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‘Coping and help seeking behaviour in women with Pelvic Floor Dysfunction – the emic perspective’

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Thesis submitted for the degree of

Doctor of Philosophy (PhD)

CITY UNIVERSITY, London

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TABLE OF CONTENTS

		Page
Table of Contents		2-10
Index to Figures		11
Index to Tables		12
Index to Appendices		13
Acknowledgements		14
Declaration		15
Watermark of conceptual model		16
Abstract		17
Chapter 1: Introduction		18-24
1.0	Rational for the area of study	18
1.1	Definition of Pelvic Floor Dysfunction	18
1.1.1	Pelvic Floor Dysfunction as a concept	19
1.2.1	The emic and etic perspective in PFD	20
1.2	Incidence and demographics of PFD	21
1.3	Symptomatology spectrum in PFD	22
1.4	Help seeking behaviour in PFD	23
1.5	Aims and objectives of the study	23
1.6	Summary	24
Chapter 2: Explication and critique of the theoretical frameworks underpinning this study		25-43
2.0	Introduction	25
2.1	Rationale for the utilisation of Culture Care Theory to underpin this study	25
2.1.1	The importance of Culture Care Theory in nursing	26
2.2	Culture Care Theory	27
2.3	The evolution of Culture Care Diversity and Universality: a theory of nursing	27

			Page
2.4	Description of the Theory of Culture Care and the Sunrise Enabler		28
2.5	Analysis and evaluation of the Theory of Culture Care Diversity and Universality		31
	2.5.1	Scope of the Theory	31
	2.5.2	Context of the Theory	32
	2.5.3	Philosophical Claims	32
	2.5.4	Conceptual Model	33
	2.5.5	Antecedent Knowledge	33
	2.5.6	Content of the Theory	34
	2.5.7	Relational Propositions	36
2.6	The application of the Theory of Culture Care Diversity and Universality to nursing practice		37
	2.6.1	Variety of settings in which Culture Care Theory has been utilised in published studies	39
2.7	Rationale for the utilisation of Shaw's Framework for the study of Coping		39
	2.7.1	The importance of the Coping Framework	40
	2.7.2	The Coping Framework	41
	2.7.3	Methodology employed to develop the framework	41
	2.7.4	Framework assumptions	42
	2.7.5	Analysis and evaluation of the Coping Framework	42
2.8	Summary		42

Chapter 3: Coping and Help Seeking Behaviour – a review of the literature 44-66

3.0	Introduction		44
3.1	Literature Search Strategy		45
	3.1.1	Findings	45
3.2	PFD as a Stressor		45
	3.2.1	The impact of PFD on Quality of Life	46
	3.2.2	The stigma, embarrassment and feelings of disgrace associated with PFD	48
3.3	Coping mechanisms		49
	3.3.1	Primary Appraisal – Event	50
		3.3.1.1 Beliefs about the illness	51
		3.3.1.2 Cognitive processes	51

				Page
			3.3.1.3 Health beliefs and Locus of Control	52
			3.3.1.4 Emotional processes	53
			3.3.1.5 Group differences and Socio-Economic factors	53
		3.3.2	Primary Appraisal – Situation	55
			3.3.2.1 Perceived severity of illness	55
			3.3.2.2 Raised Awareness	57
		3.3.3	Secondary Appraisal – Condition	57
			3.3.3.1 Emotions	58
			3.3.3.2 Social Support	58
		3.3.4	Coping behaviour	58
		3.3.5	Secondary Appraisal – Cue	59
			3.3.5.1 Barriers to help seeking	59
			3.3.5.1.1 Evidence with respect to women who do not seek help	63
			3.3.5.2 Factors which promote help seeking	63
	3.4	Summary		65
Chapter 4: Methodology				67 - 82
4.0	Introduction			67
	4.1	Research question		67
		4.1.1	Study aims	67
		4.1.2	Study assumptions	67
		4.1.3	Inclusion criteria	68
		4.1.4	Exclusion criteria	68
	4.2	Rationale for the use of Leininger's Culture Care Diversity and Universality: a theory of nursing and ethnographic methods to underpin the study		68
	4.3	Rational for the use of Shaw's Framework of coping		70
	4.4	Dual role of nurse and researcher		71
	4.5	Research Study Phases		72
		4.5.1	Phase One – One Life Health Care History	72
			4.5.1.1 Sampling methods for Phase 1	73
			4.5.1.2 Data Analysis methods used throughout the study	74
			4.5.1.2.1 Life Health Care History	75
	4.6	Modification of Shaw's Framework of Coping		75
	4.7	Modification of Leininger's Sunrise Enabler		75
	4.8	Phase Two – Semi-structured interviews		76

			Page
	4.8.1	Thematic development of questions and question format	76
	4.8.2	Sampling methods for Phase Two	78
	4.8.3	Data Analysis	78
4.9		Phase Three Focus Groups – the emic perspective of women with PFD from diverse cultures	78
	4.9.1	Sampling methods for Phase Three	79
	4.9.2	Thematic development of Focus Group questions and question format	79
	4.9.3	Data Analysis	79
4.10		Qualitative Criteria for trustworthiness used throughout the Study	79
	4.10.1	Credibility	80
	4.10.2	Confirmability	80
	4.10.3	Dependability	81
	4.10.4	Transferability	81
4.11		Ethical considerations	81
	4.11.1	Data Protection	82
4.12		Summary	82
Chapter 5: Results Phase One			83-101
5.0		Life Health Care History	83
5.1		Background history of the Life Health Care Informant	83
5.2		Ethnography – 'Juggling with aspects of my life to cope with PFD'	83
5.3		Themes extrapolated from the Life Health Care History	87
	5.3.1	Kinship and Social Factor	89
		5.3.1.1 Kinship – Knowledge	89
		5.3.1.2 Kinship – Social Support	89
		5.3.1.3 Societal Pressure	89
	5.3.2	Political and Legal Factors	89
	5.3.3	Cultural Values, Beliefs and Lifeways	90
		5.3.3.1 Women in society	90
		5.3.3.2 Role and status of women	90
	5.3.4	Religious and Philosophical Factors	91
		5.3.4.1 Religious beliefs and health	91

