra22 = 0) Ra22 = 9.

if (Ra23 > 6 or Ra23 = 0) Ra23 = 9.

if (Ra24 > 6 or Ra24 = 0) Ra24 = 9.

if (Ra25 > 6 or Ra25 = 0) Ra25 = 9.

if (Ra26 > 6 or Ra26 = 0) Ra26 = 9.

if (Ra27 > 6 or Ra27 = 0) Ra27 = 9.
```

```
if (Ra28 > 6 or Ra28 = 0) Ra28 = 9.
if (Ra29 > 6 or Ra29 = 0) Ra29 = 9.
if (Ra30 > 6 or Ra30 = 0) Ra30 = 9.
if (Ra31 > 6 or Ra31 = 0) Ra31 = 9.
if (Ra32 > 5 or Ra32 = 0) Ra32 = 9.
if (Ra33 > 5 or Ra33 = 0) Ra33 = 9.
if (Ra34 > 5 or Ra34 = 0) Ra34 = 9.
if (Ra36 > 5 or Ra36 = 0) Ra36 = 9.

***Recode to correct for skips not taken into account.
if ra3=3 ra4=3.
if ra6=3 ra7=3.
if ra9=3 ra10=3.
if ra9=3 ra11=3.
if ra10=3 ra11=3.
if ra21=1 ra22=1.

**************************************************************************************************************
******************************************************************************
***  Recode missing answers where possible ***.
count sf36m=ra1 ra3 to ra36 (9).
freq sf36m.
```

```
***  Check the numbers of missing data items ***

COUNT pfm = ra3 ra4 ra5 ra6 ra7 ra8 ra9 ra10 ra11 ra12  (9)  .

count rpm=ra13 to ra16 (9).

count bpm=ra21 ra22 (9).

count ghm=ra1 ra33 to ra36 (9).

count vtm=ra23 ra27 ra29 ra31 (9).

count sfm=ra20 ra32 (9).

count rem=ra17 to ra19 (9).

count mhm=ra24 ra25 ra26 ra28 ra30 (9).


recode Ra1 to Ra36(9 = sysmis).

****recoding etc of individual scales****.


**PHYSICAL FUNCTIONING.

f ra6=3 ra7=3.

if ra9=3 ra10=3.

if ra9=3 ra11=3.

if ra10=3 ra11=3.


**BODILY PAIN.
```

```
recode ra21 (1 = 6.0) (2 = 5.4) (3 = 4.2) (4 = 3.1) (5 = 2.2) (6 = 1.0).


**scoring for ra22 if both ra22 and ra21 are answered**.

if (ra22 = 1 and ra21 = 1) rra22 = 6.

if (ra22 = 1 and (ra21 > 1 and ra21 < 7))  rra22 = 5.

if (ra22= 2 and (ra21> 0 and ra21 < 7))  rra22= 4.

if (ra22= 3 and (ra21 > 0 and ra21< 7))  rra22 = 3.

if (ra22= 4 and (ra21 > 0 and ra21 < 7))  rra22 = 2.

if (ra22 = 5 and (ra21 > 0 and ra21 < 7))  rra22 = 1.


**scoring for rra22 if ra21 not answered**.

do if sysmis(ra21) & rra22>0.

recode rra22 (1=6) (2=4.75) (3=3.5) (4=2.25) (5=1).

end if.

recode ra21 (1 = 6.0) (2 = 5.4) (3 = 4.2) (4 = 3.1) (5 = 2.2) (6 = 1.0).


**GENERAL HEALTH.

recode Ra1 (1 = 5.0) (2 = 4.4) (3 = 3.4) (4 = 2.0) (5 = 1.0).

recode Ra34 Ra36 (1 = 5) (2 = 4) (3 = 3) (4 = 2) (5 = 1).


**VITALITY.
```

```
recode Ra23 Ra27 (1 = 6) (2 = 5) (3 = 4) (4 = 3) (5 = 2) (6 = 1).


**SOCIAL FUNCTIONING.

recode Ra20 (1 = 5) (2 = 4) (3 =3) (4 = 2) (5 = 1).


**MENTAL HEALTH.

recode Ra26 Ra30 (1 = 6) (2 = 5) (3 = 4) (4 = 3) (5 = 2) (6 = 1).


**TRANSITION.

compute tr = Ra2.


** Recode items to the mean of other subscale items if 50% or less missing***

do repeat rr=ra3 to ra12.

if pfm<=5 & missing(rr) rr=mean(ra3 to ra12).

end repeat.


do repeat rr=ra13 to ra16.

if rpm<=2 & missing(rr) rr=mean(ra13 to ra16).

end repeat.

do repeat rr=ra21 rra22.

if bpm<=1 & missing(rr) rr=mean(ra21,rra22).
```

```
end repeat.
do repeat rr=ra1,ra33 to ra36.
if ghm<=2 & missing(rr) rr=mean(ra1,ra33 to ra36).
end repeat.

do repeat rr=ra23 ra27 ra29 ra31.
if vtm<=2 & missing(rr) rr=mean(ra23,ra27,ra29,ra31).
end repeat.

do repeat rr=ra20 ra32.
if sfm<=1 & missing(rr) rr=mean(ra20,ra32).
end repeat.

do repeat rr=ra17 to ra19.
if rem<=1 & missing(rr) rr=mean(ra17 to ra19).
end repeat.

do repeat rr=ra24,ra25,ra26,ra28,ra30.
if mhm<=2 & missing(rr) rr=mean(ra24,ra25,ra26,ra28,ra30).
end repeat.
```

```
***Compute raw scale scores.

compute pf=ra3+ra4+ra5+ra6+ra7+ra8+ra9+ra10+ra11+ra12.

compute rp=ra13+ra14+ra15+ra16.

compute bp=ra21+rra22.

compute gh=ra1+ra33+ra34+ra35+ra36.

compute vt=ra23+ra27+ra29+ra31.

compute sf=ra20+ra32.

compute re=ra17+ra18+ra19.

compute mh=ra24+ra25+ra26+ra28+ra30.


***Transform raw scale scores to 0-100 scale.

compute tpf=100*(pf-10)/20.

compute trp=100*(rp-4)/4.

compute tbp=100*(bp-2)/10.

compute tgh=100*(gh-5)/20.

compute tvt=100*(vt-4)/20.

compute tsf=100*(sf-2)/8.

compute tre=100*(re-3)/3.

compute tmh=100*(mh-5)/25.
```

```
***labelling.

variable label tpf "TPF SF-36 physical functioning".

variable label trp "TRP SF-36 role-physical".

variable label tbp "TBP SF-36 bodily pain".

variable label tgh "TGH SF-36 general health".

variable label tvt "TVT SF-36 vitality".

variable label tsf "TSF SF-36 social functioning".

variable label tre "TRE SF-36 role-emotional".

variable label tmh "TMH SF-36 mental health".

EXECUTE.

DELETE VARIABLES RA1 RA2 RA3 RA4 RA5 RA6 RA7 RA8 RA9 RA10 RA11 RA12 RA13 RA14
RA15 RA16 RA17

  RA18 RA19 RA20 RA21 RA22 RA23 RA24 RA25 RA26 RA27 RA28 RA29 RA30 RA31 RA32

  RA33 RA34 RA35 RA36 sf36m pfm rpm bpm ghm vtm sfm rem mhm rra22 tr pf rp bp

  gh vt sf re mh.
```

13.7.3 Recodes for HOS98A

```
******recodes for HOS98a incontinence Jodie Avery 20/01/03**************.


*******country of birth 5 groups**********.
recode counborn (1=1) (2=2) (3=3) (102=4) (8,101,103,104,18,105=5) into cob5.
value label cob5 1 "Australia" 2 "UK/Ireland" 3 "Other Europe"
4 "Asia" 5 "Other".
execute.


**************Income 4 groups**************************.
recode incz9x5  (1 = 1) (2=2) (3,4=3)  (5=4) into income4.
value label income4 1 "Up to $20,000" 2 "$20,001-$40,000"
   3 "$40,001 or more" 4 "Not stated" .
execute.


***************all anal incontinence************************
compute analinc=0.
if (j8.1=1) analinc=1.
if (j8.2=2) analinc=1.
variable label analinc "ANALINC faecal or flatus incontinence".
value label analinc 0 "no" 1 "yes".
freq analinc.


*****Chronic Lung disease*********************************
recode cld (1=1) (2=0) into cdcld.
variable label cdcld "Recode either/or b1b bronch, b2b emph, b10 asthma into chronic lung disease".
value label cld 1 "Chronic lung disease" 0 "No chronic lung disease".
fre cdcld.
```

```
******asthma************
compute asthma=0.
if (b9=1 and b10=1 and b11=1) asthma=1.
variable label asthma "ASTHMA recode b9 b10 b11".
value label asthma 0 "no" 1 "yes".
freq asthma.

*******education*******
recode edn (1=1) (2=1) (3=1) (4=2)  (5=3) (6=4) into postedn.
variable label postedn "No post school vs types post school education".
value label postedn 1 "No post school education" 2 "Trade Qualifications " 3 "Certificate/Diploma" 4 "Bachelor Degree".
fre postedn.


********agegroups***********
recode age14grp (1=1) (2=1) (3=1) (4=2) (5=2) (6=3) (7=3) (8=4) (9=4) (10=5) (11=5) (12=6) (13=6) (14=7)  into oldagegp.
variable label oldagegp "7 age groups youngest combined".
value label oldagegp 1 "15-29" 2 "30-39" 3 "40-49" 4 "50-59" 5 "60-69" 6 "70-79" 7 "80+".
fre oldagegp.

***************all incontinence (check)***********************.
compute totinc=0.
if (j8.1=1) totinc=1.
if (j8.2=2) totinc=1.
if (j9recode=1) totinc=1.
if ( j10recod=1) totinc=1.
variable label totinc "TOTINC faecal, flatus, stress and urinary incontinence".
value label totinc 0 "no incontinence" 1 "incontinence".
```

```
freq totinc.


*****Anal Incontinence *********************************.

recode j8.1 (1=1) (0=0) into flatinc.

variable label flatinc "Recode j8.1  Flatus incontinence".

value label flatinc 1 "Flatus incontinence" 0 "No Flatus incontinence".

fre flatinc.


recode j8.2 (2=1) (0=0) into fecinc.

variable label fecinc "Recode j8.2  Fecal incontinence".

value label fecinc 1 "Fecal incontinence" 0 "No Fecal incontinence".

fre fecinc.


*****Severe Urinary Incontinence *********************************.

recode j15 (1=1) (2=0) (9=0) into severe.

variable label severe "severe urinary incontinence aids recode j15".

value label severe 1 "Yes" 0 "No/refused ".

fre severe.


*******Parity*************************.

compute parity = j2a + j2b + j2c.

variable label parity "parity".

if id = 461 parity = 9.

if id = 518 parity = 9.

recode parity (0 = sysmis).

fre parity.


*********Types of Combined Delivery*******.

compute deltype = 0.
```

```
variable label deltype "combined type of delivery".
if j2a >= 1 deltype =1.
if j2b >= 1 deltype =2.
if j2c >= 1 deltype =3.
if (j2a >= 1 and j2b >= 1) deltype =4.
if (j2a >= 1 and j2c >= 1) deltype =5.
if (j2b >= 1 and j2c >= 1) deltype =6.
if (j2a >= 1 and (j2b >= 1 and j2c >= 1)) deltype =7.
if j2.9 = 9 deltype = 9.
value label deltype 0 "no deliveries" 1 "at least one caesarean" 2 "at least one instrumental" 3 " at least one spontaneous vaginal"
4 "at least one caes and one instrumental" 5 "at least one caes and one vaginal" 6 "at least one instrumental and one vaginal"
7 "at least one caes, one instrumental and one vaginal" 9 "Refused".
fre deltype.


*********Caesarean Emergency*********.
recode j2a.1 (1=1) (2=0) into csemerge.
variable label csemerge "emergency caesarean whilst in established labour".
value label csemerge 1 "emergency caesarean" 0 "elective caesarean".
fre csemerge.


*********Combined Incontinence (Anal and Urinary)************.
compute combinc=0.
if (uriincon=1 and analinc=1) combinc=1.
variable label combinc "COMBINC both urinary and anal incontinence".
value label combinc 0 "no" 1 "yes".
freq combinc.


* Custom Tables.
```

```
CTABLES
  /VLABELS VARIABLES=q95 DISPLAY=LABEL
  /VLABELS VARIABLES=sf1 DISPLAY=DEFAULT
  /TABLE sf1 [C][COUNT 'Count' F40.0, ROWPCT.COUNT 'Row %' PCT40.1,
  COLPCT.COUNT 'Column %' PCT40.1] BY q95
  /SLABELS POSITION=ROW
  /CATEGORIES VARIABLES=q95 sf1 ORDER=A KEY=VALUE EMPTY=INCLUDE TOTAL=YES
  POSITION=AFTER.

********For age sex standardisation********.
* Custom Tables.
CTABLES
  /VLABELS VARIABLES=uriincon oldagegp DISPLAY=DEFAULT
  /TABLE oldagegp [C] BY uriincon [COUNT F40.0, ROWPCT.COUNT PCT40.1, COLPCT.COUNT
PCT40.1]
  /SLABELS POSITION=ROW
  /CATEGORIES VARIABLES=uriincon oldagegp ORDER=A KEY=VALUE EMPTY=INCLUDE
TOTAL=YES POSITION=AFTER.

SORT CASES BY sex .
SPLIT FILE
  SEPARATE BY sex .

SPLIT FILE
  OFF.

* Custom Tables.
CTABLES
  /VLABELS VARIABLES=stresinc oldagegp DISPLAY=DEFAULT
  /TABLE oldagegp [C] BY stresinc [COUNT F40.0, ROWPCT.COUNT PCT40.1, COLPCT.COUNT
PCT40.1]
```

```
  /SLABELS POSITION=ROW
  /CATEGORIES VARIABLES=stresinc oldagegp ORDER=A KEY=VALUE EMPTY=INCLUDE TOTAL=YES POSITION=AFTER.