			Page
	5.3.5	Personality Factors	91
		5.3.5.1 Personality traits	91
		5.3.5.2 Emotions	91
		5.3.5.3 Permission	91
		5.3.5.4 Coping Mechanisms	92
	5.3.6	Educational Factors	92
		5.3.6.1 Knowledge	92
		5.3.6.2 Communication and language	93
		5.3.6.3 Perception of the problem	93
	5.3.7	Technological Factors	93
		5.3.7.1 Health Beliefs	93
		5.3.7.2 Knowledge of services	94
	5.3.8	Socio-Economic Factors	94
	5.3.9	Care Influencers	94
		5.3.9.1 Trigger to help seeking	94
		5.3.9.2 Barrier to help seeking	94
		5.3.9.3 Facilitator of help seeking	95
	5.3.10	Summary of thematic analysis	95
5.4		Expositional Analysis	96
	5.4.1	Sunrise Enabler	96
	5.4.2	Shaw's Framework of Coping	99
5.5		Conclusion	101
Chapter 6: Results of Phase Two			102-128
6.0	Introduction		102
6.1		Demographics	102
6.2		Thematic analysis of interview transcripts	103
		6.2.1 Synthesis of Primary and Secondary Appraisal	107
6.3		Thematic Exposition	107
	6.3.1	Kinship and Social factors	108
		6.3.1.1 Kinship – Knowledge	108
		6.3.1.2 Kinship - Social Support	108
		6.3.1.3 Social – Societal Pressure	109
	6.3.2	Political and Legal Factors	111
	6.3.3	Cultural Values, Beliefs and Lifeways	111
		6.3.3.1 Women in Society	111
		6.3.3.2 Role and status of women	112
	6.3.4	Religious and Philosophical Factors	112
		6.3.4.1 Religious beliefs and health	112

		Page
6.3.5	Personality Factors	113
6.3.5.1	Personality traits	113
6.3.5.2	Emotions	114
6.3.5.3	Permission	114
6.3.5.4	Coping strategies	115
6.3.6	Educational Factors	115
6.3.6.1	Knowledge	116
6.3.6.2	Communication and Language	117
6.3.6.3	Perception of the problem	118
6.3.7	Technological Factors	118
6.3.7.1	Health Beliefs	118
6.3.7.2	Knowledge of services	119
6.3.8	Socio-Economic Factors	120
6.3.9	Care Influences	120
6.3.9.1	Trigger to help seeking	121
6.3.9.2	Barriers to help seeking	121
6.3.9.3	Facilitator of help seeking	122
6.3.10	Ideal world comments	124
6.3.10.1	Aids to help seeking	124
6.3.10.2	Service improvement	124
6.3.11	Summary of thematic analysis	125

Chapter 7: Results of Phase Three		129-174
7.0	Introduction	129
7.1	Turkish Focus Group	130
7.1.1	Ethnohistory	130
7.1.2	Demographics	130
7.1.3	Kinship and Social Factors	131
7.1.3.1	Kinship – Knowledge	131
7.1.3.2	Kinship – Social Support	131
7.1.3.3	Social – Societal Pressure	132
7.1.4	Political and Legal Factors	132
7.1.5	Cultural Values, Beliefs and Lifeways	132
7.1.5.1	Women in Society	132
7.1.5.2	Role and status of women	134
7.1.6	Religious and Philosophical Factors	135
7.1.6.1	Religious beliefs and health	135
7.1.7	Personality Factors	136
7.1.7.1	Personality Traits	136
7.1.7.2	Emotions	136

			Page
		7.1.7.3 Permission	136
		7.1.7.4 Coping strategies	137
	7.1.8	Educational Factors	137
		7.1.8.1 Knowledge	137
		7.1.8.2 Communication and language	138
		7.1.8.3 Perception of the problem	139
	7.1.9	Technological Factors	139
		7.1.9.1 Health beliefs	139
		7.1.9.2 Knowledge of services	140
	7.1.10	Socio-Economic Factors	140
	7.1.11	Ideal world comments	141
		7.1.11.1 Aids to help seeking	141
		7.1.11.2 Service improvement	141
		7.1.11.3 Summary Of Turkish Focus Group Thematic analysis	142
7.2		African Focus Group	144
	7.2.1	Ethnohistory	144
	7.2.2	Demographics	144
	7.2.3	Kinship and Social Factors	144
		7.2.3.1 Kinship – Knowledge	144
		7.2.3.2 Kinship – Social Support	145
		7.2.3.3 Social – Societal Pressure	145
	7.2.4	Political and Legal Factors	146
	7.2.5	Cultural Values, Beliefs and Lifeways	146
		7.2.5.1 Women in Society	146
		7.2.5.2 Role and status of women	148
	7.2.6	Religious and Philosophical Factors	149
		7.2.6.1 Religious beliefs and health	149
	7.2.7	Personality Factors	149
		7.2.7.1 Personality Traits	149
		7.2.7.2 Emotions	149
		7.2.7.3 Permission	150
		7.2.7.4 Coping strategies	150
	7.2.8	Educational Factors	150
		7.2.8.1 Knowledge	151
		7.2.8.2 Communication and language	151
		7.2.8.3 Perception of the problem	152
	7.2.9	Technological Factors	152
		7.2.9.1 Health beliefs	152
		7.2.9.2 Knowledge of services	153
	7.2.10	Socio-Economic Factors	154

			Page
	7.2.11	Ideal world comments	154
		7.2.11.1 Aids to help seeking	154
		7.2.11.2 Service improvement	154
		7.2.11.3 Summary of African Focus Group Thematic Analysis	155
7.3	Orthodox Jewish Focus Group		158
	7.3.1	Ethnohistory	158
	7.3.2	Demographics	158
	7.3.3	Kinship and Social Factors	159
		7.3.3.1 Kinship – Knowledge	159
		7.3.3.2 Kinship – Social Support	159
		7.3.3.3 Social – Societal Pressure	161
	7.3.4	Political and Legal Factors	161
	7.3.5	Cultural Values, Beliefs and Lifeways	161
		7.3.5.1 Women in Society	161
		7.3.5.2 Role and status of women	162
	7.3.6	Religious and Philosophical Factors	163
		7.3.6.1 Religious beliefs and health	163
	7.3.7	Personality Factors	164
	7.3.8	Educational Factors	165
		7.3.8.1 Knowledge	165
		7.3.8.2 Communication and language	166
		7.3.8.3 Perception of the problem	166
	7.3.9	Technological Factors	167
		7.3.9.1 Health beliefs	167
		7.3.9.2 Knowledge of services	167
	7.3.10	Socio-Economic Factors	168
	7.3.11	Ideal world comments	168
		7.3.11.1 Aids to help seeking	168
		7.3.11.2 Service improvement	169
		7.3.11.3 Summary of Orthodox Jewish Focus Group Thematic Analysis	170
7.4	Summary		172
Chapter 8:	Discussion		175-189

			Page
8.1	Defining Opprobrium		175
	8.1.1	The impact of opprobrium on help seeking behaviour	175
	8.1.2	Conceptual Framework – Opprobrium Appropriation	179
8.2	Critique of findings		181
	8.2.1	Knowledge	181
	8.2.2	Embarrassment and shameful conditions	181
	8.2.3	Coping Mechanisms	182
	8.2.4	Coping an help seeking pathway	183
	8.2.5	Personality	184
	8.2.6	Care Influencers	184
	8.2.7	Race and help seeking	185
8.3	Pelvic Floor Dysfunction		186
8.4	Limitations of the study		187
8.5	Summary		188
Chapter 9:	Conclusion		190-197
9.1	Recommendations for practice and service development		190
9.2	Areas for future research		193
9.3	Publication strategy		195
9.4	Summary		197
References			198-232
Appendices			233-252
Watermark of conceptual model			253

INDEX TO FIGURES

		Page
Figure 2.1	The Sunrise Enabler (Leininger)	30
Figure 2.2	Framework for the study of coping, illness behaviour and outcomes (Shaw)	41
Figure 4.1	Study paradigm and theoretical perspective	70
Figure 5.1	Adaptation of Sunrise Enabler	98
Figure 5.2	Adaptation of Shaw's Framework of Coping	100
Figure 6.1	Thematic categorisation of the Sunrise Enabler	105
Figure 6.2	Sunrise Enabler depicting the influences impacting on help seeking behaviour	106
Figure 7.1	Turkish Focus Group Thematic Analysis applied to Leininger's Sunrise Enabler	143
Figure 7.2	African Focus Group Thematic Analysis applied to Leininger's Sunrise Enabler	157
Figure 7.3	Orthodox Jewish Focus Group Thematic Analysis applied to Leininger's Sunrise Enabler	171
Figure 8.1	Conceptual Framework – Opprobrium appropriation and its impact on help seeking behaviour in women with PFD	180

INDEX TO TABLES

		Page
Table 1.1	Symptom spectrum in PFD	22
Table 2.1	Leininger's assumptions about human caring and nursing	29
Table 2.2	Leininger's Research Enablers	31
Table 3.1	Barriers to help seeking behaviour	61-62
Table 3.2	Factors which promote help seeking behaviour	64
Table 4.1	Research Study Pathway	72
Table 5.1	Example of Thematic Analysis	88
Table 6.1	Informant Demographics	103
Table 6.2	Synthesis of Primary and Secondary appraisal.	107
Table 6.3	Summary of Care Influences	122-123
Table 6.4	Summary of Phase Two Thematic Analysis	127
Table 7.1	Demographics of Turkish Focus Group Informants	131
Table 7.2	Demographics of African Focus Group Informants	144
Table 7.3	Demographics of Orthodox Jewish Focus Group Informants	159
Table 7.4	Synthesis of constructs identifying Universality	173
Table 8.1	Recurrent findings of stigma, shame, embarrassment, fear of failure and reproach as seen in the data	177-178
Table 9.1	Publications related to research	195
Table 9.2	Presentations elated to research	196

INDEX TO APPENDICES

		Page
Appendix 1	Life Health Care History interview guides	233
Appendix 2	Phase Two semi structured interview guide	240
Appendix 3	Phase Three semi structured interview guide	244
Appendix 4	Consent and patient information regarding the study	247

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DECLARATION

The study undertaken in this thesis has been all my own work. All informants in the study were interviewed by me and all thematic analysis undertaken by me alone. Data analysis was reviewed and confirmed by my supervisors.

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ABSTRACT

Pelvic Floor Dysfunction (PFD) encompasses symptoms that rarely occur in isolation and include urinary and faecal incontinence, rectal evacuatory dysfunction and pelvic organ prolapse. It impacts on the quality of life of at least one third of adult women, with recent reviews suggesting that pelvic floor prolapse may occur in up to 50% of parous women. PFD is associated with a delay in seeking help. Why women with PFD seek or do not seek help for their symptoms has been unclear but is recognised as being multi-factorial.

Aim To learn from women with PFD, to understand the coping mechanisms they develop to live with PFD, and the triggers which prompt their seeking help.

Methodology This study, grounded in the naturalist paradigm, was a micro-ethnographic study focusing on the emic perspective of a defined group, women diagnosed with PFD, who presented to an East London Hospital for treatment. Leininger's Culture Care theory and ethno-nursing methods were used to facilitate knowledge generation. The study took place in three consecutive phases, each informing the next phase. **Phase 1 -** One Life Health Care History. This was an instrumental case study which obtained a personalised and longitudinal account of the woman's health, care and illness experiences from a lifetime perspective. **Phase 2 -** Eight semi structured interviews; these focussed on the themes generated from a review of the literature pertaining to coping and help seeking behaviour, and themes generated from Phase 1, which were continued until saturation was achieved. **Phase 3 -** Focus groups from three cultures (Turkish, Orthodox Jewish and African) which represent the ethnic mix of the local population. These explored universality and diversity amongst different cultural groups with respect to coping and help seeking behaviour.

Results This study has identified universality and diversity in coping and help seeking behaviour in women with PFD. Personality and culture have a significant impact on coping and help seeking behaviour, and lack of knowledge is a barrier to help seeking. Social taboo and the role of women in society influenced the coping behaviours of women. Women developed masking and containment strategies, and avoided aspects of social interaction to ensure their PFD problems remained secret. The fear of disgrace (opprobrium) and the delay in seeking help is linked to the woman's position in her society, and the degree to which women appropriate opprobrium is dependent on their personality and their cultural feelings of self-worth as women in their own communities.

Recommendations If women are to be encouraged and supported to seek help for their PFD, it will be imperative to raise public knowledge and awareness of PFD. Public Health Departments, in conjunction with GP practises, will be key in promoting awareness and advertising integrated PFD services, ensuring posters and information leaflets are translated and displayed in facilities frequently used by women. Facilitating ease of access to PFD services will require the development of integrated PFD services, with community based self referral clinics or drop-in clinics being made available. Health care providers need education and support to ensure they empower women to seek help by giving them permission to discuss any PFD concerns they may have.

C**onclusions** The contribution to knowledge from this study include the lay care practices that women with PFD employ in order to cope with the problem, and an appreciation of the laycare practices utilised by women. Understanding of care influencers has facilitated recommendations for service and practice development. Areas for further research have been identified. The increasing prevalence of PFD is well known, with studies suggesting that over the next 30 years the number of women seeking help for PFD symptoms will increase at twice the population growth rate. Knowledge and understanding of women's coping and help seeking behaviour is essential if services are to be developed to meet this growing need. Knowledge generated from this research in relation to opprobrium appropriation makes a unique contribution to the discipline of nursing.

CHAPTER 1: INTRODUCTION

'Coping and help seeking behaviour in women with Pelvic Floor Dysfunction – the emic perspective'

1.0 Rationale for the area of study

Principally affecting females, Pelvic Floor Dysfunction (PFD) describes functional clinical problems which seldom occur in isolation (Davis & Kumar 2003, Barber et al 2001). These problems include urinary and faecal incontinence, 'obstructed defaecation' and pelvic organ prolapse. PFD (with its range of clinical symptoms) is associated with stigma, embarrassment and a delay in seeking medical help (Davis & Kumar 2003, Norton et al 1998, Royal College of Physicians 1995). Traditionally, women with PFD symptoms have been treated for their presenting symptom in isolation, and until recently, integrated PFD services have not been available in the UK. Consequently PFD as a concept is poorly understood and there is little evidence with regard to help seeking behaviour in respect of women with PFD. There are data available with respect to coping and help seeking behaviour in individual symptoms (e.g. urinary incontinence, faecal incontinence, pelvic organ prolapse) but the coping and help seeking behaviours of women with PFD (usually experiencing symptoms from at least one of the three pelvic compartments) is not described. The justification for this field of enquiry was determined by the lack of data. Equally the literature suggests that women with PFD do not seek help immediately following symptom onset, unless they consider them very severe (Davis & Kumar 2003, Shaw 2001). Rather, women appear to cope with one symptom for many years and not seek help until the symptom worsens or an additional symptom develops.