* Custom Tables.
CTABLES
  /VLABELS VARIABLES=urgeinc oldagegp DISPLAY=DEFAULT
  /TABLE oldagegp [C] BY urgeinc [COUNT F40.0, ROWPCT.COUNT PCT40.1, COLPCT.COUNT PCT40.1]
  /SLABELS POSITION=ROW
  /CATEGORIES VARIABLES=urgeinc oldagegp ORDER=A KEY=VALUE EMPTY=INCLUDE TOTAL=YES POSITION=AFTER.
```

13.8 PUBLICATIONS

Avery J, Stocks N, Duggan P, Braunack-Mayer A, Taylor A, Goldney R, MacLennan A: Identifying the quality of life effects of urinary incontinence with depression in an Australian population. *BMC Urology*. 2013; **13**(11).

Citations:

The above paper has been cited in the following publications:

1. White, Alexandra J., Bryce B. Reeve, Ronald C. Chen, Angela M. Stover, and Debra E. Irwin. Coexistence of urinary incontinence and major depressive disorder with health-related quality of life in older Americans with and without cancer. *Journal of Cancer Survivorship* 2014: 1-11.
2. Tu, Albert, and Steinbok, Paul. Occult tethered cord syndrome: a review. Child's Nervous System. 2013; **29**(9): 1635-1640.
3. Cai, Wenzhi, Juan Wang, Li Wang, Jingxin Wang, and Li Guo. Prevalence and risk factors of urinary incontinence for post-stroke inpatients in Southern China. *Neurourology and Urodynamics.* 2013. DOI: 10.1002/nau.22551

Avery *et al. BMC Urology* 2013, **13**:11
http://www.biomedcentral.com/bmcurol/13/11

BMC Urology

RESEARCH ARTICLE **Open Access**

Identifying the quality of life effects of urinary incontinence with depression in an Australian population

Jodie C Avery[1,3,4*], Nigel P Stocks[1], Paul Duggan[2], Annette J Braunack-Mayer[3], Anne W Taylor[4], Robert D Goldney[5] and Alastair H MacLennan[2]

Abstract

Background: To explore the additive effect of urinary incontinence, in people with comorbid depression, on health related quality of life.

Methods: Males and females, 15 to 95 years (n = 3010, response rate 70.2%) were interviewed face to face in the 1998 Autumn South Australian Health Omnibus Survey.

Results: Self-reported urinary incontinence was found in 20.3% (n=610), and depression as defined by the PRIME-MD in 15.2% (n=459) of the survey population. Urinary incontinence with comorbid depression was found in 4.3% of the overall population. Univariate analysis showed that respondents with urinary incontinence and comorbid depression were more likely to be aged between 15 and 34 years and never married when compared to those with incontinence only. Multivariate analysis demonstrated that in people with incontinence, the risk of having comorbid depression was increased by an overall health status of Fair or Poor, or the perception that their incontinence was moderately or very serious. Respondents reporting that they experienced incontinence with comorbid depression scored significantly lower than those experiencing incontinence without depression on all dimensions of the SF-36.
The interaction of the presence of incontinence and the presence of depression was significantly associated with the dimensions of physical functioning.

Conclusions: Depression and incontinence both reduce QOL. When they occur together there appears to be an additive effect which affects both physical and mental health, perhaps by increasing a person's negative perceptions of their illness. Clinicians should identify and manage comorbid depression when treating patients who have incontinence to improve their overall QOL.

Background

Associations between urinary incontinence and depression have been found previously [1,2]. Explanations for this relationship include biochemical factors [1], or the severity of incontinence [3]. For instance in animal models, lowering monoamines such as serotonin and noradrenaline in the central nervous system lead to depression, urinary frequency and a hyperactive bladder [1]. Alternatively depression may be a result of persistent urinary incontinence, and individuals with altered monoamines in the central nervous system could manifest both depression and an overactive bladder [4]. It is also likely that psychosocial factors can help explain why people with incontinence may become depressed [5].

The prevalence of depression in those experiencing urinary incontinence varies in both clinical and population surveys from 20% to 40% [6-8]. Most studies consider the occurrence of depression and incontinence, without giving consideration to the chronological order or causal pathway of these comorbidities [5-7,9-11]. Some studies determine actual prevalence [7,8], some quote mean scores from depression scales [12], and some suggest a higher risk of depression in those with incontinence [13]. Many

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studies report the association between incontinence and depression, but venture no further [5,6,9].

Clearly incontinence and depression can affect quality of life (QOL) but only a few studies report this outcome. One population study of women with incontinence found that those with major depression reported significantly lower incontinence-specific quality of life using the I-QOL questionnaire [14]. A second telephone study of women with a mean age of 59 years, reported that major depression predicted the onset of urinary incontinence, but incontinence did not predict the onset of depression [15]. No studies have explored the impact on QOL due to the interaction between incontinence and depression.

This paper examines the QOL in people with urinary incontinence and depression in a population sample of Australian men and women. Our research focuses on psychosocial factors that could explain why people with urinary incontinence get depressed. Potentially this may be a result of incontinence limiting what they are able to do in their everyday lives. We hypothesized that the health related QOL of people with urinary incontinence and depression would be lower than that of people experiencing one of these conditions alone.

Methods

Data analysed in this study were collected in the 1998 Autumn South Australian Health Omnibus Survey (SAHOS) [16]. SAHOS has investigated a range of health issues since 1990 on an annual basis. It is a representative population survey using a clustered, self-weighting, systematic, multistage area sample of metropolitan and country areas with populations of more than 1000 people and interviews are conducted face-to-face with those aged fifteen years or over. The nature of an omnibus survey means that a number of not necessarily related questions regarding different topics are included from different users. Thus a number of questions not originally intended to be studied together may be analysed to answer a research question.

Data for this survey were weighted by age, sex and geographical location, correcting for any sample bias and providing accurate estimates for the local population overall [17]. The response rate was 70.2% (n = 3010). Questions submitted for SAHOS are reviewed by a management committee. The methodology has been peer reviewed and ethics approval was obtained from the Women's and Children's Hospital Human Research Ethics Committee and the South Australian Department of Health Human Research Ethics Committee [16].

In order to determine whether respondents experienced urinary incontinence, they were asked whether they had ever lost any urine when they did not mean to, when they coughed, sneezed or laughed, or if they had ever suddenly felt the urge to go to the toilet, but had accidentally wet themselves before reaching the toilet. Respondents were considered to have urinary incontinence if they answered "yes" to either or both of these questions. These questions reflect the definitions of urinary incontinence used by the International Continence Society (ICS) at the time of the survey, as being "the complaint of any involuntary leakage of urine in the context of type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life" [18].

An assessment of depression over the last month was made using the Primary Care Evaluation of Mental Disorders Questionnaire Patient Health Questionnaire (PRIME - MD PHQ) [19]. In this study, the various mental disorders that can be identified with this questionnaire have been collapsed to indicate major depressive syndrome, other depressive syndrome or no depressive syndrome.

The Medical Outcomes Study SF36 was also completed by all respondents in order to assess health related quality of life over the last four weeks. Standard interpretation and scoring methods for the SF-36 were used, and the instrument has been validated for use in an Australian population [20,21].

Demographic information collected for this analysis included gender, age, marital status, household size, country of birth, highest education level achieved, annual household income, work status and area of residence.

Univariate analyses were conducted using SPSS Version 15.0. [22]. Odds ratios and statistical significance ($p<0.05$) were determined for each demographic subgroup to find which had the highest prevalence of incontinence with depression.

The relationship between a number of variables, incontinence and depression were also explored using multivariate logistic regression analyses. A model was constructed using related variables ($p<0.25$) In order to determine a model to predict statistically significant urinary incontinence with comorbid depression, related variables ($p<0.25$) were entered into a logistic regression [23]. Variables determined to be insignificant were progressively omitted until a satisfactory model was obtained. The associations were examined to ensure there were no multicollinearity effects.

For the analysis of health related quality of life, means were generated for each dimension of the SF36 for the following groups: the overall population; those with no incontinence and no depression; those with incontinence only; those with depression only; and those with incontinence and depression. Analysis of variance with a factorial structure (for depression and incontinence) was used to determine whether the mean scores of each of the eight dimensions of the SF36 were significantly different for each of these groups effects using SAS [24] and to determine any interaction.

Results

Sample characteristics

Of the n=3010 participants in this study, 48.7% were male and 51.3% were female. The sample is described in Table 1 and these proportions are representative of the sex and age groups of the South Australian population.

Prevalence of urinary incontinence and depression

Table 2 examines the prevalence of urinary incontinence, depression (major or other depressive syndrome) and urinary incontinence with depression by various demographic variables. Urinary incontinence affected 20.3% (n=610) of the study population (male 4.4%, female 35.3%). Female respondents, born in the UK or Ireland, or who were widowed were significantly more likely to experience incontinence when compared with other groups. Those younger than 55 years, with trade or degree qualifications, never married, or a household income of above A$40,000 per annum, were significantly less likely to experience incontinence.

Respondents with a major (6.7%) or other depressive (8.6%) syndrome made up 15.2% (n=459) of the study population (male 13.3%, female 17.1%). Females, those separated or divorced, or never married were more likely to experience depression compared to other groups, whereas those with a certificate or diploma or degree or higher, or with a household income greater than A$40,000 per annum were less likely to experience depression.

Table 1 Overall sample demographics

	Sample demographics		
Variable	**n**	**%**	**95% CI**
Sex			
Male	1466	48.7	(46.9–50.5)
Female	1544	51.3	(49.5–53.1)
Age Group			
16–39 years	1388	46.1	(44.3–47.9)
40–59 years	1002	33.3	(31.6–35.0)
55 plus years	677	22.5	(21.0–24.0)
Country of Birth			
Australia	2267	75.3	(73.7–76.8)
UK/Ireland	382	12.7	(11.5–13.9)
Other	382	12.7	(11.5–13.9)
Marital Status			
Married / De facto	1851	61.5	(59.7–63.2)
Separated / Divorced	220	7.3	(6.4–8.3)
Widowed	187	6.2	(5.4–7.1)
Never Married	749	24.9	(23.4–26.5)
Income			
Up to $40,000	1484	49.3	(47.5–51.1)
$40,001 to $80,000	834	27.7	(26.1–29.3)
$80,001 plus	247	8.2	(7.3–9.2)
Not stated	445	14.8	(13.6–16.1)
Overall	**3010**	**100.0**	

Data Source: South Australian Health Omnibus Survey Autumn 1998
Note The weighting of the data can result in rounding discrepancies or tables not adding.

Overall it was found that 4.3% of the population experienced urinary incontinence with comorbid depression. There was a statistically significant higher rate of major or other depressive syndrome in the urinary incontinent (20.5% [n=125/610]) compared with those without urinary incontinence (13.9% [n=333/2399]). Of these respondents with urinary incontinence, 29.3% of males and 19.5% of females experienced a major or other depressive syndrome. It was found that those aged 16 to 34 years and never married were significantly more likely to experience depression if they also had urinary incontinence, whereas those with a bachelor's degree or higher, a household income of A$40,001 to A$80,000 per annum or did not state their income, were significantly less likely to experience depression if they were urinary incontinent.

Multivariate analysis showed that variables jointly identified as increasing the risk urinary incontinence with depression were those with Fair or Poor overall health and those who thought that their urinary incontinence was moderately or very serious. Respondents who had a household income between A$40,001 and A$80,000 per annum or did not state their income, were not current smokers, and had a lifetime occupation of being a tradesperson were less likely to have incontinence with depression (model $\times^2 = 167.22$, df = 53, $p < 0.001$) (Table 3).

UI, depression and quality of life

Health-related quality of life was assessed for people with different combinations of urinary incontinence and depression. Groups that were mutually exclusive were compared using analysis of variance for significant differences. Mean scores adjusted for age and sex for each of the eight dimensions of the SF-36 scale were calculated and results are presented in Table 4.

Respondents who reported that they experienced urinary incontinence with depression scored significantly lower than those experiencing neither urinary incontinence nor depression, and also with those with urinary incontinence but no depression, on all dimensions of the SF-36 (Physical Functioning (PF), Role Physical (RP), Bodily Pain (BP), General Health (GH) (Vitality (VT), Mental Health (MH), Social Functioning (SF), Role Emotional (RE) ($p < 0.05$)). Additionally this group scored significantly lower on most dimensions than those with depression only (PF ($p < 0.001$); RP, GH, RE ($p < 0.05$)).

Overall, respondents with depression only, scored significantly lower across all dimensions of the SF-36 (PF, RP, ($p > 0.05$) BP, GH, VT, RE, MH ($p<0.001$)), when

Table 2 Univariate analysis of urinary incontinence and depression

	Population with Incontinence*				Population with Depression*				Population with Incontinence and Depression**			
Variable	**n**	**%**	**OR (95% CI)**	**p value**	**n**	**%**	**OR (95% CI)**	**p value**	**n**	**%**	**OR (95% CI)**	**p value**
Sex												
Male	65/1464	4.4	1.00		194/1464	13.3	1.00		19/65	29.3	1.00	
Female	546/1546	35.3	11.74 (8.97–15.37)	**<0.001**	264/1546	17.1	1.35 (1.11–1.65)	**<0.001**	106/546	19.5	0.58 (0.33–1.03)	0.065
Age Group												
55 plus years	272/853	31.9	1.00		118/853	13.9	1.00		50/272	18.4	1.00	
35–54 years	256/1070	23.9	0.67 (0.55–0.82)	**<0.001**	154/1070	14.4	1.04 (0.80–1.35)	0.753	50/256	19.5	1.08 (0.70–1.66)	0.742
16–34 years	83/1087	7.6	0.18 (0.13–0.23)	**<0.001**	186/1087	17.1	1.28 (1.00–1.65)	0.050	25/83	30.7	1.97 (1.13–3.45)	**0.017**
Area												
Metropolitan	417/2068	20.1	1.00		324/2068	15.7	1.00		92/417	22.1	1.00	
Country	194/942	20.6	1.03 (0.85–1.25)	0.758	134/942	14.2	0.89 (0.72–1.11)	0.742	33/194	17.2	0.73 (0.47–1.14)	0.163
Education												
No post school education	397/1682	23.6	1.00		298/1682	17.7	1.00		90/397	22.6	1.00	
Trade Qualifications	28/373	7.5	0.26 (0.17–0.39)	**<0.001**	53/373	14.1	0.76 (0.56–1.05)	0.096	6/28	21.5	0.94 (0.37–2.38)	0.889
Certificate/Diploma	131/599	21.8	0.90 (0.72–1.13)	0.373	74/599	12.4	0.66 (0.50–0.87)	**0.003**	24/131	18.1	0.76 (0.46–1.25)	0.280
Degree or higher	55/356	15.4	0.59 (0.43–0.80)	**0.001**	33/356	9.3	0.48 (0.33–0.70)	**<0.001**	6/55	10.6	0.41 (0.17–0.99)	**0.047**
Country of Birth												
Australia	439/2266	19.4	1.00		340/2266	15.0	1.00		88/439	20.0	1.00	
UK/Ireland	91/381	23.9	1.31 (1.01–1.69)	**0.042**	58/381	15.3	1.02 (0.76–1.38)	0.889	21/91	22.9	1.19 (0.69–2.05)	0.524
Other	81/363	22.2	1.19 (0.91–1.55)	0.209	60/363	16.5	1.11 (0.83–1.51)	0.478	17/81	20.6	1.04 (0.58–1.87)	0.894
Marital Status												
Married / De facto	439/1851	23.7	1.00		248/1851	13.4	1.00		78/439	17.7	1.00	
Separated / Divorced	57/221	26.0	1.13 (0.82–1.55)	0.453	52/221	23.7	2.01 (1.43–2.82)	**<0.001**	14/57	24.2	1.49 (0.77–2.85)	0.233
Widowed	73/187	39.2	2.07 (1.52–2.83)	**<0.001**	26/187	14.1	1.06 (0.69–1.64)	0.783	17/73	23.4	1.42 (0.78–2.57)	0.249
Never Married	40/748	5.4	0.18 (0.13–0.26)	**<0.001**	129/748	17.3	1.35 (1.07–1.70)	**0.011**	16/40	39.5	3.03 (1.54–5.97)	**<0.001**
Income												
Up to $40,000	357/1484	24.1	1.00		284/1484	19.2	1.00		96/357	26.8	1.00	
$40,001 to $80,000	132/834	15.8	0.59 (0.48–0.74)	**<0.001**	96/834	11.5	0.55 (0.43–0.70)	**<0.001**	12/132	9.2	0.28 (0.15–0.52)	**<0.001**
$80,001 plus	40/247	16.1	0.61 (0.42–0.87)	**0.006**	22/247	9.1	0.42 (0.27–0.66)	**<0.001**	6/40	16.3	0.53 (0.22–1.27)	0.155
Not stated	82/444	18.4	0.71 (0.55–0.93)	**0.013**	56/444	12.6	0.61 (0.45–0.83)	**0.002**	11/82	13.4	0.42 (0.21–0.83)	**0.012**
Overall	**610/3010**	**20.3**			**459/3010**	**15.2**			**125/610**	**20.5**		

Data Source: South Australian Health Omnibus Survey Autumn 1998.
Note The weighting of the data can result in rounding discrepancies or tables not adding.
*Of the total population.
**Of those with Incontinence.

Table 3 Multivariate analysis of variables which determined incontinence with co-morbid depression

Variables	n	%	OR (95% CI)	p value
Overall health status				
Excellent	9/106	8.7	***1.00***	
Very Good	24/198	12.3	1.48 (0.61–3.62)	0.385
Good	20/154	13.2	1.32 (0.51–3.38)	0.568
Fair	51/116	44.1	9.84 (3.80–25.48)	**<0.001**
Poor	20/37	54.6	12.74 (3.78–42.95)	**<0.001**
Income				
Up to $40,000	96/357	26.8	***1.00***	
$40,001 to $80,000	12/132	9.2	0.30 (0.14–0.68)	**0.004**
$80,001 plus	6/40	16.3	0.38 (0.12–1.22)	0.106
Not stated	11/82	13.3	0.41 (0.18–0.95)	**0.037**
Smoking status				
Current smoker	40/115	34.5	***1.00***	
Ex smoker	32/188	16.8	0.46 (0.23–0.95)	**0.035**
Non smoker	54/308	17.5	0.46 (0.24–0.89)	**0.021**
Lifetime Occupation				