The rationale for this study is to understand the coping mechanisms and help seeking behaviour of this group of women. The research question is 'What are the reasons for women with Pelvic Floor Dysfunction not seeking help earlier in the course of their symptomatology?'

1.1 Definition of Pelvic Floor Dysfunction

PFD describes a spectrum of clinical problems (Slieker-ten et al 2009, Varma et al 2008, Pescatori 2006, Davis & Kumar 2003, Barber et al 2001, Manning et al 2001, Maglinte et al 1999, Jackson et al 1997, Snooks et al 1984), with urinary and faecal incontinence, pelvic organ prolapse and defeacatory disorders being most commonly experienced. Traditionally the symptoms of PFD have been divided into three compartments: anterior, middle and posterior, according to their anatomical origins. Anterior compartment symptoms include urinary incontinence or difficulty in micturition, middle compartment symptoms those of sexual dysfunction and pelvic organ prolapse, whilst posterior compartment symptoms involve faecal incontinence, rectal prolapse and rectal evacuatory dysfunction (variably termed disordered defaecation, obstructed defaecation outlet obstruction) (Davis & Kumar 2003, Smith & Witherow

2000, Nager et al 1997). Many women experience symptoms from more than one compartment simultaneously, or symptoms can develop sequentially over time; indeed, weakness or injury to any of the pelvic floor structures (nerves, muscles ,supporting tissues) can predispose a woman to multiple compartment problems (Slieker-ten et al 2009, Varma et al 2008, Pescatori 2006, Davis & Kumar 2003, Barber et al 2001, Smith & Witherow 2000).

1.1.1 Pelvic Floor Dysfunction as a concept

Any lack of awareness or appreciation of the concept of pelvic floor dysfunction probably arises through: 1. the historical delivery of health care services (especially in the UK) for women with symptoms originating in pelvic floor dysfunction; and 2. a lack of understanding of the pathoaetiologies and pathophysiologies underlying symptomatology. Thus, traditionally, women presenting to primary care with primary symptoms originating in the anterior pelvic compartment (urinary incontinence, difficulty in micturition) might be referred to a Urologist, those with middle compartment symptoms (prolapse, perineal dragging/heaviness, lump in the vagina [rectocele, enterocele, cystocele], or a problem with intercourse) to a Gynaecologist, and those with posterior compartment symptoms (faecal soiling, incontinence, evacuatory dysfunction [sensation of blockage or incomplete evacuation, difficulty and straining in passing stool, necessity of digital or other manoeuvres to aid defaecation (symptoms which have been reported in 26% of women attending a clinic for their primary symptoms of urinary incontinence or pelvic organ prolapse)(Varma et al 2008, Jelovsek et al 2005) to the Coloproctologist. The emergence of the speciality of Urogynaecology and of Pelvic Floor Dysfunction Clinics resulted from the realisation that many subjects with primary complaints relating to one compartment, when questioned also had symptoms relating to another compartment, and that, in these women, symptoms originated in global pelvic floor weakness, with multiple abnormalities on investigation (Pescatori et al 2006). Current understanding of the mechanisms of pelvic floor weakness remain somewhat limited, perhaps due to the complexities of normal physiology and function, but the acknowledgement of ‘polysymptomatology, development of multidisciplinary PFD Clinics and advances in physiological research and imaging, have led to dramatic improvements in both service delivery of this huge need, and in treatments offered. The complexity of pelvic floor function is exemplified by the physiology of faecal continence and defaecation. Both rely on the integrated and coordinated normal function of the central, autonomic, and enteric nervous systems acting on the visceral and somatic musculature of the hind-gut tube, the pelvic floor and anal sphincter complex. Thus, dysfunction might originate in central/behavioural influences, ageing, pregnancy/childbirth, chronic straining, myopathy, neuropathy and connective tissue disorders. In reality, dysfunction is usually multifactorial in origin, with childbirth and obstetric events acknowledged to be the primary initiating event, but with often a lag period of about two decades before symptom onset, when other factors (ageing, the menopause etc) impact (Lunniss 2004). The imaging modalities of real time ultrasound and dynamic MR have confirmed the global nature of pelvic floor weakness in many women who may present with perhaps only one main symptom, with some postulating that the weakness

itself primarily originates in the supporting connective tissue structure of the pelvic floor structures (Petros & Swash 2008). A recent study by Slieker-ten et al (2009) investigated the prevalence of pelvic organ prolapse symptoms and signs and their relation with bladder and bowel disorders in a general female population. The aim of the study was to obtain normative data on the prevalence of pelvic organ prolapse and pelvic floor dysfunction symptoms and signs and to identify associations. Validated pelvic floor dysfunction symptom questionnaires were sent to a cross section of Dutch women aged 45 to 85 years. A response rate of 62% was achieved and results identified that anatomical locations of pelvic organ prolapse and pelvic floor dysfunction symptoms correlated significantly with incontinence of flatus, the feeling of anal prolapse, need for manual evacuation of stool, vaginal bulging, and constipation. The author's report the prevalence of bladder and bowel symptoms to be high, and that pelvic organ prolapse was found to be strongly associated with obstructive bowel symptoms. It is suggested that comprehensive assessment of women presenting with a (one) pelvic floor dysfunction symptom should be undertaken and strategies should be developed to alleviate obstructive bowel disorders associated with pelvic organ prolapse. This represents a further example perhaps, of the way in which, in Europe, PFD integrated services are considered to be the optimal way in which to provide treatment and management to women with PFD. Importantly, implicit in current knowledge of PFD is the realisation that symptomatology is non-specific in relation to underlying cause, and that symptoms may originate without necessarily any identifiable structural weakness. Central influences, perhaps best exemplified by the potential impact of sexual abuse on pelvic floor function (Leroi et al 1995), are increasingly acknowledged to be of major significance in some individuals, especially those in whom there is evidence of dyssynergic defaecation (lack of co-ordination of straining with skeletal muscle relaxation during attempted defaecation) (Beck et al 2009, Rao et al 2004).

The discussion above resides in classical medical methodological philosophy (history, examination, investigation and treatment) and reflects the etic perspective of Pelvic Floor Dysfunction. The fact that many women will initially report one PFD symptom only, and will not use or are unaware of the term PFD, reflects the difference between the etic (as described above) and the emic perspective of PFD and hence strengthens the justification and rationale for this study.

1.1.2 The emic and etic perspective in PFD

Emic and etic are anthropological terms that refer to two different perspectives of human behavior or viewpoints. The emic perspective is a description of behavior or belief from a person within the culture or group. The etic perspective is a description of behavior or belief by an observer of a culture or group. In this research, emic refers to the views, beliefs and practices of women with PFD with respect to coping and help seeking behaviour, and etic to the knowledge

and beliefs of the medical/nursing profession with respect to coping and help seeking behaviour in women with PFD. PFD is a term which embraces a multitude of symptoms or symptom complexes relating to an individual's perception and personal satisfaction with bodily functions which relate to the pelvic floor. It is essentially an etic term which is not used by women with PFD symptoms. Women present complaining of a symptom. If multiple symptoms are discovered on history and examination, an explanation of how these symptoms link can be made . The traditional focus on individual symptoms is entirely reasonable but the raising of public awareness with respect to PFD is considered necessary if women are to have more knowledge about their bodies and available treatments (should they wish to seek help). The fact that currently women are unfamiliar with the tem PFD emphasises the gulf between the emic and etic perspective in PFD. Until services are better advertised and knowledge is raised amongst women of the potential variety of pelvic floor symptoms they might experience, this will continue to be an issue which might impact on a woman's help seeking behaviour.

1.2 Incidence and demographics of PFD

Epidemiological data relating to the incidence of PFD, for reasons including attitudes towards reporting of symptoms and advice seeking, is limited. Nevertheless, PFD affects up to 1 in 3 women, with Maher et al (2004) suggesting in a Cochrane review, that pelvic floor prolapse may occur in up to 50% of parous women. The incidence and increasing prevalence of PFD is supported by Luber et al (2001) whose work suggested that over the next 30 years the number of women seeking help for PFD symptoms will increase at twice the population growth rate. Luber's study examined the demand on a PFD clinic in the USA, with future service demand predicted by using data from the US Census Bureau. Although the modeling of this study population and data are not generalisable to the United Kingdom (UK), there are certain aspects which can reasonably be assumed to apply to both populations. As in the USA, the UK population has an increasing percentage of women over the age of 60, and those over 60 are more likely to seek care for PFD than their younger cohorts (Luber et al 2001). Equally 50% of women seeking help from a PFD service were in the 30-60 year age group. With the 30-60 year age group being more knowledgeable consumers of health care services, and with increasing publicity regarding incontinence issues it is reasonable to assume an increase in service demand. In a general UK sample of 1,333 women with a mean age of 48 yrs, 50% reported stress urinary incontinence symptoms and there was an increasing prevalence with advancing years (Kuh et al 1999). These data have been replicated in the Australian population, with information from The Royal Women's Hospital Clinical Practice Guidelines (2004) for the Urogynaecology Pelvic Floor Service, showing that 46% of Australian women have some form of PFD, with one in three women over the age of 65 yrs being affected by urinary incontinence. Up to 50% of parous women will suffer PFD with resulting prolapse, and up to 20% of these women will be symptomatic (Sze et al 2002, Beck et al 1991). Additionally women over the age of 80 years have an 11% risk of surgery for either prolapse or incontinence and a re-operation rate of approximately 30% (Olsen et al 1997). Swanson et al (2005) report on a Canadian study in which women over the age of 45 years from two family practice clinics were mailed a

questionnaire assessing general health and continence status. The 61% response rate found more than half of the responders reporting urinary incontinence. The majority of studies identified in this review report the incidence of a presenting symptom, for example stress urinary incontinence, rather than a lifetime longitudinal incidence of pelvic floor symptoms; interestingly there are little data that examine co-existing pelvic floor symptoms (Wang et al 2006, Smith & Witherow 2000, Jackson et al 1997). Presumably this relates to the historical medical perspective of treating symptoms in isolation that is specialty based (Urology, Gynaecology, Coloproctology).

1.3 Symptomatology spectrum in PFD

Many women with PFD may experience symptoms from all three compartments simultaneously (Varma et al 2008, Pescatori et al 2006, Jelovsek et al 2005, Barber et al 2001, Smith & Witherow 2000, Table 1.1), or they can develop sequentially over time. The literature suggests that only the most severe symptoms are likely to be presented to the doctor (Slieker-ten et al 2009, Davis & Kumar 2003, Jackson et al 1997). This is a finding informally observed in my own practice, with women being referred with faecal incontinence symptoms who, on taking a history, are found to also have longstanding urinary incontinence for which they have not sought medical help (Pretlove et al 2006, Shaw 2001, Roe et al 1999, Norton et al 1998, Ashworth & Hagan 1993).

The range of symptoms which may be experienced by women with PFD		
Symptoms		**References**
Urinary Symptoms	Stress incontinence Urge incontinence Urinary urgency Urinary frequency Nocturia Urinary retention	Varma et al 2008, Jelovsek et al 2005, Hunskaar et al 2000, Bump & Norton 1998, Theofrastous & Swift 1998
Bowel Symptoms	Faecal Incontinence Obstructed defaecation Constipation Rectal prolapse	Pescatori et al 2006, Pretlove et al 2006, Fuller et al 2005, Wang et al 2005, Faltin et al 2006, Knowles et al 2000, Bump & Norton 1998, Floch & Dowd 1998, Jackson et al 1997, Nygaard et al 1997, Kamm 1994, Jorge & Wexner 1993, Sandler et al 1984
Sexual Dysfunction	Dyspareunia Lack of sensation	Barber et al 2002, Shaw 2002
Pelvic organ prolapse	Pelvic pain Low back pain	Slieker-ten et al 2009 , Varma et al 2008, Jelovsek et al 2005, Barber et al 2002, Olsen et al 1997

Table 1.1 Symptom Spectrum in PFD

1.4 Help seeking behaviour in PFD

Little is understood of the factors that precipitate women with PFD to seek help for their symptoms (Davis & Kumar 2003, Harris 1999, Norton et al 1998, Ashworth & Hagan 1993, Grimby et al 1993). The socio-economic, cultural and religious factors which impact on women's attitudes towards seeking help for their symptoms are also poorly understood. A number of studies have demonstrated the negative impact of PFD symptoms on quality of life (Davis & Kumar 2003, Luber et al 2001, Norton et al 1998) and yet background evidence and clinical experience suggest that women with PFD do not seek help immediately following symptom onset, unless they consider them very severe (Davis & Kumar 2003, Shaw 2001). Rather, women appear to cope with one symptom for many years and not seek help until the symptom worsens or an additional symptom develops. Chapter 3 presents a review of the literature pertaining to coping and help seeking behaviour in women with individual PFD symptoms and the general constructs with regard to coping and help seeking in chronic illness. The absence of data regarding coping and help seeing behaviour in relation to women with PFD reinforces the rationale for this study.