Not employed	31/119	26.3	***1.00***	
Managers & Administrators	6/33	18.3	0.70 (0.21–2.33)	0.561
Professionals	9/56	15.3	1.00 (0.29–3.47)	0.995
Para-Professionals	5/39	12.8	0.34 (0.08–1.40)	0.135
Tradespersons	7/42	16.9	0.25 (0.07–0.90)	**0.034**
Clerks	23/141	16.1	0.82 (0.37–1.84)	0.636
Sales or Service workers	19/87	21.8	1.01 (0.43–2.36)	0.989
Drivers & Machine Operators	4/16#	23.9	–	–
Labourers	22/76	28.2	0.65 (0.26–1.58)	0.337
Not stated	0/1#			
How serious				
Not very, not serious, refused	92/504	18.3	***1.00***	
Very/moderately serious	33/102	32.6	2.30 (1.20–4.41)	**0.012**
Overall	125/610	20.5		

Data Source: South Australian Health Omnibus Survey Autumn 1998.
Note The weighting of the data can result in rounding discrepancies or tables not adding.
Numbers too small for statistical analysis.

compared with those respondents who had no depression and no urinary incontinence, and significantly lower than those with urinary incontinence only (PF, RP, BP ($p > 0.05$), GH, VT, SF, RE, MH ($p<0.001$)).

Those respondents with incontinence only, scored significantly lower across most dimensions of the SF-36 except for Social Functioning (PF, RP, BP, GH, VT, RE, MH ($p > 0.05$)), when compared with those respondents who had no depression and no urinary incontinence.

The interaction term was statistically significant for PF, RP, GH, and RE. For BP, VT, SF and MH the main effect for depression and the main effect for urinary incontinence were both statistically significant. For ease of interpretation the interaction means for all standardized scores are presented in Table 4.

For each of the standardized scores, the mean score for each combination of depression and urinary incontinence is presented graphically in an interaction plot (Figure 1). The lines drawn between the means allow visual interpretation of the interactions.

The effect of depression results in a much greater reduction in mean score for both the not incontinent group and the incontinent group. However, the significance of the interaction (for PF, RP, GH and RE) is most likely due to those who have both depression and urinary incontinence having a significantly greater reduction

Table 4 SF36 Mean Scores for people with urinary incontinence, depression and combinations of these conditions (adjusted for age and sex)

	n	PF	RP	BP	GH	VT	SF	RE	MH
No Incontinence and No Depression	2066	88.07	84.93	75.55	77.92	69.39	92.67	95.16	85.04
General Population	*3010*	***85.31***	***79.82***	***72.54***	***73.91***	***64.35***	***87.90***	***87.83***	***79.99***
Incontinence without Depression	486	85.00[aa]	78.58[aa]	72.72[aa]	74.25[aa]	65.46[aa]	91.10	91.53[aa]	82.40[aa]
Depression without Incontinence	333	77.49[aabb]	64.29[aabb]	61.84[abb]	60.13[ab]	43.90[ab]	67.56[ab]	58.12[ab]	58.37[ab]
Incontinence with Depression	125	66.33[abc]	49.88[abcc]	56.11[ab]	50.60[abcc]	40.94[ab]	61.41[ab]	46.72[abcc]	55.28[ab]
p-value for interaction term		0.0002	0.046	0.27	0.02	0.54	0.09	0.02	0.97

[a] Statistically significantly lower (*t* test p<0.001) than those with no incontinence and no depression.
[aa] Statistically significantly lower (*t* test p<0.05) than those with no incontinence and no depression.
[b] Statistically significantly lower (*t* test p<0.001) than those with incontinence but no depression.
[bb] Statistically significantly lower (*t* test p<0.05) than those with incontinence but no depression.
[c] Statistically significantly lower (*t* test p<0.001) than those with depression but no incontinence.
[cc] Statistically significantly lower (*t* test p<0.05) than those with depression but no incontinence.

in score, compared to those with depression who are not urinary incontinent. Although this reduction in mean score was observed for the other SF36 score variables (BP, VT, SF and MH) also, the difference was not large enough to be statistically significant.

Discussion

In this face to face survey of 3010 South Australians self-reported urinary incontinence was found in 20.3% (n=610), depression in 15.2% (n=459) and both in 4.3% of respondents. Those with urinary incontinence and comorbid depression were more likely to be aged between 15 to 34 years and never married when compared to those with only incontinence. Multivariate analysis demonstrated that in those with urinary incontinence, an overall health status of Fair or Poor, or the perception that their incontinence was moderately or very serious, increased the risk of having comorbid depression. Depression had a marked effect on QOL for the general population and a significant, additive effect on those with incontinence. Respondents who reported that they experienced urinary incontinence with comorbid depression scored significantly lower than those experiencing incontinence without depression on all dimensions of the SF-36. The interaction between urinary incontinence and depression had a significant effect on the physical functioning dimensions of quality of life.

The quality of life of people who experience urinary incontinence with depression, in both adult females and males of all age groups, has not been assessed previously via population surveys using face to face interviews. Other studies have assessed this qualitatively, or have discussed stigma, and other problems associated with incontinence including depression. But how urinary incontinence and depression interact and affect QOL has not been considered [25-28]. A lack of population data prompted the retrospective analysis of an existing dataset, already available from the 1998 SAHOS, where questions regarding urinary incontinence, depression and quality of life were asked together. At the time of this study, the questions about urinary incontinence were not validated, however they reflected the definition used by the International Continence Society (ICS) [18]. They have since been validated by other authors [29].

This study has several limitations. Firstly the symptoms of urinary incontinence were not clinically quantified. However, in a population study of this size, it would not be practical to clinically examine cases for this condition, and prevalence rates using self-report have been found to be similar and cost less compared to those found from diagnostic tests [30]. Secondly because recall times differ for urinary incontinence, depression and the quality of life measures, it is possible, that depression and urinary incontinence did not co-exist when the survey was administered. However urinary incontinence and depression are relapsing and remitting conditions and it is difficult to examine the temporality and causality in a cross sectional study. Lastly the use of the PRIME MD in this study to determine depression deviates slightly from the original intentions of its authors [19], as the initial depression screening questions were not used, and the mood module was administered to all in the study. However the prevalences of urinary incontinence (20.3%) [31] and major (6.7%) or other (8.6%) depressive syndrome (15.2%) [32] are comparable with other studies. Circumstances where both these conditions occur together (20.5% of those with urinary incontinence) are also equivalent to international studies [3,7].

Univariate analysis indicates that younger people, and those never married were more likely to experience depression when they had urinary incontinence. This is not unexpected, as incontinence is often considered a disease of older women who have had children, possibly a plausible explanation for their incontinence. In the above group, there may not be an explanation for the condition, leading to a state of low mood and depression.

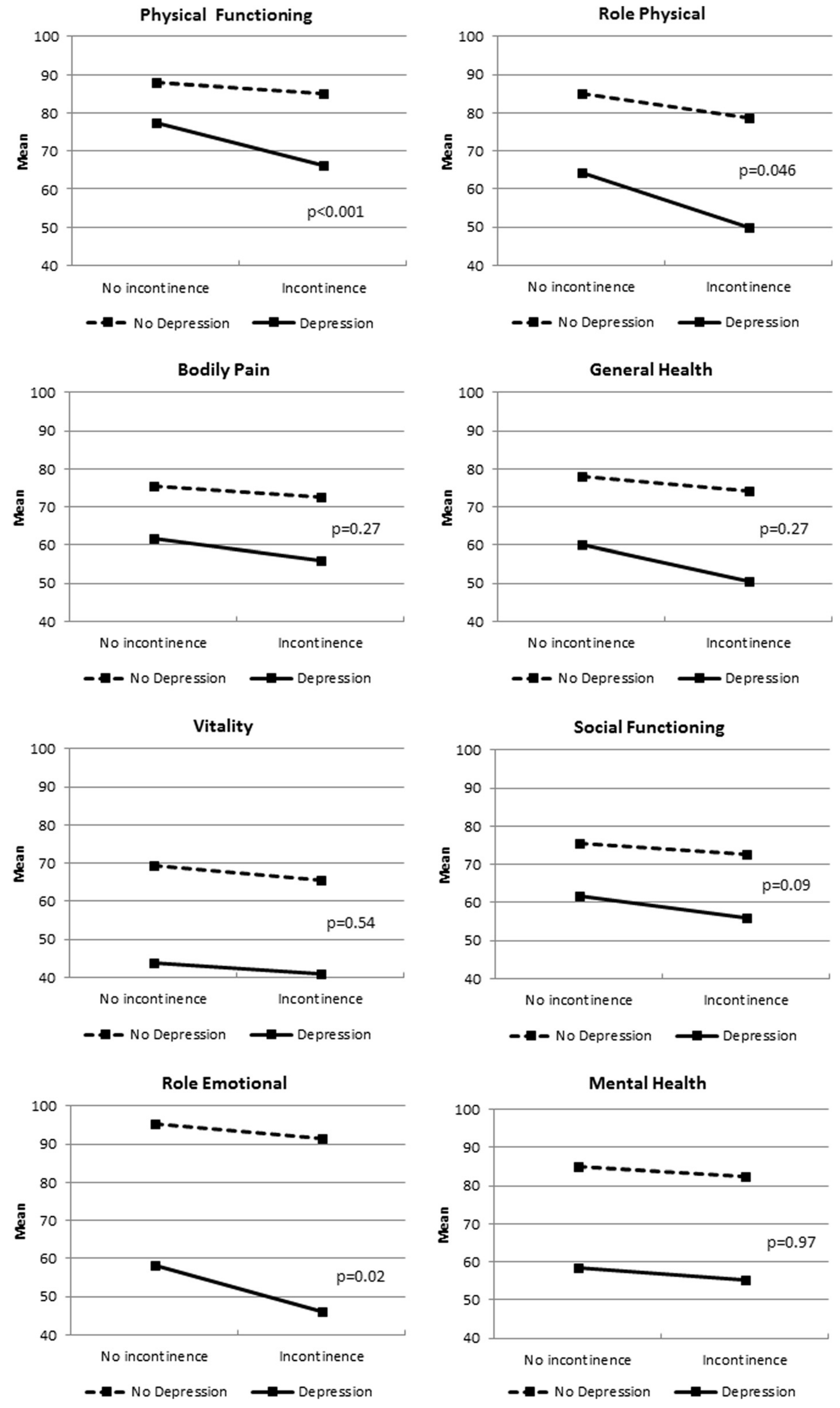

Figure 1 Quality of Life interaction plots for people with and without Incontinence, and with and without Depression (adjusted for age and sex).

In the multivariate analysis, self-reported Fair or Poor health, and the perception that one's own urinary incontinence was moderately or very serious were strongly predictive of having incontinence with depression. This may indicate that one's own perceptions of a condition, and their overall health may lead to an increased likelihood of experiencing mental illness. However as this study was cross sectional, we were unable to determine whether the depression was caused by incontinence, or a person's depression increased their perception of symptom severity. This will be explored in future qualitative work.

In the quality of life analysis, we compared respondents with "Incontinence with depression" to those with "Incontinence without depression". "Incontinence with depression" describes respondents who answered in the positive for any of the incontinence questions, and includes those who also scored positively for depression by the PRIME-MD. "Incontinence without depression" includes respondents with urinary incontinence, not diagnosed with depression by the PRIME-MD in this survey. Respondents with urinary incontinence and depression scored significantly lower on all dimensions of the SF 36, with depression scoring lower than urinary incontinence and those with both conditions together scoring lowest of all. When these conditions occur together, there was a major additive effect particularly in the Mental Health scales, greater than that with either condition alone. It appears that depression increases a person's negative perceptions of their physical symptoms (incontinence) reducing their QOL scores further than would be expected if either condition occurred independently. This effect is also reflected in the interaction between incontinence and depression and its impact on the QOL dimensions that measure physical functioning.

It may be that identifying and treating depression in a person with urinary incontinence, a patient's mental health (QOL) will not only improve but also, indirectly their physical QOL.

Conclusions

Depression and urinary incontinence both reduce QOL. When they occur together there appears to be an additive effect which affects both physical and mental health. Clinicians should identify and manage comorbid depression when treating patients who have incontinence to improve their overall QOL.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

JCA drafted the manuscript, NS is her primary PhD supervisor, and PD, ABM and AT are co supervisors. AT also manages the SAHOS survey where the data from this study originated and also had editorial input into the paper, RDG and AHM are the original owners of the data, formulating the original questions regarding depression and urinary incontinence in this survey. All seven authors edited and approved the paper.

Author's information

JCA is a candidate for a PhD in Medicine.

Acknowledgements

The authors are extremely grateful for the assistance of Michelle Lorimer, Senior Statistician, Data Management and Analysis Centre, The University of Adelaide.

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Australian and New Zealand Continence Journal, v. 20(1), pp. 7-13

14 APPENDICES FOR SECTION 2

14.1 ETHICS DOCUMENTATION FOR QUALITATIVE STUDY

14.1.1 Approval and Cover Sheet

THE UNIVERSITY
of ADELAIDE

RESEARCH BRANCH
RESEARCH ETHICS AND COMPLIANCE UNIT

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CRICOS Provider Number 00123M

4 October 2011

Professor N Stocks
Discipline of General Practice

Dear Professor Stocks

PROJECT NO: H-243-2011
Experiences and associations of the psychosocial factors of urinary incontinence

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.

The ethics expiry date for this project is: 30 September 2012

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

per **PROFESSOR GARRETT CULLITY**
Convenor
Human Research Ethics Committee

THE UNIVERSITY of ADELAIDE

RESEARCH BRANCH
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CRICOS Provider Number 00123M

Applicant: Professor N Stocks

School: General Practice

Project Title: ***Experiences and associations of the psychosocial factors of urinary incontinence***

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Project No: **H-243-2011** RM No: 0000012430

APPROVED for the period until: **30 September 2012**

It is noted that this study will be conducted by Jodie Avery, PhD candidate.

Refer also to the accompanying letter setting out requirements applying to approval.

PROFESSOR GARRETT CULLITY
Convenor
Human Research Ethics Committee

Date: 29 SEP 2011

1 4 SEP 2011

RM: 12430

PROJECT NO: H/243/11

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE
ETHICS APPLICATION COVER SHEET

SUMMARISING THE PROTOCOL AND INCLUDING INVESTIGATORS' SIGNATURES

COVER SHEET AND APPLICATIONS MUST BE TYPED

Applications will be considered according to requirements of the National Statement on Ethical Conduct in Human Research (2007).
An application should include: (1) this **cover sheet**; (2) the proposal addressing the **list of headings**; (3) participant **information sheet**; (4) participant **consent form**, and (5) **independent complaints procedure statement** (please access these online at http://www.adelaide.edu.au/ethics/human/guidelines/applications/).
Submit **ELEVEN** copies of the application to the Secretary, Human Research Ethics Committee, Research Ethics and Compliance Unit, Research Branch, Level 7, 115 Grenfell Street, The University of Adelaide SA 5005 Ph. (08) 8303 6028, Fax (08) 8303 7325, email sabine.schreiber@adelaide.edu.au

Please attach this to the front of the application.

APPLICANT Name include title Professor/Dr/Ms/Mr **and Position**

Professor Nigel Stocks, Professor and Head, Discipline of General Practice,
School of Population Health and Clinical Practice
Faculty of Health Sciences, University of Adelaide

Ms Jodie Avery, PhD Candidate, Discipline of General Practice,
School of Population Health and Clinical Practice /
Senior Research Associate, Discipline of Medicine, School of Medicine
Faculty of Health Sciences, University of Adelaide

Professor Annette Braunack-Mayer, Head,
School of Population Health and Clinical Practice
Faculty of Health Sciences, University of Adelaide

Dr Paul Duggan, Senior Lecturer, Discipline of Obstetrics and Gynaecology,
School of Paediatrics and Reproductive Health
Faculty of Health Sciences, University of Adelaide

If this is a student project the principal supervisor is to be the applicant.

DEPARTMENT including campus/institution contact address

Discipline of General Practice,
School of Population Health and Clinical Practice
Faculty of Health Sciences, University of Adelaide
L11, Terrace Towers Building
178 North TerraceAdelaide SA 5005
Australia

Phone No and email address

Nigel Stocks w: 8303 3460; e: nigel.stocks@adelaide.edu.au
Jodie Avery w: 8313 1217 h: 8373 7807; m: 0410519941; e: jodie.avery@adelaide.edu.au

OTHERS INVOLVED

Ms Jodie Avery, PhD Candidate,
Discipline of General Practice, School of Population Health and Clinical Practice,
School of Population Health and Clinical Practice /
Senior Research Associate, Discipline of Medicine, School of Medicine
Faculty of Health Sciences, University of Adelaide

If this is a student project please indicate name/department/candidature

PROJECT TITLE

Experiences and Associations of the Psychosocial Factors of Urinary Incontinence.

LOCATION OF RESEARCH

Various sites in metropolitan Adelaide, South Australia

DATE PROJECT TO BEGIN

October 2011

ESTIMATED DURATION OF PROJECT

3 months

SOURCE OF FUNDING

PHCRED (Primary Health Care Evaluation and Development) Bursary 2011

AIMS OF PROJECT please give concise description in lay terms

The research hypotheses of this part of the overall dissertation are:

- The quality of life of women with incontinence is adversely affected by co-morbid depression;
- Perceptions of symptom severity of women with incontinence are adversely affected by co-morbid depression;
- The social networks and support of women with incontinence are adversely affected by co-morbid depression; and
- Health service utilisation by women with incontinence is adversely affected by co-morbid depression.

The specific objective of the qualitative component of this study is:

- To analyse how mental health and urinary incontinence interact.

The aims of this study are:

- To explore the subjective experience of the burden of urinary incontinence in relation to mental health;
- To explore how people understand the relationship between urinary incontinence and depression
- To explore how and why women in the community with urinary incontinence seek help.

PLAN/DESIGN OF PROJECT brief description in lay terms

Urinary incontinence in women can be a result of a number of different causes and conditions and can affect those experiencing it in varying ways. Thus a qualitative study using narrative analysis to examine transcripts from in-depth interviews with individuals regarding their experiences with psychosocial outcomes, including help seeking, for those with urinary incontinence will be undertaken. Incorporating a qualitative component of this study will be useful so that the complexity and in-process nature of meanings can be explored. The interview schedule has been developed from a review of the literature surrounding incontinence and depression, as well as from the results of the initial quantitative studies. Recruitment will take place over a period of three months.

In depth interviewing is a focused technique that aims to explore the complexity and in-process nature of meanings, similar to a conversation. Interviews will be carried out with approximately 20 participants in either their own homes or another convenient to the participant, allowing for the greatest information flow between the researcher and the participants. The interviews will be carried out by Jodie Avery and possibly another research assistant (Amy Baker).

The PRIME MD Patient Health Questionnaire will be administered to each participant, in order to determine whether they are experiencing depressive symptoms. Questions will also asked regarding their own particular experience of incontinence and depression, the severity of their condition, their health status, their help seeking behaviour and service usage and daily living and activities they participate in, and their own rationale and interpretation regarding the aetiology of the condition.

The analytical technique used for this section will be narrative analysis. A narrative basically refers to talk organised around consequential events. This collection of stories may assist in defining temporality in the exploration of the variables of incontinence, depression and associated psychosocial factors. Sequence is necessary, if not sufficient for a narrative. Narrative analysis refers to the whole of a person's account, in contrast to a thematic analysis. This technique has been found to be most useful in the analysis of the experience of chronic illness. Data for this study will then be systematically analysed using QSR Nvivo software.