1.5 Aims and objectives of the study

This study aimed to learn from women with PFD, to understand the coping mechanisms they develop to live with PFD and the triggers that prompt help seeking, whilst gaining knowledge of cultural diversity and universality in women with PFD from different cultural backgrounds. The primary aims were:

- To understand the underlying reasons why women with PFD don't seek help earlier in their symptomatology.
- To understand the coping mechanisms that women with PFD employ to compensate for or mask their symptoms.
- To understand the 'triggers' for women seeking help.
- To delineate cultural universality and diversity in women with PFD from different cultural backgrounds.
- To develop a conceptual model that can facilitate understanding of coping and help seeking in women with PFD.
- To make recommendations for how services can be targeted and developed to more adequately meet the needs of women with PFD.

These aims have been achieved and the findings are described in this thesis. At present there is no universal understanding of how women with PFD define the impact of their symptoms or of the coping mechanisms they develop to manage their PFD problems. It is postulated that through this research, a deeper understanding of issues surrounding women seeking, or not seeking, medical treatment for PFD will be gained. Without an understanding of the emic perspective of women with PFD with regard to coping and help seeking behaviour there is the

potential that future service developments will not adequately address the needs of this group of women. As stated previously, the literature indicates that demand on PFD services will increase over the next 30 years, at approximately twice the rate of growth of the same population (Luber et al 2001). With greater insight, recommendations for service development, provision and availability of services and health education programmes can be made to specifically meet the needs of women with PFD. Therefore the research that is delineated in this thesis is essential to overcome this expanding problem.

1.6 Summary

The study aims to understand the coping and help seeking behavior of women with PFD. Knowledge concerning pelvic floor related symptoms is lacking. Specifically, very little is known in relation to women with symptoms seeking help.

This research is grounded in the naturalist paradigm and is a micro-ethnographic study focusing on the emic perspective of a defined group: women with PFD who present to a London Hospital for treatment. PFD as a concept is now well documented in the literature, but traditionally services have been fragmented and emphasis placed on the presenting symptom only. Integrated PFD services are well established in the USA, Australia and many parts of Europe but are relatively novel in the UK. As integrated and holistic services are developed in the UK to treat women with PFD, an understanding of their coping and help seeking behavior is necessary if services are to truly reflect the needs of women.

In the following Chapter the works of Leininger (2002, 1997, 1990, 1988, 1985, 1985a, 1978, 1970) and Shaw (1999, 2001, 2006) are described and critiqued. Their appropriateness as the theoretical perspective and framework to underpin this study are discussed, with particular reference to the way in which these theories facilitate understanding from the perspective of women with PFD, and allow identification of the emic perspective with regard to coping and help seeking behaviour in women with PFD.

CHAPTER 2: EXPLICATION AND CRITIQUE OF THE THEORECTICAL FRAMEWORKS UNDERPINNING THIS STUDY

2.0 Introduction

Leininger's Culture Care Diversity and Universality: a theory of nursing (2002, 2001, 1997, 1990, 1988, 1985, 1985a, 1978, 1970) is the theoretical perspective that was chosen to underpin this study. This explanation of the literature pertaining to Leininger's Culture Care Diversity and Universality, whilst critiquing the theory itself, aims to establish the appropriateness of the theory to underpin this research study and the rationale for its use. A key text informing the critique of Culture Care Theory is Fawcett's model for analysis and evaluation of conceptual models of nursing (Fawcett 1993, 1989, 1980). Fawcett is a nurse theorist whose specialist academic area is the development of frameworks for analysis and evaluation of nursing theories and models.

Since the late 1990s, Shaw has been investigating the help seeking behaviour of people with urinary incontinence. In preparation for the studies Shaw undertook; a review of the literature within health psychology was undertaken to identify models of coping and health behaviour. From this review Shaw developed a theoretical framework to enable researchers to utilise psychosocial variables when investigating help seeking health behaviours (Shaw 1999). Shaw's Framework is reviewed and evaluated in respect of its appropriateness in the exploration of coping and help seeking behaviour in women with PFD.

2.1 Rationale for the utilisation of Culture Care Theory to underpin this study

At the beginning of the research process, once the aims and rationale for the study had been formalised, it became apparent that an ethnographic research framework would be needed to support the enquiry on which this study is based. This research has sought to illuminate the emic perspective of women with PFD, and to facilitate an understanding of the coping and help seeking strategies which they have developed and used throughout their experience of living with PFD. Reading anthropological and ethnographic texts (Denzin & Lincoln 2000, Roper & Shapira 2000, Savage 2000, Agar 1997, Polit & Hungler 1997, Baillie 1995, Boyd 1990, Guber & Lincoln 1988, Lincoln & Guba 1985, Spradley 1979) led me to discover that only one ethnographic method had been applied to, and developed specifically for nursing, and had practical tools to facilitate discovery. This was Culture Care Theory. In addition to supporting the discovery of emic perspectives, Culture Care Theory also facilitates the discovery of how culture impacts on people's experiences of health. This was considered important for two reasons. Firstly women with PFD (regardless of ethnicity) can be considered a cultural sub-group, as the care needs of women cannot be subsumed under those of men. Secondly, in the ethnically diverse area in which I work, understanding universality and diversity of coping and help

seeking behaviour amongst women (with PFD) from different ethnic backgrounds was seen as essential to ensure future service developments would meet the needs of the local population.

Culture Care Theory is congruent with methods that support the discovery of emic perspectives, rather than methods that follow the preconceived views of the researcher. Leininger postulates that ethnomethods (ethnography, ethno-nursing, ethnohistory, ethnoscience) are the methods of choice when nurses only know some aspect of care or other phenomena from a professional (etic) perspective but do not know the client's emic views.

The methods chosen to address this study had to facilitate understanding from the perspective of women with PFD, allow identification of the lay care beliefs that impact on their coping and help seeking behaviour (the emic perspective) and reveal the tacit knowledge within this group in relation to coping and help seeking. Leininger's Culture Care Theory can legitimately be applied to the cultural understanding of a group who have a shared disease process (PFD); particularly when the disease process is a common, female predominant chronic problem which is known to be socially stigmatizing (Vandoninck et al 2004, Davis & Kumar 2003, Roe & Doll 2000, Bump & Norton 1998, Norton et al 1998, Bernard & Krupat 1994, Ashworth & Hagan 1993, Goldstein et al 1992). Marked differences between emic and etic perspectives identify areas of cultural conflicts and potential non-compliance between health service and client (Leininger 1990). This encapsulates and addresses the aims of this study: to understand the emic perspective of women with regard to coping and help seeking behaviour in order that etic advice and service provision may be culturally congruent.

Culture Care Theory has been described and published, the theory critiqued by leading nursing academics (Fawcett 2002, George 2002, Wesley 1992, Parker 2001, Tomey & Alligood 2002), used in the clinical arena by multiple nurse practitioners (Mahoney 2001, Spangler 2001, Saewyc 2000, Carr 1998, Polaschek 1998, McFarland 1997, Miller 1997, Preston 1997, Rosenbaum 1997, 1996, Finn 1994, Cohen 1991) and mandated by national bodies in the USA to provide transcultural nursing education and clinical services (National Advisory Council on Nurse Education 1996, American Academy of Nursing 1995, Institute of Medicine 1994).

2.1.1 The importance of Culture Care Theory in nursing

McCance et al (1999), in a paper exploring the utility of caring theories consider that Caring as a central concept within nursing has led to the development of several caring theories, the most well known being Madeleine Leininger's Theory of Culture Care and Jean Watson's Theory of Human Caring, both of which were formulated in the 1970's. Leininger's Culture Care Theory is considered to be fundamental to nursing behaviour in the 21st century (Murphy 2006) and the

delivery of culturally congruent care in this era of rapid globalisation has emerged as more than just a focus within nursing care (Webber 2008). Webber (2008), in a paper exploring the emergence of nursing laws, considers that currently only Orem (The Law of Self-Care) and Leininger (The law of culturally congruent care) meet the criteria for logical adequacy, teleologia, practical applicability and universality, and as such constitute nursing's first laws.

Culture Care Theory has been analysed and presented in many key nursing textbooks such as the work of Fawcett (2000), George (2002), Wesley (1992), Parker (2001), Tomey & Alligood (2002). It has also featured extensively in Journal papers: Fawcett 2002, Saewyc (2000), Carr (1998), Polaschek (1998), Rosenbaum (1997 1996), Cohen (1991). Transcultural nursing has become recognised in nursing as one of the most significant and growing trends in the 21st century (Seisser 2002). In the USA, national mandates require education in the health professions to take innovative approaches to ensure the delivery of culturally congruent care (National Advisory Council on Nurse Education 1996, American Academy of Nursing 1995, Institute of Medicine 1994).

2.2 Culture Care Theory

The central tenet of Culture Care Theory is that culturally congruent care is essential for clients' wellbeing or to become and remain healthy. The theory was developed using selected culture constructs from both anthropology and nursing. The basis of this theory is that the knowledge, beliefs and experiences of a culture (or group) are important factors in maintaining health (Leininger 1985). Factors such as world views, social structure and cultural practices cannot be separated from health, wellness, illness or health service utilisation. Leininger (1978) postulates that all human cultures have forms, patterns, expressions and structures of care which impact on health or illness status and health service utilisation. Leininger maintains that there is a major cultural gap between generic and professional care values and practices, and reducing the knowledge gap between nurses and diverse cultures remains a problem in nursing. This professional nursing knowledge gap perpetuates cultural imposition, which can lead to destructive care practices.

2.3 The evolution of Culture Care Diversity and Universality: a theory of nursing

In the 1950s Madeleine Leininger was working as a Psychiatric Clinical Nurse Specialist in a child guidance home with children from diverse cultural backgrounds. She identified a lack of understanding amongst the nursing staff of how the children's cultural background might be influencing their behaviour and consequently their care needs. Leininger considered that in order to care for children from different cultural backgrounds, she would need to develop her knowledge of the role cultural factors played in health. She undertook a PhD in anthropology, the discipline primarily focused on human cultures. Her field studies were in New Guinea where she undertook an ethnographic and ethno-nursing study of the Gadsup people (2001a). It was

during the course of this study that Leininger came to understand that care beliefs and attitudes towards health and illness are embedded in the values, world views and life patterns of people (Cohen 1991), and came to consider that anthropological knowledge was a missing knowledge domain in nursing. Leininger published her first textbook on transcultural nursing in 1970, Nursing and Anthropology: Two Worlds to Blend. It was in this text that she postulated the need for the field of transcultural nursing by discussing the nature, rationale and need for a transcultural nursing theory base (Leininger 2002, 1970). Initially, little interest was shown within the nursing profession for the concept of transcultural nursing but Leininger persisted with the dissemination of her ideas, motivated by the belief that the world was moving more rapidly towards multiculturalism than the nursing profession realised. She did not publish her first theoretical text on Culture Care Diversity and Universality until 1991. It is now in its third edition.

Whilst developing her theory of nursing, Leininger was simultaneously developing transcultural nursing courses. Leininger herself admits that interest in her ideas was slow to become established. Between 1960 and 1974 only 45 nurses took graduate courses in anthropology or enrolled on her transcultural nursing courses. With the development of the Transcultural Nursing Society in 1973, the idea of transcultural nursing became more widespread and widely discussed at conferences and in nursing journals. The written dissemination of ideas pertaining to transcultural nursing theory became even more widespread in 1989 with the launch of the Journal of Transcultural Nursing, established by Leininger, and of which she was editor until 1995.

2.4 Description of the Theory of Culture Care and the Sunrise Enabler

Leininger considers that care is the essence of nursing, and that culture care would provide a distinctive context to explain and interpret nursing as a discipline (Leininger 1990, 1988, 1978). The theory aimed to establish the nature of caring from a cultural perspective and facilitate the understanding of the care differences and similarities between cultures. The theory is based on a number of assumptive premises relating to care and culture and these are outlined in Table 2.1. To support these assumptions Leininger defined the theoretical orientations related to the theory. The definitions are provisional guides to inductive or deductive acquisition of data (Leininger 1988, 1978).

Caring	Nursing	Curing
Human caring is a universal phenomenon but the expression, processes and patterns vary among cultures	Every nursing care situation has transcultural caring behaviours, needs and implications	Differences exist between the essence and essential features of caring and curing behaviour and processes
Caring behaviours and functions vary with social structure features of any designed culture	Caring should be considered the essence and unifying intellectual and practice dimension of nursing	There can be no curing without caring but there may be caring without curing
Caring has biophysical, psychological, cultural, social and environmental dimensions which can be studied and practised to provide holistic care to people	To provide therapeutic nursing care, the nurse should have the knowledge of caring values, beliefs and practices of clients	
Caring acts and processes are essential for human development, growth and survival	The identification of universal and non-universal folk and professional caring behaviours, beliefs and practices will be important to advance the body of nursing knowledge	
	Transcultural caring behaviours, forms and processes have yet to be verified from diverse cultures; when this body of knowledge is procured, it has the potential to revolutionize present day nursing practices	

Table 2.1 Leininger's Assumptions about Human Caring and Nursing (1988)

Leininger developed the Sunrise Enabler to depict both the care assumptions and theoretical definitions (Figure 2.1). The Sunrise Enabler identifies potential influences that might explain care related to historical, cultural, social structure, worldview, environmental and other factors. Leininger incorporates within the Enabler constructs embedded in social structure such as religion, kinship, politics and economics. Gender, age and ethnicity are embedded in family ties and specific practices. Leininger states that the Enabler is not the theory *per se* but a conceptual picture (Leininger 1988). It can be argued that the Enabler is a holistic depiction of the diverse components of the theory, allowing the nurse to obtain a holistic perspective and to discover and assess care phenomena. The Enabler depicts the worldview of the individual client, the lay and professional care practices and the nursing care decisions and actions. The Enabler helps to discover potential and actual influences on care and health phenomena, relating them to historical, cultural, religious and other social structure factors.