PARTICIPANTS

- Source:

Three sources for recruitment of women with urinary incontinence and depression have been identified. Initially, patients from the Women's Health Centre, Royal Adelaide Hospital with urinary incontinence with or without depression will be identified, as will patients from a suburban private gynaecology practice. Additionally, in order to achieve a cross section of subjects from the community, access to the Medical Director database will be sought from the Discipline of General Practice, University of Adelaide whereby patients who have been treated for urinary incontinence will be identified. Medical Director is a simple to use prescription writing, medication and electronic patient management system. It can generate chronic disease statistics and medication use statistics by demographics within a general practice. Intensity sampling, a sampling technique aiming to select cases that manifest the experience being examined intensely, may be used to identify potential recruits however, the method of sample selection will be determined once an appropriate data source is identified.

- Age range:

Approximately 20 interviews with women 18 years and over will be included.

- Selection criteria:

  - Women who experience urinary incontinence, with and without depression
  - Women who are able to provide informed consent.

- Exclusion criteria
  - Women who are Non-English speaking
  - Women who have dementia, or a severe or acute neurological disease (e.g. epilepsy, acute CVE, severe Parkinson's disease, acute confusion) or a severe psychiatric disorder like bipolar disorder, schizophrenia).

ETHICAL IMPLICATIONS OF PROJECT

In order to maintain the privacy of eligible women, initial contact will be made by their consulting clinician. An information sheet describing the study, as well as a consent form will be provided to potential subjects. Then, if interested, subject details will be passed on to the researcher.

As intimate personal details will be disclosed during the interview with subjects from potentially vulnerable groups, such as frail and elderly women, this may raise concerns about confidentiality and informed consent. The subject will be assured of their anonymity, such that they will be given pseudonyms, and their personal or identifying details will be kept separately from their interview data. This data will be kept in a locked filing cabinet within the Discipline of General Practice, separate from the identification key associated with subject's pseudonyms. The subject will also be made aware that they are free to withdraw from the study at anytime, and that their treatment will not be affected by any decision they make about their involvement in the study. If the subject or the researcher feels that the subject has suffered any harm or distress from the interview, they will be referred back to the consulting clinician.

If the subject or the researcher feels that the subject has suffered any harm or distress from the interview, they will be referred back to the consulting clinician. If psychological issues are uncovered during the interview, the interviewing researcher will encourage the woman to return to their clinician to discuss any such issues. The interviewing researcher is not in a position to provide psychological counselling and we do not think that this would be appropriate. The researcher will encourage the woman to return to their clinician to discuss any psychological issues. The researcher may also provide information on websites about depression, and indicate other resources (eg counselling) that the participant may wish to access, such as Beyond Blue or the Lifeline telephone helpline. Depending on the nature of the distress or adverse event, the researcher may seek to facilitate an appointment with the treating clinician or the participants GP.

If a participant becomes distressed, the interviewer will stop the interview and ascertain if the participant would like external help. If appropriate and with participant permission, the treating clinician may be contacted by phone. In addition the researcher would provide information about websites and resources that they may wish to access (eg Beyond Blue, the Lifeline telephone helpline). We will prepare a leaflet with a list of resources that will be offered to all participants at the end of the interview. Depending on the nature of the distress or adverse event, the interviewer may seek permission to facilitate an appointment with the treating clinician or the participant's GP. In addition the interviewer will be able to contact Prof Nigel Stocks, an experienced GP, at any time if they require help or assistance with a distressed participant. No psychological assessment of the participants will be undertaken in this study. Only in depth interviews, or previous tests undertaken by clinicians, will be used to describe the women's psychological condition.

Additionally, as these subjects may be visited at home, it will be important to provide an adequate introduction and referral of the researcher by the recruiting practitioner. This will include providing information about the professional background of the researcher as a health professional to assure participants of the confidentiality of the research and help allay fears of talking about the personal and sensitive topic of UI. As researchers will be entering interviewees' homes, a record of appointment times and addresses will be supplied to a responsible party at the University, in case of any problems that may be encountered.

DRUGS

Will drugs be administered to participants? **NO**

- If so give name of drug(s)
- Dosage:
- Method of administration

Is the administration for therapeutic purposes? **NO**

Will the project be conducted under the

Clinical Trials Notification (CTN) Scheme? **NO**

Clinical Trials Exemption (CTX) Scheme? **NO**

Is Commonwealth Department of Health permission required? **NO**

If so, has permission been obtained? **NO**

SIGNATURE OF ALL INVESTIGATORS NAMED IN THE PROTOCOL

Professor Nigel Stocks, 30 8 2011

Ms Jodie Avery

Professor Annette Braunack-Mayer

Dr Paul Duggan

Date

14.1.2 List of Headings

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

LIST OF HEADINGS APPLYING TO ALL APPLICATIONS

Guidance information for completion of this form is notated in (*italics)* under each heading. Please complete all headings.

APPLICATIONS MUST BE TYPED

1. **TITLE**

Experiences and Associations of Psychosocial Factors and Urinary Incontinence.

2. **INVESTIGATORS & QUALIFICATIONS**

(Also provide brief details of the researchers' previous experience with the specific research techniques that will be used in this study.)

Prof Nigel Stocks, BSc MBBS DipPH MD FRACGP FAFPHM.

- Expert in mental health problems in the community and preventive activities in general practice.
- Responsible for reading and editing proposals, methodology and transcripts.

Ms Jodie Avery, BA BAppSc MPH, PhD Candidate.

- Experienced in facilitating in-depth interviews and performed qualitative analysis on those interviews as part of a Master's Dissertation.
- Experienced in the management and facilitation of qualitative and quantitative research studies
- Experienced in undertaking quantitative and qualitative analysis using a number of different techniques as part of employment.

Professor Annette Braunack-Mayer, BMedSci (Hons) PhD.

- Research interests revolve around the intersection of ethics, qualitative research methods and social analysis in health care, particularly concerning general practice
- Teaches postgraduate qualitative research techniques.
- Responsible for reading and editing proposals, methodology and transcripts concerning this study.

Dr Paul Duggan, MBChB, MMedSc, MD, DipObst, Grad Cert Ed (Higher Ed), FRANZCOG.

- Responsible for providing urogynaecological consultation around the topic area of urinary incontinence and mental health.

3. PURPOSE OF THE STUDY

- **Aims** (*What research hypothesis is being investigated? What benefits does the study aim to produce?)*

The research hypotheses of this part of the overall dissertation are:

- The quality of life of women with incontinence is adversely affected by co-morbid depression;
- Perceptions of symptom severity of women with incontinence are adversely affected by co-morbid depression;
- The social networks and support of women with incontinence are adversely affected by co-morbid depression; and
- Health service utilisation by women with incontinence is adversely affected by co-morbid depression.

The specific objective of the qualitative component of this study is:

- To analyse how mental health and urinary incontinence interact.

The aims of this study are:

- To explore the subjective experience of the burden of urinary incontinence in relation to mental health;
- To explore how people understand the relationship between urinary incontinence and depression
- To explore how and why women in the community with urinary incontinence seek help.

- **Rationale** *(Explain your research methodology and its appropriateness to achieving the study aims. Provide evidence that the sample size is adequate to establish a valid research result.)*

A qualitative study will use narrative analysis to examine transcripts from in-depth interviews with women who have urinary incontinence and a mental health condition, regarding their experiences and psychosocial outcomes, including burden and help seeking. As part of a larger study this qualitative component will explore the complexity and in-process nature of meanings for participants[76,361].

A narrative is a story, that has a structure, characters and a plot, and may help make sense of an individual's beliefs about the world, the meaning of illness or can provided insight into behaviours[361,452,453]. In-depth interviews will collect narratives about women's experience of urinary incontinence and its intersection with psychological and psychosocial factors. These narratives will be analysed from a phenomenological perspective. Phenomenology can be described as studying situations in the everyday world from the viewpoint of the experiencing person[413], and each individual's life world is different[361].

The sample size of approximately twenty women has been chosen in order to achieve "theoretical saturation", when no additional data are being found whereby the properties of the theme can be developed. As similar instances are seen over and over again, the researcher becomes empirically confident that a category is saturated[454]. Other studies in this area have found that a sample size of approximately twenty subjects or less has achieved this[118,402,452,455,456].

4. BACKGROUND

Incontinence is not often considered without some mention of the associated psychological effects, such as psychological distress, depression and anxiety[15,329]. The International Continence Society (ICS) takes great care in its definition of urinary incontinence, to incorporate its association with psychological and psychosocial factors[33]. An examination of mental health in combination with the psychosocial aspects of incontinence, has generally been neglected[19,21,30,34-43].

The empirical literature shows that there is a relationship between urinary incontinence and mental health[15,329], and that mental health is associated with a reduction in help seeking[215,308,440]. However, research focussing on exploring these psychological effects of incontinence has been minimal, mostly concentrating on older people, women or samples of convenience[16-18,327]. There have been no studies concerning the interaction of incontinence, depression and help seeking, a combination which we would expect to be common. Additionally, few recent investigations have concentrated on the impact of mental health upon psychosocial issues relating to incontinence such as on quality of life, management and coping behaviours, social connectedness, and beliefs and knowledge of the condition, focussing more upon risk factors such as gender, age, cognitive impairment and physical health[15,19,20,327]. This study will facilitate an investigation into these interactions.

Many psychosocial factors, including reduced quality of life and help seeking, that are associated with incontinence may be adversely impacted upon by depression[21,31,65,441]. However, we do not understand the temporality of these conditions. It is not known if depression is a result of the experience of urinary incontinence, or whether those with urinary incontinence may already be experiencing depression, prior to becoming incontinent.

Incontinent people experiencing co-morbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[15,16,27-30,327]. Clearly, for the 30% of those with incontinence who also suffer from depression, an opportunity to reduce the burden of incontinence is presented, as treating depression may be more successful than treating incontinence[21-24].

The qualitative literature provides some insight into the relationship between urinary incontinence, depression and psychosocial factors. This literature explores incontinence in relation to psychological and psychosocial factors, such as help seeking and quality of life. However it does not address the intersection of these factors.

Two recent qualitative studies undertaken with both older men and women used semi structured interview and analysed these using two different analytical techniques. The first of these studies from the United Kingdom in 2004 examining people over 65 years of age, used grounded theory[416] to explore why people with urinary incontinence did not seek help, and then attempted to identify ways that this may be overcome[118]. It was found that personal attitudes and practical barriers prevent older people for seeking help for urinary incontinence. The second of the studies, undertaken in 2008, examining the experiences of both men and women between the ages of 59 to 93 years, was from Germany[457]. Using one main question about what bothered the subject about the involuntary loss of urine or stool, this study used content analysis[458] to conclude that mental stress factors were predominant in this situation.

Other qualitative studies in this area have primarily focused upon women only. The first of these studies, from the United Kingdom in 1999, interviewed forty-two postpartum women aged 21 to 45 years with stress urinary incontinence, and using discourse analysis, and demonstrated that although they experienced both physical and psychological symptoms, few of these women ever sought professional care or advice for their symptoms[396]. Another study from Hong Kong examined an older group of nine women aged 42 to 77 years, using content analysis, again examining community dwelling women's experience of incontinence, and found these women were eager to share their psychological distress, fears and coping strategies[459]. A study from the United States again used two semi structured interviews with seventeen women aged between 28 and 86 years. From a narrative analysis of these interviews, the lived experienced and meaning of the women was explored[452]. This study found that long term female incontinence is incorporated into a larger life story and that personal control, management, maintaining social worth and social membership were important.

A number of recent studies have embraced similar methodological techniques whereby the analysis of these studies has been undertaken using a phenomenological approach. In order to gauge women's experience of living with long term urinary incontinence, a Swedish study interviewed fourteen women, aged between 34 and 52 years and found commonly that the women discussed two main themes. They were in a vulnerable situation which meant they had no control over their lives and experienced powerlessness. Additionally, they were found to be striving for adjustment which meant that they tried to manage their condition in different ways in order to achieve some kind of control and maintain a kind of normality[402]. Another Swedish study used descriptive interviews and a phenomenological analytical technique to examine eleven women aged 66 to 89 years who desired no further treatment for their condition. This study also discovered themes along the lines of adjustment and acceptance including learning to live with it despite its difficulties, other illnesses are more important, and reluctance to seek care[456]. A third study used semi-structured interviews with fifteen Chinese women aged 24 to 81 years to examine perceptions and experiences, looked at three main categories of questions, knowledge, impact on quality of life, and treatment experiences, and these in turn identified three main themes, including uncertainty, self-blame, avoidance, emotional isolation and desire for treatment[455].

A metasynthesis of the qualitative literature undertaken by the researcher has found that many of the issues associated with depression and incontinence have not been addressed, including the intersection with other psychosocial factors.

5. PARTICIPANTS

- **Source**

Three sources for recruitment of women with urinary incontinence and depression have been identified. In order to achieve a cross section of subjects from the community, patients from the Women's Health Centre, Royal Adelaide Hospital with urinary incontinence will be identified, as will patients from a suburban private gynaecology practice. Additionally, general practices associated with our Discipline will be approached to be part of the study. Intensity sampling, a sampling technique aiming to select cases that manifest the experience being examined intensely, may be used to identify potential recruits[415] however, the method of sample selection will be determined once an appropriate data source is identified.

- **Number**

Approximately 20 interviews will be completed in order to achieve "theoretical saturation"[454].

- **Age range**

Women 18 years and over will be included.

- **Selection & exclusion criteria** *(How and by whom will screening be conducted?)*

Screening will be conducted by the recruiting clinician prior to the subjects being included in the study

Selection Criteria:

- Women who experience urinary incontinence, with and without depression
- Women who are able to provide informed consent.

Exclusion Criteria:

- Women who are Non-English speaking
- Women who have dementia, or a severe or acute neurological disease (e.g. epilepsy, acute CVE, severe Parkinson's disease, acute confusion) or a severe psychiatric disorder like bipolar disorder, schizophrenia).
-

6. PARTICIPANT RECRUITMENT

- **Procedures** *(Please explain how you will recruit volunteers onto the study. How will people be approached and asked if they are willing to participate? How and by whom will names and contact details be accessed?)*

Two groups of women will be selected. In both cases, the treating clinicians will be screening and selecting the women. We will aim for approximately equal numbers in both groups.

The first group will be women with urinary incontinence where there is no documented history of depression. However, we would expect that approx 19.5% of the women with urinary incontinence will also have depression.

The second group will be women with urinary incontinence who have depression documented in their case notes and/or who have ever been treated for depression.

The follow procedures will be followed depending on the type of medical practice where recruitment takes place:

General practice:

Practice staff will identify patients who have been treated for urinary incontinence with or without depression from their electronic databases (Medical Director[460]) or case notes. GPs in the practice will examine the list of identified patients and exclude those who they believe should not be approached to be part of the study (e.g. dementia, severe co-morbid conditions, recent bereavement, language barriers – see below). The practice will write to suitable women to inform them about the study and enclose a study information sheet and consent form. Patients wishing to participate will contact Jodie Avery at the University and arrange a suitable time to be interviewed. We have used similar recruitment methods in several previous studies including home blood pressure monitoring and the secondary prevention of heart disease.

Hospital and private practice clinics:

Patients identified by clinicians, with urinary incontinence with or without depression will be provided with information about the study by their specialist and asked if they would consider being a part of the study. If they agree, they can either contact Jodie Avery directly or consent for their contact details to be provided to her. In both cases, a letter will then be sent to potential participants inviting them to take part in the study, outlining information about the interview process as well as informing consent, which will be obtained from all participants.

- **Material** *(Provide a copy of any advertisements, flyers or other material to be used.)*

See included consent form, information pamphlet and clinician letter.

- **Payment** *(Provide details of and the rationale for any payment or reimbursement to participants.)*

Nil

7. PRELIMINARY STUDY (if any)

As part of the wider PhD project of which this qualitative study is a part, analysis of pre existing data from the South Australian Health Omnibus Survey is presently being undertaken. The quantitative analysis will identify associations between depression, urinary incontinence and psychosocial factors, such as help seeking and quality of life.

8. STUDY PLAN & DESIGN

(Include a detailed description of all planned interactions between researchers and study participants.

Include a copy of any questionnaires or interview schedules to be used.)

Urinary incontinence in women can be a result of a number of different causes and conditions and can affect those experiencing it in varying ways. Thus a qualitative study using narrative analysis to examine in-depth interviews with individuals regarding their experiences with psychosocial outcomes including help seeking for those with urinary incontinence will be undertaken. Incorporating a qualitative component of this study will be useful so that the complexity and in-process nature of meanings can be explored[76,361]. The interview schedule will be developed from a metasynthesis of the literature surrounding incontinence and depression, as well as from the results of the initial quantitative studies. Recruitment will take place over a period of three months.

In-depth interviewing is a focused technique that aims to explore the complexity and in-process nature of meanings, similar to a conversation[361]. Interviews will be carried out with approximately 20 participants in either their own homes or another convenient to the participant, allowing for the greatest information flow between the researcher and the participants. The interviews will be carried out by Jodie Avery and another research assistant (Amy Baker). Initially, an assessment of depression will be made using the mood module of the Primary Care Evaluation of Mental Disorders Questionnaire Patient Health Questionnaire (PRIME - MD PHQ)[130]. This questionnaire has been validated against structured and longer diagnostic schedules which are able to detect a number of mental disorders. In this study, the various mental disorders that can be identified with this questionnaire will be collapsed to indicate major depressive syndrome, other depressive syndrome or no depressive syndrome.

Then, questions will be asked regarding their own particular experience of incontinence and depression, the severity of their condition, their health status, their help seeking behaviour and service usage and daily living and activities they participate in, and their own rationale and interpretation regarding the aetiology of the condition.

The interviewees will be asked to think back to when they first noticed that they were having problems with urinary incontinence. They will be questioned about how urinary incontinence has affected their lifestyle, their emotions, their feeling and their mood. Prompts such as “When did you first notice your condition?”, “Why did you think there was a problem / seek help in the first place?”, “Who did you see about your problem”, “What did they tell you?”, “How did you feel about what you found out?” and “What happened next?” will be used to draw out important issues

The analytical technique used for this section will be narrative analysis. A narrative basically refers to talk organised around consequential events[453]. This collection of stories may assist in defining temporality in the exploration of the variables of incontinence, depression and associated psychosocial factors. Sequence is necessary, if not sufficient, for a narrative[393]. Narrative analysis refers to the whole of a person's account, in contrast to a thematic analysis[393]. This technique has been found to be most useful in the analysis of the experience of chronic illness. Data for this study will then be systematically analysed using N*Vivo 9[394]software..

9. DRUGS

Nil used

10. EFFICACY

(What is known from previous studies regarding the safety and effectiveness of the proposed intervention?)

No intervention

11. DATE OF PROPOSED COMMENCEMENT

October 2011

12. ETHICAL CONSIDERATIONS

(*Provide a clear description of any potential risks to participants (including physical, emotional, social or legal) and the steps that will be taken to address these risks.*
Outline the protocol that will be followed in the eventuality of any adverse event(s).
Provide details of procedures to maintain participant confidentiality during data collection and reporting of results.
Describe how you will you provide detailed information about the study to people and how and when consent will be obtained.
Include a participant information sheet and a consent form. Information and consent guidelines plus a consent form template can be downloaded from http://www.adelaide.edu.au/ethics/human/guidelines/applications/)

In order to maintain the privacy of eligible women, initial contact will be made by their consulting clinician. An information sheet describing the study, as well as a consent form will be provided to potential subjects. Then, if interested, subject details will be passed on to the researcher.
As intimate personal details will be disclosed during the interview with subjects from potentially vulnerable groups, such as frail and elderly women, this may raise concerns about confidentiality and informed consent. The subject will be assured of their anonymity, such that they will be given pseudonyms, and their personal or identifying details will be kept separately from their interview data. This data will be kept in a locked filing cabinet within the Discipline of General Practice, separate from the identification key associated with subject's pseudonyms. The subject will also be made aware that they are free to withdraw from the study at any time, and that their treatment will not be affected by any decision they make about their involvement in the study.

If the subject or the researcher feels that the subject has suffered any harm or distress from the interview, they will be referred back to the consulting clinician. If psychological issues are uncovered during the interview, the interviewing researcher will encourage the woman to return to their clinician to discuss any such issues. The interviewing researcher is not in a position to provide psychological counselling and we do not think that this would be appropriate. The researcher will encourage the woman to return to their clinician to discuss any psychological issues. The researcher may also provide information on websites about depression, and indicate other resources (eg counselling) that the participant may wish to access, such as Beyond Blue or the Lifeline telephone helpline. Depending on the nature of the distress or adverse event, the researcher may seek to facilitate an appointment with the treating clinician or the participants GP.

If a participant becomes distressed, the interviewer will stop the interview and ascertain if the participant would like external help. If appropriate and with participant permission, the treating clinician may be contacted by phone. In addition the researcher would provide information about websites and resources that they may wish to access (eg Beyond Blue, the Lifeline telephone helpline). We will prepare a leaflet with a list of resources that will be offered to all participants at the end of the interview. Depending on the nature of the distress or adverse event, the interviewer may seek permission to facilitate an appointment with the treating clinician or the participant's GP. In addition the interviewer will be able to contact Prof Nigel Stocks, an experienced GP, at any time if they require help or assistance with a distressed participant.
No psychological assessment of the participants will be undertaken in this study. Only in-depth interviews, or previous tests undertaken by clinicians, will be used to describe the women's psychological condition.

Additionally, as these subjects may be visited at home, it will be important to provide an adequate introduction and referral of the researcher by the recruiting practitioner. This will include providing information about the professional background of the researcher as a health professional to assure participants of the confidentiality of the research and help allay fears of talking about the personal and sensitive topic of UI. As researchers will be entering interviewees' homes, a record of appointment times and addresses will be supplied to a responsible party at the University, in case of any problems that may be encountered.

13. SAFETY & ECOLOGICAL CONSIDERATIONS

- Radiation, toxicity, biodegradability *(Where radiation exposure is an aspect of the proposal, researchers must comply with the Code of Practice for the Exposure of Humans to Ionizing Radiation for Research Purposes (2005) http://www.arpansa.gov.au/pubs/rps/rps8.pdf and provide specific information set out in Clause 2.1 of the above Code.)*

Not applicable

- Researcher safety *(Is there any possible risk to the health or safety of the researcher(s)? If so, what precautionary measures will be taken?)*

As stated above, researchers will be entering interviewees' homes. A record of appointment times and addresses will be supplied to a responsible party in case of any problems that may be encountered.

14. RESEARCH DATA RECORDING & STORAGE

(Provide details of how the data will be recorded, eg audiotape, videotape, or written notes. Describe how, where and for how long the data will be stored.)

In-depth interviews will be digitally recorded and also documented as transcripts. The interviewees will be given pseudonyms, and the key to these pseudonyms will be kept separately from the recordings, notes and transcriptions. Results from the PRIME-MD will also be stored separately from identifying information. The recordings will be transcribed by a research assistant who will maintain high standards of confidentiality.

The transcripts of interviews will be stored until the researcher's investigations are complete, for a minimum of five years. The transcripts will be kept in locked filing cabinet in the researcher's office in the Discipline of General Practice, separate from the identification key.

15. ANALYSIS & REPORTING OF RESULTS

(Describe how the data will be analysed and who will have access to the research data and results. How will the results be published? Will participants receive the results?)

After transcription data will managed using N*Vivo 9[394] software by the researcher. The transcriptions of interviews will be analysed for themes. Research papers resulting from the analysis of the data will be produced and published in peer reviewed journals, contributing toward a doctoral thesis.

16. OTHER RELEVANT INFORMATION

Nil

17. OTHER ETHICS COMMITTEES TO WHICH PROTOCOL HAS BEEN SUBMITTED

(If the project involves research conducted overseas, give details of any local ethics clearance procedures that apply to it.)

Nil, but once ethics approval has been obtained from the University, the Royal Adelaide Hospital will also give approval.

18. PROPOSED FUNDING SOURCE

(If researchers will receive any personal payment for conducting the study, this must be disclosed to the Committee.

If the study has a commercial sponsor, this must be mentioned on the participant information sheet.)

A PHCRED (Primary Health Care Evaluation and Development) Bursary ($5000) has been awarded to Jodie Avery to assist in undertaken this project. This will allow a part time research assistant to be employed to undertake a proportion of the interviews, and transcription of the interviews.

19. REFERENCES

(See main document reference list)

14.1.3 Project Status Report H-243-2011

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Project No:	H-243-2011 Rm Code:
Title:	Experiences and Associations of the psychosocial factors of urinary incontinence
Applicant:	Professor Nigel Stocks
Department:	Discipline of Medicine
Telephone:	8303 3460
Email:	Nigel.stocks@adelaide.edu.au
Others Involved:	**Ms Jodie Avery,** PhD Candidate, Discipline of General Practice, School of Population Health and Clinical Practice / Senior Research Associate, Discipline of Medicine, School of Medicine Faculty of Health Sciences, University of Adelaide **Professor Annette Braunack-Mayer,** Head, School of Population Health and Clinical Practice Faculty of Health Sciences, University of Adelaide **Associate Professor Paul Duggan,** Senior Lecturer, Discipline of Obstetrics and Gynaecology, School of Paediatrics and Reproductive Health Faculty of Health Sciences, University of Adelaide

Date first approved:	4/10/2011	Annual expiry date:	30/09/2012

STATUS OF PROJECT	COMPLETE
Reason if project has not commenced Expected completion date?	

Have there been any changes to the project in the last year which may affect its ethical approval?

NO

Are there likely to be any changes to the project in the next twelve months which may affect its ethical approval?

NO

If yes, give details of changes (if insufficient space, please attach a separate sheet):

Have any participants withdrawn from the study? **NO**

If yes, give number of participants who have withdrawn and reasons if known?

Have any adverse reactions or events occurred (including reactions to the administration of drugs) in the progress of the project in the last twelve months?

NO

If yes, give details below (or in an attachment)

Please provide a brief report on the project's progress:

Letters of invitation to participate in this study and information sheets were sent to 177 women who Associate Professor Duggan at the RAH deemed to be eligible for this study, i.e. they were being treated for incontinence through the Women's Health Centre at the hospital. Of these women, 21 women replied to the letter and consented to be interviewed. Another three women had heard about the study and were interested in participating and as they represented the younger age groups where there were a lack of interested women. The women were contacted by Jodie Avery and appointments were made to interview these women over the period 22/03/12 to 26/06/12. The interview schedule was piloted on the 14/03/2012 with a woman known to the researcher who gave consent to participate in the study.

Over the time period, five women were unable to be interviewed for a number of reasons, i.e. they could not be contacted, they did not contact the researcher back after a certain time, or were too busy. One interview was not completed as the researcher did not feel safe once arriving at participant's house, so an apology was made to the participant.

Twenty interviews were completed with women who had experienced incontinence aged 43 years to 88 years, in their homes by Jodie Avery. As the majority of interviews were undertaken at night, the interviewer left a record of the address she was attending with her partner and she also rang home as soon as the interview was completed as most interviews were undertaking some way away.

All participants also completed a PRIME – MD PHQ questionnaire. The interviews were generally 45 mins in length.

The interviews were transcribed by a transcribing service, and stored in a password protected file on a computer. The PRIME MD results are currently being entered into a password protected database.

The interviews are currently being analysed.

Applicant’s signature	Date:

Please return to the Secretary, Human Research Ethics Committee,

Research Ethics and Compliance Unit, Research Branch, Level 7, 115 Grenfell St, The University of Adelaide, SA 5005

The University of Adelaide Human Research Ethics Committee

Renewal of Approval – Approved by the Convenor on behalf of the Committee

Date:

Project No:	H-243-2011	**Approval is current for the period until:**

14.1.4 Recruitment letter

Government of South Australia
SA Health

ROYAL ADELAIDE HOSPITAL
North Terrace
Adelaide SA 5000
Tel: +61 8 8222 4000
Fax: +61 8 8222 5939
ABN 80 230 154 545
www.rah.sa.gov.au

WOMENS HEALTH CENTRE
GYNAECOLOGY UNIT

Tel: (08) 8222 5587
Fax: (08) 8222 5645

Head of Unit
Dr Paul Duggan

Visiting Specialists Dr Terence
Broom Dr R Alan Down
Dr Jane Elliott
Dr Graham Hamdorf
Dr Carolyn Marlow Prof Robert
Norman Dr Ann Olsson
Dr Majid Rasekhi-Komleh
Dr Ken Rollond
Dr Priya Selva-Nayagam

16 April 2012

Dear Madam

Ms Jodie Avery is undertaking a PhD study, supervised by Professor Nigel Stocks. As part of this research, they would like to invite you to be involved in a study entitled:

Mental Wellbeing, Lifestyle and Urinary Incontinence

The aim of this study is to observe how mental health and urinary incontinence effects your lifestyle, and your wellbeing. This letter has been sent out by the hospital on behalf of the University of Adelaide and your personal information has not yet been passed on to the researchers.

The researchers would like to come and talk to you for about an hour about you own personal experiences of incontinence and mental health. They will also be asking you some shorter questions regarding your mental health status.

If you think that this study would be of interest to you, you may let the clinic staff know, and they can provide your contact details to Jodie Avery, or you may even contact Jodie directly. Then, either Jodie or Amy Baker, a researcher who is helping with the study will contact you to arrange a time to come and talk to you and a time and place convenient to you both.

A copy of the study information sheet is included for your information. We hope this study will contribute to making life easier for people with urinary incontinence.

If you are able to assist us in this important project or you require any more information before you make your decision, Jodie can be contacted via 0410519941 or email Jodie.avery@adelaide.edu.au or, as can Professor Stocks, nigel.stocks@adelaide.edu.au or 8303 3460.

Yours sincerely

DR PAUL DUGGAN
HEAD OF UNIT (GYNAECOLOGY)

THE UNIVERSITY OF ADELAIDE
AUSTRALIA

14.1.5 Participant Information Sheet

Participant Information Sheet

Mental Wellbeing, Lifestyle and Urinary Incontinence

Urinary incontinence distresses and complicates the lives of many women. We are conducting a research project about urinary incontinence to gather information which may eventually contribute to better management of this condition. We invite you to participate in this study. Please read the following information to help you decide whether you would like to participate in this project. Take it home and discuss it with others if you wish. If you have any questions, or there are some things that you do not understand, please feel free to ask us.

What is the purpose of the project?

We would like to know what affect urinary incontinence has had on your life socially, and whether it has effected the feelings you have about yourself and your mental wellbeing. We will be giving you the opportunity to discuss your own experiences, and tell us just how this condition has affected your everyday life. This is a topic that has been identified in the past by researchers, but has not been greatly explored. We will be inviting 20 women with urinary incontinence to participate in this study.

What will happen to me if I take part?

If you decide to take part, a researcher will come and visit you at your home, or if you prefer, another location. You will be asked a number of questions about your experiences of urinary incontinence. With your permission the researcher will audio record your conversation. The conversation will take approximately 45minute to one hour.

What are the possible benefits of taking part?

This study is for information gathering only. Whilst there are no immediate benefits for those people participating in the project, it is hoped that this study will contribute to greater understanding about urinary incontinence, its management and treatment. Many people also find that participating in a research study such as this is a very interesting experience.

What are the possible disadvantages and risks of taking part?

During the interview, you may feel uncomfortable about some of the questions that are being asked, as we understand this may be a sensitive subject for you to discuss. If there are any areas that you do not want to share, please feel free to tell the researcher and she will move onto the next section. Please also remember that you are free to stop the interview at any time. If any problems do arise during the interview, we will seek your permission to contact your doctor and let you know about others places that might be able to help you.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do not want to take part, you will not be discriminated against in anyway and your health care will not be affected in any way. If you decide that you would like to take part, you will be given this information sheet to keep and be asked to sign a consent form. You will still be free to withdraw at any time, without giving any reason.

Will my taking part in this project be kept confidential?

All information which is collected about you during this research study will be kept strictly confidential. Any information which is made public will have your name and address removed so that you cannot be recognised at all. We may publish some of the information that you tell us, but will assure that it cannot be traced back to you.

For more information

This project has been approved by the University's Human Research Ethics Committee. Please see the attached independent complaints form if you wish to speak to someone not directly involved in the project.

If you would like any more information about the project, you can contact the project co-ordinator:

Name: Jodie Avery, PhD Candidate
Email jodie.avery@adelaide.edu.au
Telephone 0410519941.

Or the Chief Investigator of this project:

Name: Professor Nigel Stocks, Discipline of General Practice
Email nigel.stocks@adelaide.edu.au
Telephone 8303 3460

What will happen to the results of the research project?

Research papers resulting from the analysis of the data will be produced and published in peer reviewed journals, contributing toward a doctoral thesis at the end of this project in approximately 2 years.

Thank you very much for taking the time to read this information. You will be given a copy of this Participant Information Sheet as well as a signed Participant Consent Form to keep.

14.1.6 Consent form

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

STANDARD CONSENT FORM

FOR PEOPLE WHO ARE PARTICIPANTS IN A RESEARCH PROJECT

1. I, ………………………………………………………………… *(please print name)*

   consent to take part in the research project entitled:

   “Mental Wellbeing, Lifestyle and Urinary Incontinence.”

2. I acknowledge that I have read the attached Information Sheet entitled:

   “Mental Wellbeing, Lifestyle and Urinary Incontinence.”

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.
5. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.
8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.
9. I also consent for the researcher to audio record the interview.

……………………………………………………………………………………………...

(signature) *(date)*

WITNESS

I have described to ……………………………………………………….. *(name of participant)*

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project**:** ……………………………………………………………………….

Name: ……………………………………………………………………………….….

……………………………………………………………………………………………...

(signature) *(date)*

14.1.7 Interview Schedule for “Experiences and Associations of Psychosocial Factors and Urinary Incontinence” Study.

The following questions will be used to guide the semi structured interviews:

1) Does urinary incontinence impact your daily life and if so what are the most troubling aspects?
2) When did you first become aware that the incontinence was happening?
    a) How did you feel about it then?
3) Why did you think there was a problem / seek help in the first place?
4) Who did you see about your problem
    a) What did they tell you?
    b) How did you feel about what you found out?
    c) What happened next?
5) Could you describe how urinary incontinence affects how you feel now?
    a) Which parts of your life does it affect the most?
6) How serious do you think your condition is?
    a) How does this make you feel?
7) What kinds of things would you like to be able to do but because of your incontinence you are unable?
8) Do you think you are in control of your incontinence or do you think it controls you life?
    a) Which aspects of your life does it control?
9) What do you think other people think about your situation?
    a) Do they know about it?
    b) If they don’t, why not?
    c) How do you explain it to your family?
10) Is there anything else you would like to tell me or add about your experiences?

14.2 ANALYSIS

14.2.1 Scoring for the Contributory Theme Ranking

	Dispositional		Relational		Situational		Philosophical		Overall		Differ-ence	Overall Control Status
	Positive	Negative	Positive	Negative	Positive	Negative	Positive	Negative	Positive	Negative		
Over 70 years, No Depression, In control, High Resilience												
Teresa 85-89 Depression Combination = ND Incontinence status = Better than before	0	0	1	0	4	0	1	0	6	0	**6**	In control
Janice 70-74 Depression Combination = ND Incontinence status = Cured	2	3	1	0	3	0	1	0	7	3	**4**	In control
Samara 70-74 Depression Combination = ND Incontinence status = Still incontinent	0	2	0	0	5	0	0	0	5	2	**3**	In control
Karina 80-84 Depression Combination = ND Incontinence status = Better than before	1	1	0	0	2	1	0	0	3	2	**1**	In control

Over 60, Self-reported depression, Still incontinent, high resilience												
Matilda 65-69 Depression Combination = SR Incontinence status = Better than before	0	3	2	0	3	0	3	0	8	3	**5**	Not in control
Naomi 75-79 Depression Combination = SR Incontinence status = Still incontinent	1	1	0	0	4	0	0	0	5	1	**4**	In control
Kaliope 60-64 Depression Combination = SR Incontinence status = Still incontinent	2	4	0	2	4	0	1	0	7	6	**1**	Not in control
Over 60, PHQ scored, still or better incontinence, in control, high resilience												
Heather 65-69 Depression Combination = PHQ Scored Incontinence status = Better than before	4	1	2	0	4	0	1	0	11	1	**10**	In control
Julia 65-69 Depression Combination = PHQ Scored Incontinence status = Still incontinent	2	1	1	0	4	0	1	0	8	1	**7**	In control

Sarah 60-64 Depression Combination = PHQ Scored and SR Incontinence status = Better than before	1	3	1	1	4	0	0	0	6	4	**2**	In control
Under 55, Self-report depression, not in control, cured now, High resilience												
Winona 40-44 Depression Combination=PHQ Incontinence status = Cured	1	3	1	0	5	0	1	0	8	3	**5**	Not in control
Hannah 40-44 Depression Combination = SR Incontinence status = Cured	1	2	1	1	2	1	3	0	7	4	**3**	Not in control
Rhonda 50-54 Depression Combination = SR Incontinence status = Cured	1	3	0	0	5	2	1	0	7	5	**2**	Not in control
Over 70, still incontinent, self-report depression, not in control, low resilience												
Martha 70-74 Depression Combination = SR Incontinence status = Still incontinent	0	4	0	4	0	2	1	0	1	10	**-9**	Not in control
Penelope 70-74 Depression Combination = SR Incontinence status = Still incontinent	0	3	1	1	1	2	1	0	3	6	**-3**	Not in control

Ruth 55-59 Depression Combination = SR Incontinence status = Still incontinent	0	5	0	0	3	1	1	1	4	7	**-3**	Not in control
Under 55, SR and PHQ, not in control, low res.												
Selena 50-54 Depression Combination = SR and PHQ Incontinence status = Still incontinent	0	1	1	0	0	3	0	2	1	6	**-5**	Not in control
Anna 45-49 Depression Combination = SR and PHQ Incontinence status = Cured	2	2	0	1	0	3	1	0	3	6	**-3**	Not in control
Under 55, SR Lifestyle factors, not in control, low res												
Delia 45-49 Depression Combination = SR Incontinence status = Still incontinent	3	5	0	1	5	3	2	1	10	10	**0**	Not in control

14.3 PUBLICATIONS

Avery J, Braunack-Mayer A, Stocks N, Taylor A, Duggan P. Psychological perspectives in urinary incontinence: a metasynthesis. *OA Women's Health* 2013; **1**(1): 9

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Research study

Ethics & Psycho-Social Issues

Psychological perspectives in urinary incontinence: a metasynthesis

JC Avery[1,2,3]*, AJ Braunack-Mayer[2], NP Stocks[1], AW Taylor[3], P Duggan[4]

Abstract

Introduction

Urinary incontinence with co-morbid depression has been found to have a significant effect on quality of life. Examining the associations between the psychosocial factors related to urinary incontinence and mental health may help in improving the care for patients with these conditions. The aim of this research study is to explore the relationship between mental health status and urinary incontinence, focusing on the role of psychosocial factors.

Materials and Methods

A search of Medline, CINAHL and SCOPUS databases yielded 15 studies on the topic, and 10 studies were found to be in scope. A metasynthesis using Noblit and Hare's approach of meta-ethnography was undertaken. This involved a number of steps including determining how studies are related and identifying major themes.

Results

Three psychosocial aspects of urinary incontinence appear to influence mental health status: living with, management of and attitudes about incontinence. Other smaller component themes included control, seeking help and personal beliefs.

Discussion

Psychosocial factors appear to mediate the relationship between urinary incontinence and mental health status. An increased awareness of the major psychosocial issues that can influence both incontinence and mental health may contribute to a better management of the condition as well as reduce the burden of the condition on individuals.

Conclusion

Incontinence and psychological well-being are intertwined and this adversely affects a number of aspects of life. Enquiring about the mental health status of those with incontinence should include an assessment of psychosocial factors to help reduce the burden of incontinence. To improve the management of these conditions, further research should investigate whether psychological issues precede incontinence or vice versa.

Introduction

Urinary incontinence is not often considered without mentioning the associated psychological effects, such as psychological distress, depression and anxiety[1,2]. The International Continence Society takes great care, in its definition of urinary incontinence (hereon referred to as incontinence), to embrace its association with psychological and psychosocial factors[3]. An examination of mental health in combination with the psychosocial aspects of incontinence has generally been neglected[4–10].

Many psychosocial factors associated with incontinence may be adversely impacted by depression. Incontinent people experiencing co-morbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[1,11–16]. We do not understand clearly how being depressed interacts with these psychosocial factors[17].

Qualitative studies present one fruitful avenue to gain a better understanding of the relationships between incontinence, depression and psychosocial factors. Although a number of individual qualitative studies of these relationships have been undertaken, there has been no attempt yet to conduct a metasynthesis of the qualitative literature in this area.

Metasynthesis enables us to become more confident about using qualitative literature to fill the evidence gaps, as findings from a number of studies may become more conclusive after a synthesis is performed[18]. An advantage of this to the individual researcher is that an investigation can be further progressed rather than continuing to undertake smaller pieces of work that may elicit very similar findings[19] and broader perspectives may be achieved than that found by the individual researcher[20].

One approach favoured by many researchers, possibly because its method is grounded in the originating paradigm of qualitative research[21], is *meta-ethnography*[22], which has its origins in educational research. It has often been applied across studies with diverse theoretical foundations[23]. This study explores

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the relationship between mental health status and incontinence in women, focusing on the role of psychosocial factors.

Materials and Methods

This work conforms to the values laid down in the Declaration of Helsinki (1964). The protocol of this study has been approved by the relevant ethical committee related to our institution in which it was performed. All subjects gave full informed consent to participate in this study.

Search Methods

Qualitative studies were sought that addressed incontinence and mental health, in either their aims or their findings. To maximise appropriate studies, broad search terms were used to encompass the full range of studies in this area. An electronic search of the Medline, CINAHL and Scopus databases was undertaken combining the terms (1) 'Urinary incontinence' as a MESH heading, and 'urinary incontinence', 'overactive bladder' or 'urethral syndrome' in the title or abstract, and (2) 'Depression', 'depressive disorder', 'mental health', 'social stigma', 'anxiety disorders', 'mood disorders' as a MESH heading, and 'depression', 'depressive', 'phobic', 'phobia*', 'mental health', 'stigma', 'stigmati*', 'fear', 'psychol*' or 'affective' in the title or abstract. To be included in the metasynthesis, studies need to be: concerned with some type of urinary incontinence, overactive bladder or lower urinary tract symptoms; observed from the respondent's own perspective; concerned with adult humans. Only articles written in English were chosen. Studies that included both women and men were included when particular themes concerning women were outlined. When searching for studies to include in this metasynthesis, we included those that concerned different types of incontinence, overactive bladder or lower urinary tract symptoms.

Search Outcome

Fifteen studies from 1993 until 2011 were identified. After reading through the articles, five were found to be out of scope; that is they did not provide discussions of incontinence and mental health status from the point of view of the person themselves (sometimes it was carer or health professional perceptions), they concentrated on service use, stigma or quality of life or they were not predominantly a qualitative study.

No previous studies were found that looked at the experiences of living with incontinence primarily from the perspective of mental health status. The studies focused on incontinence, and mental health issues arose as part of the examination. Table 1 summarises each article with regard to the sample, methodology, aims and finding of the study.

The quality of each of the included study was scrutinised using the Critical Appraisal Skills Program tool[24]. All included studies were found to sufficiently address all the criteria.

Using thematic analysis, each study included in the metasynthesis was initially read a number of times to identify overarching themes[25]. Once the major themes were determined, the studies were coded using Nvivo 9[26]. The results from the studies themselves were coded as themes and subthemes using a constant comparative method[27]. Then, the emerging themes from each of the studies were compared against each other, to examine important psychosocial aspects that mediated incontinence and mental health.

Results

Incontinence is associated with a number of psychological issues. Some of these issues are primarily defined as major mental health issues, such as depression and anxiety; there are also other psychological issues connected with incontinence such as embarrassment, fear, self-esteem issues, worry, vulnerability, shame, paranoia and uncleanliness[28–36].

Three main psychosocial themes became evident from the literature as potential influences on the association between incontinence and mental health: day-to-day living with incontinence; the management of incontinence; and attitudes about incontinence (Figure 1).

Living with urinary incontinence

A first major theme emerged from the literature related to living with incontinence. This theme concerned relationships, particularly those of an intimate nature not only with a partner or spouse but also with friends, family; restrictions on activities; as well as overall quality of life. The nature of incontinence, with its complex issues in many different areas, means that, particularly when seeking help, those with incontinence do not know where to start discussing their problem[30]. Some papers described the problem in terms of its practical effects, but others concentrated on how the condition affected them emotionally. The greatest effect on quality of life appeared to result from coping with urgency[29]. The mental health of those with incontinence was affected on a day-to-day basis, and included depression, hopelessness, as well as anxiety. The exhaustion from broken sleep could compound such feelings. Some incontinent women also felt that their depression was making them ill in other ways[29].

The effect incontinence had on relationships, both intimate and social, was a major issue. Avoiding any kind of sexual relationship, even with a longstanding partner was common.

'You can't be physically attractive if you are not clean'[29].

'Aye it is terrible. Good job I don't have a man, my husband is dead. I am by myself. But it is really embarrassing'[29].

It seemed, for those with incontinence, that not having an intimate relationship could be best for all

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Table 1 Analyses of qualitative studies concerning incontinence and depression

Author	Date	Country	Condition, sample, survey setting/methods	Aim	Questions	Findings/main themes
Ashworth, P.D., Hagan, M.T	1993	United Kingdom,	UI 28 women 25–55 years In-depth interviews phenomenological	To discover the meaning of their condition for the sufferers themselves	Concerned the subject's experience of incontinence these include her attitude to her body, her perceptions of other people and their reactions to her, her attitude to herself, and the impact of incontinence on her daily activities	Incontinence is a taboo, a socially unacceptable topic of conversation (inhibiting the approach to health professionals). Reactions of apathy, or may perpetually teeter on the edge of taking ameliorative action: rational ways of tackling the problem are often not followed. The problem is seen as one of personal control.
Mason, L. Glenn, S. Walton, I. Appleton, C.	1999	United Kingdom	SUI 42 postpartum women 21–45 years Part of larger study, interviews discourse analysis	To examine the effects of SUI on women in their childbearing years	Please describe how having stress incontinence affects your life?	Many experience physical and psychological symptoms of SUI after delivery, few sought professional care or advice for their symptoms.
Horrocks, S. Somerset, M. Stoddart, H. Peters, T.	2004	United Kingdom,	UI 9 men, 2 women, over 65 Semi-structured interviews grounded theory	Explore reasons why older people living in the community do not present for help with problems of UI and to identify was in which they may be assisted to access continence services	*13 questions:* 'How would you describe your general health at the moment? I noticed from your questionnaire that you experienced some urine leakage. When did you first become aware that this was happening? How did you feel about it?' etc.	Personal attitudes and practical; barriers prevent older people for seeking help for UI.
Teunissen, D. Van Den Bosch, W. Van Weel, C. Lagro-Janssen, T.	2006	The Netherlands	UI 56 men and 314 women independently living aged 60 and over. In depth interviews, grounded theory.	To determine the impact of uncomplicated UI incontinence on quality of life in elderly men and women in the general population and to identify factors with the greatest effect	Does UI impact your daily life and if so what are the most troubling aspects?	UI in the elderly affects mostly emotional wellbeing. Men report 'being out of control as most important. Women consider 'being impelled to take precautions' to be most important.

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Table 1 *(Continued)*

Author	Date	Country	Condition, sample, survey setting/methods	Aim	Questions	Findings/main themes
Hägglund, D., Ahlström, G.	2007	Sweden	UI 14 women 34–52 years Had sought professional help interviews, phenomenological hermeneutic	Illuminate the meanings of women's experiences with UI	'Could you tell me about your experiences with urine leakage, please?' 'Can you tell me more about this situation when you leak urine?' 'What did you feel?' 'How did you experience the situation?' 'What happened?' 'How do you deal with the situation?'	Being in a vulnerable position means that women had no control over UI and experience powerlessness. Striving for adjustment means that women tried to handle their UI in different ways to regains power and continue to live as normal. *Subthemes*: living in readiness, making urine leakage comprehensible, accepting living with UI and being familiar with the situation.
Doshani, A. Pitchforth, E. Mayne, C.J. Tincello, D.G.	2007	United Kingdom	UI South Asian Indian Women 30–85 years Focus groups Grounded theory/constant comparative method.	To explore views and experiences of UI and perceptions of care among South Asian Indian women.	1. Have you heard about anyone having UI? 2. How did you or they (relatives or friends who suffer from UI) cope with it? 3. Why do you think UI occurs? 4. Do you know of any treatment available for UI? 5. Would you be willing to try alternative therapies? 6. Who would you like to see if you developed this condition and why? 7. Why do you think most women don't seek help for this problem? 8. How do you think we can increase awareness within the community about UI? 9. How do you think we can improve the services provided in the NHS for managing women with UI? 10. If any of the participants answered that they or a family or friend suffered from UI, they would be asked if they would be willing to share the experience with the group, including issues around access to care, treatment and how satisfied they were with the received care.	Normalization/management of symptoms Help seeking/access to health care Suggestion for improved service.

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Table 1 *(Continued)*

Author	Date	Country	Condition, sample, survey setting/ methods	Aim	Questions	Findings/main themes
Hagglund, D. Wadensten, B.	2007	Sweden	UI 13 women 37–52 years had not sought professional help Interviews, Phenomenological hermeneutic	To illuminate the meaning of women's lived experiences of their behaviour when seeking care for long term UI.	Please tell me what you feel would lead you to seek professional help for UI. When do you need professional help, what treatment do you need, and how do you deal with the UI?	Being in an affected situation; Having personal beliefs about seeking care Having desired expectations about care
Nicolson, P. Kopp, Z. Chapple, C.R. Kelleher, C.	2008	United Kingdom	OAB Men and women 51–85 years 8/10 In-depth semi-structured interviews and group interviews Thematic and interpretive analysis	Report the perceptions of patients with OAB about their health related quality of life and psychological consequences	Explored issues around health related quality of life	Experience of urgency Fear and coping strategies Anxiety about everyday living Depression and hopelessness Embarrassment Self-esteem sexuality and embodiment Many sufferers avoid admitting to the condition and/or seeking treatment, the psychological costs to them are even greater than with a diagnosed illness because the disruption remains unacknowledged and therefore unresolved.
Hemachandra, N.N. Rajapaksa, L.C. Manderson, L.	2009	Sri Lanka	SUI married women, aged 15–49, 6 focus group discussions, 8 key informant interviews, 5 case studies, Phenomenological	To discuss how SUI affects women's lives and how they manage the problem	Detailed information on perceptions, decision making around seeking medical advice, actual help seeking and management strategies and the mental, emotional, physical and sexual consequences of SUI	Although UI affected outdoor activities, sexual life, and sense of wellbeing, women did not consider it a health problem, rarely discussed it with others, and rarely sought treatment.

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Table 1 (*Continued*)

Author	Date	Country	Condition, sample, survey setting/ methods	Aim	Questions	Findings/main themes
Elstad, E.A. Taubenberger, S.P. Botelho, E.M. Tennstedt, S.L.	2010	USA	LUTS 151 black, white and Hispanic men and women In-depth interviews Grounded theory	Characterise the stigma of daytime frequency and urgency and differentiate it from the stigma of UI Describe race/ethnic and gender differences in the experience of stigma among a diverse sample of individuals with LUTS	Questions related to own experiences of having LUTS, as well as their impression on what other people think of individuals with LUTS and 1. Speculate on how they might feel in certain situations; 2. Provide their perception of how others view them; and 3. Discuss their own opinions about others who experience LUTS.	Stigma associated with frequency and urgency – not just UI Stigma of frequency/ urgency is rooted in social interruption, Loss of control of the body, and speculation as to the nature of a non-specific 'problem'. Stigma of LUTS goes beyond incontinence to include behaviours associated with frequency and urgency

UI, urinary incontinence; SUI, stress urinary incontinence; LUTS, lower urinary tract symptoms; OAB, overactive bladder.

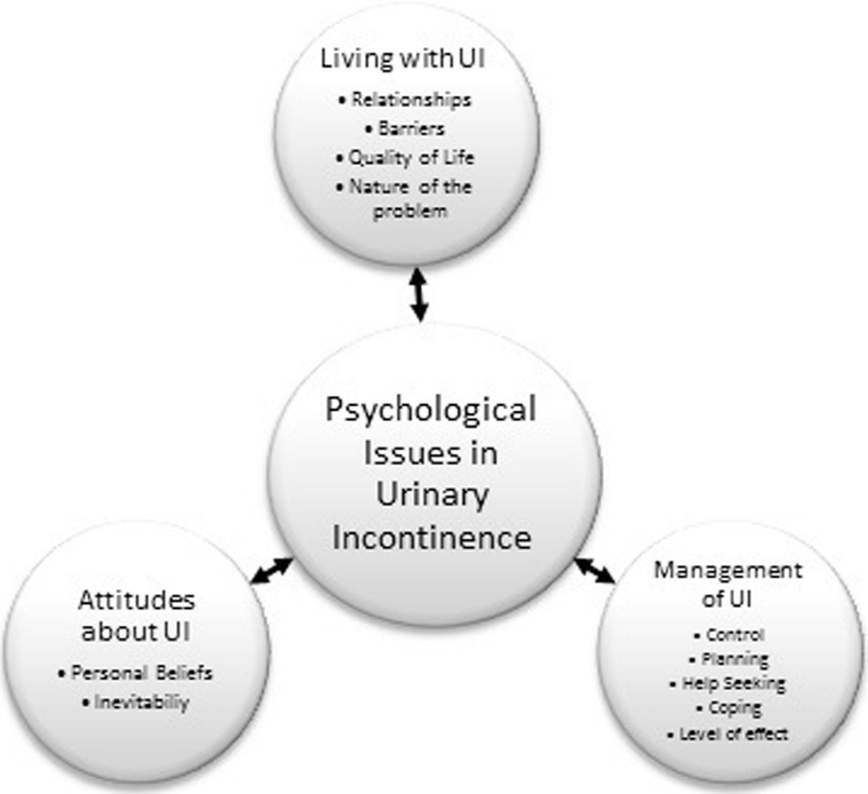

Figure 1: Psychological factors influencing psychosocial issues in urinary incontinence

concerned, particularly if partners commented on the smell or leakage during sexual relations[28,29,34]. However, lack of intimacy seemed to also increase tension in the household as well as negative feelings.

'My husband says that I stink (muthra gadai) because of it. Sometimes he does not like to be near me. He no longer has sex with me. I am always worrying whether he sees other women. Then I feel sorry for myself. But who can help me with this?' (Renuka, 40 years)[31].

As a result of the condition, a woman's body became irrelevant, that is she may no longer feel attractive, resulting in further self-esteem issues[30]. These themes illustrate the pressure for satisfactory relationships and intimacy, and this may contribute to poorer mental health in those with incontinence.

Major restrictions in many life activities also occurred because of incontinence, including the inability to exercise, especially aerobics or swimming. Running for the bus or playing

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with children was also restricted. The role as mother was interrupted because of incontinence.

'*My little girl's eight now, and I can't run around and play with her. If she says 'race you,' I say 'no – you'll have to race your dad.*'[28].

Even coughing, sneezing or raising one's voice could cause an accident, and this was quite a problem in the public setting[28,30,37]. Social roles were greatly restricted: working, going to visit friends, going to the cinema or shopping[31] were all activities that were found to be problematic. Physical activity, appropriate social roles and social inclusion are important factors for good mental health, and it is evident that these were affected by incontinence.

A range of other feelings were also associated with incontinence, which in turn affected day-to-day living. These included embarrassment in discussing their condition with family, friends and care providers, which affected help-seeking behaviour[28,29,31,33,34]. The women experienced embarrassment when having to make frequent trips to the bathroom[32]. Experiences of associated shame with a problem of such a private nature contributed towards such feelings[35].

Constantly aware, stressed and worried about having an accident and others finding out, or not being able to find a bathroom in time, weighed heavily on these people[28,29,31]. Fear also pervaded any sense of wellbeing that could occur, as there was always the chance of an accident or leakage[28,29,31]. For those with incontinence, the psychosocial aspects of day-to-day living adversely affected psychological wellbeing.

Management of urinary incontinence

Another consistent theme in the literature was the need for people with incontinence to 'manage' their condition. Managing incontinence had both practical and psychological components. The practical management themes included planning, constant awareness, specific behaviours, avoidance of activities, barriers to adequate management and help-seeking. Psychological management themes included those of coping, disclosure, explanations of causes and control.

Management of incontinence was most commonly undertaken by planning. People with incontinence discussed 'designing their life around it'[29], using protection, taking precautions or preventing accidents in a number of different ways[28–32,37].

'*I think to myself, when I get to the hill with the birch trees I'm not going to have to urinate, and when I get to the boulder, I can't hold myself any longer. But just quitting thinking about it, having someone along with me on the walk, then the thought doesn't enter my mind and I manage the walk, it is psychological*'[34]

Not disclosing their condition was one way that life could be made more bearable. Some people kept their condition hidden, even from their partners and family[28]. Others were worried that if they revealed their condition, even by using others' toilets, they would become stigmatized[30–32,34]. Further, incontinence was particularly hidden for men, as it was seen as a woman's problem and as a private thing, not to be disclosed[35].

'*Because as long as nobody knew – so in a way it was a problem. Didn't want my husband to find out.*'[28]

Control of one's incontinence could be construed either positively or negatively. Some women had only a minor problem that they had 'control over'; however, others saw their problem as something they could not control, leading to desperation, powerlessness and anger[28,36,37]. Some of those experiencing incontinence felt that it reflected a lack of control in their life more generally[30], as they were not able to control their own bodily functions[35].

A number of other issues surrounded the management of incontinence. Coping referred to the management of urgency and preventing accidents[29], but it also concerned the ability to just get on with life, by having various strategies to get through each day, including denial of the situation[30]. Having to be constantly aware of the situation was necessary but tiresome[28]. Avoiding activities that would lead those with incontinence into dangerous situations seemed to be a much used tactic, as well as the use of camouflaging clothing[29,35].

'*Well I am going out tonight and I am sick [with worry]. I don't go out normally – I don't. Not even like say going to the doctor's, because if I have an 'accident' I will die.' (female patient)*[29]

Finally, behaviours that could lead to the person with incontinence to be seen as different were undertaken. These included the constant use of toilets at functions, frequent use of toilets at private residences when visiting, trying to avoid having accidents, avoiding intimate activities such as sex, or flying on planes, going for long walks and other activities, which led sufferers to become socially undesirable[32]. Not being in control contributed towards the level of anxiety.

One important component of managing incontinence is help-seeking, specifically addressed in seven of the studies, and a major focus in five. Hagglund and Ahlstrom report that women felt 'wounded by health care staff'; they were not followed up in the provision of protective pads, particularly if they were younger[36]. In all studies, the theme of embarrassment with regard to help-seeking emerged[28,31,34]. Confidentiality and privacy were other barriers. A number of papers suggested that certain characteristics of the health practitioner could assist in encouraging help-seeking, such as the gender of the practitioner[31,33], ethnicity[33], or the type of health professional,

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for example general practitioner[31,33], nurse[33,34] or allied health professional[33].

'You know, in our area, all the doctors are men. Then how can I discuss 'woman's stuff' with them. I feel embarrassed'[31]

The women in the studies found that they were treated differently by different practitioners; however, overall they were not satisfied with the information and care that they had received. Problems such as these were regarded as barriers to help-seeking[35].

Attitudes about urinary incontinence

People experiencing incontinence held a number of different attitudes along a continuum, from those who completely normalised their symptoms, to those that found the whole experience taboo.

At one end of the continuum, some women saw incontinence as a sequel to pregnancy and birth and accepted that it was inevitable[28,31]. Ageing was also cited as a reason for the problem, along with associated weakness of the body, previous surgery and medication use, as well as compounding chronic conditions[33,35]. Rationalising incontinence in this way made it a little easier to cope with it[34].

If the symptoms of incontinence could be normalised in ways such as above, associated problems could be minimised[28]. Incontinence was not often mentioned as a disease or a health problem, and arguments were made that it was a normal state:

'I think it is a usual occurrence in women. It is not a disease. Child bearing, aging, heavy work may aggravate it' (Malini, 34 years, focus group discussion).[31]

It was taken for granted that incontinence was just a normal part of ageing or having children[33,35], and it was also seen as a 'natural thing'[34].

'I didn't bring this injury on myself, I've ended up with a bladder control problem, I associate it with giving birth and having children since it didn't happen before that, it's a natural thing, it's nothing I could of done something about'[34]

Many people with incontinence did not consider that it was actually a medical condition[30]. These attitudes affected their help-seeking behaviour, as well as perceptions about the condition[35]. Some of those with incontinence were very clear in the attribution of cause they gave to their condition so that they blamed themselves, believing they could have prevented it through pelvic exercise[28,36].

At the other end of the continuum, the shame and embarrassment of incontinence meant for some that it was a taboo subject with stigma attached. It could not be discussed with friends and family. Those who were incontinent worried about the smell, having accidents and the frequency with which they visited the bathroom. They were often very concerned by what other people thought, and many spent much time concealing their condition[28,31,32]. The attitudes these women attributed to other people were often unfounded.

'If I go to someone's house and I have to go to the bathroom a lot, maybe it might not be the right time to go to the bathroom to pee, but since I have this weakness in my bladder, I have to go right away... I worry because I think other people are going to think 'what's wrong with her? Why is she going to the bathroom so much?'... It's truly not normal for someone to need to go to the bathroom so much!' (Hispanic woman)[32]

The age of the affected person affected their attitudes, with younger people more likely to conceal their problem at all costs[36]. The taboo about incontinence also affected help-seeking behaviour[29,34,35]. Some women experienced stigma as a result of the relationship of incontinence to the genital area, as it was 'bad' or 'dirty', and needed to be concealed[30,31]. Others thought that it would be less of a problem if it was talked about more publicly, perhaps if there were a 'champion' with incontinence who wanted to share their experiences[33].

If people with incontinence believed they were not in control of their own bodies, they could experience a kind of disembodiment, which led to low self-esteem, resulting in other problems either physical or psychological. Feelings of vulnerability developed from a lack of control in one's life[36].

'But making light of it does not always work: I try to make a joke of it, but sometimes you've really got to feel down. You know, you get awful down.'[29]

The impact of the condition had much to do with how those with incontinence perceived it. Did they accept the condition, or deny it? Did they think that their personality was such that they would not let it become a problem? Did they feel that it would get better, thus showing signs of hope? Positive perceptions such as these meant a reduced impact on life.

'Won't let it become a problem; it's not in my personality, will always find ways round it.'[28]

The opposite was also the case, where those who worried about incontinence, more likely to be impacted[28]. It was also evident that, once people got older and experienced other conditions, the impact of incontinence, in the scheme of things, was lessened[33,35]. Further, with women, as the role of women included both family and career duties, the problems of incontinence, and things that affected the women themselves, were less of a priority[34].

Discussion

Incontinence is associated with poorer mental health[38], and there are many psychosocial factors that mediate this relationship. Qualitative studies investigating incontinence are often concerned with particular aspects of the condition, such as quality of life or help seeking.

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However, the impact incontinence has on mental health is part of a bigger story. The synthesis of studies in this area demonstrates that psychological factors mediate a number of other issues, such as help seeking, related to incontinence.

Three main psychosocial themes—living with, management of, and attitudes about incontinence—were identified from the nine studies analysed, with a number of subthemes falling under each of these areas. When the three main themes were examined in each study, key components emerged: how living with incontinence affected relationships and quality of life, the restrictions that occurred and the actual nature of the problem; how the management of incontinence included control, planning, coping and seeking help, and that the level of effect on one's life could be due to their own feelings about the condition; and attitudes about incontinence that included personal beliefs about aspects of the condition, such as the inevitability of it, and anxiety about, what other people thought.

The studies included in this metasynthesis also covered different population groups of people with incontinence, with variation by gender, age, ethnicity and whether or not help had been sought. Although some differences between groups, such as gender and ethnic groups, could be found, the similarities between such groups may enable more directed assistance for the management of incontinence and similar conditions, as these findings show that many of the practical problems of incontinence can have an impact on emotional problems, and taking care of the psychological wellbeing may reduce the burden of managing the condition and increase overall quality of life.

As no previous studies have been found that addressed women's experiences of living with incontinence primarily from the perspective of their mental health status, the strength of this synthesis is it combines the evidence from a number of studies, enabling us to draw wider conclusions about our research questions. This metasynthesis indicates the importance of alleviating the psychological issues associated with incontinence, via a consideration of the major psychosocial aspects. If the condition is treated, taking into account the aspects of management, day-to-day living and attitudes, there may be reduced psychological burden and better outcomes for those with the condition.

Incontinent people experiencing co-morbid depression may be less likely to seek help for their incontinence, their quality of life may be lower, they may be more socially isolated, their perception of symptom severity may be greater and their use of health services may be less when compared to individuals with incontinence who are not depressed[1,11–16]. Clearly, for the 30% of those with incontinence who also suffer from depression, an opportunity to reduce the burden of incontinence is presented, as treating depression may be more successful than treating incontinence[4,39–41].

Conclusion

Previous studies have described the relationship between incontinence and mental health, and poorer mental health is associated with a reduced help seeking. There have been no studies exploring the interaction of incontinence, depression and help seeking, a combination, which we would expect to be common. Additionally, few recent investigations have concentrated on the impact of mental health problems upon psychosocial issues that relate to incontinence such as on quality of life, management and coping behaviours, social connectedness and beliefs and knowledge of the condition, focussing more on risk factors such as gender, age, cognitive impairment and physical health.

Here, an opportunity for further investigations into these interactions is presented. When managing a condition such as incontinence, especially when treatment is not successful, it is imperative to take into account lifestyle, coping and management strategies, as well as attitudes surrounding the condition. Routine questions could be asked of patients attending general practices regarding symptoms to identify those with incontinence who may not be aware of available treatments. Referral should be encouraged to specialist services, because, for instance, continence advisors can provide detailed information and advice about day-to-day living. In turn, those with the condition may be able to assist in breaking down the taboos surrounding the condition by sharing their stories.

Incontinence and psychological wellbeing are intertwined and this adversely affects a number of aspects of life. Enquiring about the mental health status of those with incontinence should include an assessment of psychosocial factors to help reduce the burden of incontinence. To improve the management of these conditions, further research should investigate whether psychological issues precede incontinence or vice versa.

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14.4 CONFERENCE PRESENTATION ABSTRACTS

Avery, J.C., Gill, T.K., Taylor, A.W. & MacLennan, A.H. (2005) Incontinence perceptions, impacts, and quality of life.
36th Public Health Association of Australia Annual Conference, Perth W.A.

Avery JC**,** Taylor AT, MacLennan AH. (Oral Presentation): *A population perspective of urinary and anal incontinence in South Australia* **14th National Conference on Incontinence,** Melbourne VIC. 2005

Avery, J.C., Wilson, I. & Braunack-Mayer, A.J. (2005) Beliefs and barriers about seeking help for incontinence.
14th National Conference on Incontinence, Melbourne, Vic.

Avery J, Braunack-Mayer A, Stocks N. (Poster Presentation): *A Metasynthesis of Psychological Perspectives of Urinary Incontinence.* **Faculty of Health Science Post Graduate Conference**, University of Adelaide. Adelaide SA. 2011.

Introduction/Background: Associations between urinary incontinence, mental health and quality of life and have been demonstrated, but further exploration into the implications of this connection is necessary. Few investigations have focused on whether psychological issues precede incontinence or vice versa. As part of a suite of mixed method studies looking at urinary incontinence and depression in the South Australian population, a qualitative metasynthesis has been undertaken. .

Methodology: In order to develop interview questions, a metasynthesis of the available literature in this area was undertaken. Using Noblit and Hare's approach, studies were selected within the scope of the topic. A determination of how studies were related was undertaken, and themes were identified. Then the studies were translated into one another, and synthesised to see whether the results were comparable, in opposition or whether they represented a line of agreement.

Results: A number of themes recurring throughout the qualitative literature with regard to incontinence and mental health were identified, including the physical, psychological and social consequences of incontinence. These themes provide a broader perspective about the issues involved in the experiences of those with urinary incontinence and mental health, than may be achieved by those already found in quantitative analysis of the issues.

Conclusion: The key distinction between an empirical amalgamation of studies and a qualitative synthesis is that the qualitative examination yields results that are interpretive, rather than the aggregative findings from quantitative studies.

Avery JC, Braunack-Mayer A, Stocks N. (Oral Presentation): *Psychological Perspectives of Urinary Incontinence: A Metasynthesis* **PHCRIS**: Canberra ACT. 2012

Aims and Rationale: Associations between urinary incontinence, mental health and quality of life and have been demonstrated, but further exploration into the implications of this connection is necessary. Few investigations have focused on whether psychological issues precede incontinence or vice versa. As part of a suite of mixed method studies looking at urinary incontinence and depression in the South Australian population, a qualitative metasynthesis has been undertaken. .

Methods: In order to develop interview questions, a metasynthesis of the available literature in this area was undertaken. Using Noblit and Hare's approach, studies were selected within the scope of the topic. A determination of how studies were related was undertaken, and themes were identified. Then the studies were translated into one another, and synthesised to see whether the results were comparable, in opposition or whether they represented a line of agreement

Findings: A number of themes recurring throughout the qualitative literature with regard to incontinence and mental health were identified, including the physical, psychological and social consequences of incontinence. These themes provide a broader perspective about the issues involved in the experiences of those with urinary incontinence and mental health, than may be achieved by those already found in quantitative analysis of the issues

Implications For policy and practice: The key distinction between an empirical amalgamation of studies and a qualitative synthesis is that the qualitative examination yields results that are interpretive, rather than the aggregative findings from quantitative studies. Psychological factors mediate a number of issues such as help seeking for urinary incontinence.

Avery, J.C., Braunack-Mayer, A., Duggan, P., Taylor, A. & Stocks, N. (2013) "It's our lot": the influence of depression on the experiences of incontinence.
41st Public Health Association of Australia Annual Conference, Melbourne Vic.

Avery JC, Stocks N, Braunack-Mayer A, Duggan P, Taylor A. (Abstract Accepted for Poster presentation): **23rd National Conference on Incontinence,** Cairns QLD. 2014

Introduction: Urinary Incontinence has been associated with psychological distress, depression and anxiety. However, few investigations have concentrated on the psychological issues relating to incontinence.

Materials & Methods: The aim of these studies was to investigate whether the depression experienced by people with urinary incontinence is associated with psychosocial factors related to incontinence. The group of studies that contribute to this project included a population study (n= 3010), examining incontinence, depression and quality of life in both men and women; another population study (n= 3037) looking at perceptions of seriousness and severity of incontinence in women; a review of the literature, and a qualitative study examining women's experience of urinary incontinence and depression.

Results: Depression and incontinence both reduce QOL. When they occur together there appears to be an additive effect which affects both physical and mental health. A review of the literature has also found that incontinence and psychological wellbeing are intertwined. Further, severity and limitations to lifestyle were found to be predictors of women perceiving that their incontinence was moderate to very serious. Finally, an exploration of how women experience incontinence in relation to their depression status has been undertaken. Women who are older and highly resilient, experience less depression and can manage their depression better. Women who do not exhibit resilience are more likely to experience depression, and their incontinence has a greater impact on their lives.

Conclusions: Those who experience incontinence and are affected by depression in their day to day lives experience a reduced quality of life. If we can identify and manage comorbid depression in women with incontinence we may improve overall quality of life. Additionally, if we target those with limitations and negative perceptions about seriousness and severity of their incontinence, we may improve help seeking in women who are already managing their incontinence. It is important to assess psychosocial factors in women with incontinence, and design age and resilience focus interventions to lessen the impact of depression and improve quality of life.

14.5 MEDIA RELEASE

Media Release
www.adelaide.edu.au/news

THE UNIVERSITY of ADELAIDE

Friday 14 June 2013

Incontinence takes mental toll on younger women

New research from the University of Adelaide shows middle-aged women are more likely to suffer depression from a common medical problem that they find too embarrassing to talk about: urinary incontinence.

However, help is available for women if they seek medical advice, researchers say.

In a study of the experiences of women with urinary incontinence, researcher Jodie Avery found that middle-aged women with incontinence (aged 43-65) were more likely to be depressed than older women (aged 65-89).

Speaking in the lead up to World Continence Week (24-30 June), Ms Avery says the younger women's self esteem is often hit hard by urinary incontinence, while older women tend to be more resilient and accepting of their condition.

"Women with both incontinence and depression scored lower in all areas of quality of life because of the impact of incontinence on their physical wellbeing," says Ms Avery, a PhD student and Senior Research Associate with the University's School of Population Health and School of Medicine.

"Key issues for younger women affected by incontinence are family, sexual relationships and sport and leisure activities.

"The most common difficulties women express about their incontinence are things like: 'I can't play netball', 'I can't go to the gym', 'I can't go for walks', or 'I can't go dancing', and these are real issues for women who are still in the prime of their lives."

Urinary incontinence affects approximately 35% of the female population. The main cause in women is pregnancy, with the number of children they have increasing their chances of becoming incontinent.

"Our studies show that 20% of the incontinent population has depression, and this is something that we need both sufferers and GPs to better understand," Ms Avery says.

"Sufferers of incontinence are often reluctant to get help, but attitudes are slowly changing. It is very important for them to seek advice about their condition. In some cases, urinary incontinence can be curable with an operation, and this is quite literally a life-changing operation for many women.

"GPs need to be aware that if their patient is suffering from incontinence, this condition is often linked with depression which needs to be treated to increase their quality of life.

"Ultimately, we hope that our research helps to raise awareness in the community about both the mental and physical issues associated with incontinence. We know it's embarrassing, but if you discuss it with your GP, your life really can change."

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