Leininger postulates that it is the interrelationship of these diverse factors which provides valuable data and helps to explain and understand the individual from a culturally congruent perspective (Leininger 1988). Social Structure is defined as the dynamic nature of interrelated structural factors of a culture and how these factors function to give meaning. In her definitions Leininger includes folk health system and professional health system to differentiate and understand lay care practices and professional care practices. The definitions conclude by

defining the three phases of culturally congruent care practice, cultural care preservation or maintenance, cultural care accommodation or negotiation and culture care repatterning or restructuring. These phases of culturally congruent care are depicted in the Sunrise Enabler (Figure 2.1).

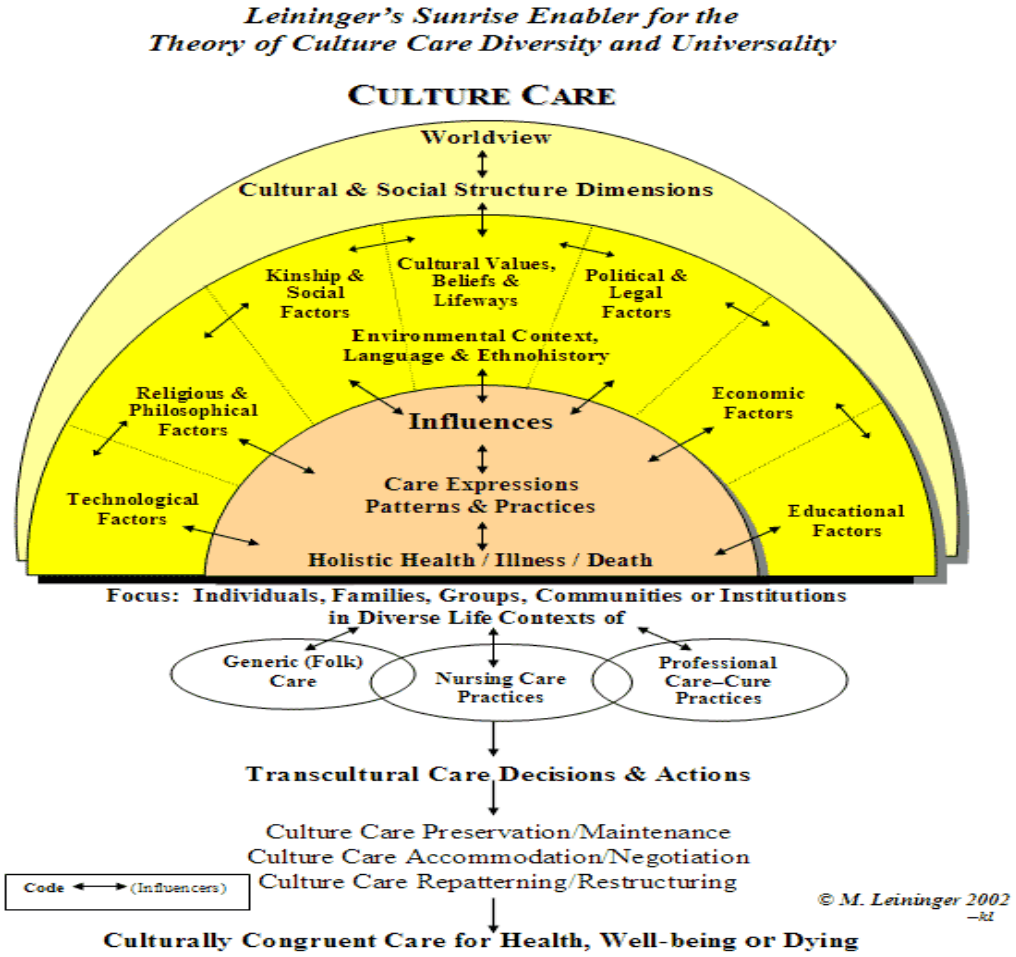

Figure 2.1 The Sunrise Enabler. Reproduced from The Transcultural Nursing Website, also printed in Leininger M (2001) *Culture Care Diversity and universality: A Theory of nursing*. Jones & Bartlett, NLN Press, New York

Cultural care preservation or maintenance refers to the assistive, supportive or enabling nursing care actions that help clients of a particular culture to preserve or maintain health (Leininger 1988). Culture care accommodation or negotiation refers to the assistive, supportive or enabling nursing care actions which help clients of a particular culture to adapt to or negotiate for a beneficial health status (Leininger 1988). Culture care repatterning or restructuring refers to the nursing care actions that help clients change their lifeways that support beneficial health (Leininger 1988).

To support the study of cultures, Leininger developed the Ethno-nursing Method, its central purpose being to facilitate the identification, documentation and discovery of in-depth data related to care and culture (Leininger 1997, 1990, 1985a). Leininger defines ethno-nursing as a naturalistic qualitative research method using open discovery processes to document, describe and understand the emic people's viewpoints and beliefs about care (Leininger 1985a). The research method has been designed to focus on emic and etic knowledge and practices related to care. Leininger has developed research enablers to facilitate Ethno-nursing Methods. The five enablers are summarised in Table 2.2.

Enabler	Function
Sunrise Enabler	Holistic research guide to discover culture care phenomena
Three Phase Observation-Participation-Reflection Enabler	A guide to enable the researcher to enter and remain with informants in their familiar or natural context whilst observing and undertaking the study
Stranger to Trusted Friend Enabler	This guide supports the researcher entering the natural context of the study to move from stranger to trusted friend
Domain of Inquiry Enabler	A guide to developing a tailor made statement focused directly and specifically on culture care relating to the culture or health phenomenon being studied
Acculturation Enabler	A guide to assessing the extent to which a cultural belief or practice has changed

Table 2.2 Leininger's Research Enablers

2.5 Analysis and evaluation of the Theory of Culture Care Diversity and Universality

The analysis of Leininger's theory is based on Leininger's publications about her theory (2002, 1997, 1990, 1988, 1985, 1985a, 1978, 1970). A key text informing the analysis and evaluation is Fawcett's model. Fawcett has undertaken an analysis of the theory using a framework which was developed in 1980 (Fawcett 2000, 1993, 1980). The main components of Fawcett's model for analysis and evaluation is a framework for identifying the context of the theory, antecedent knowledge and the content of the theory. The framework describes the stages of theory evaluation (establishing significance, internal consistency, parsimony and testability). Evaluation of the theory is based upon the results of the analysis of the theory as well as on the publications by others who have used the theory.

2.5.1 Scope of the Theory

Leininger states that the purpose of the theory is to discover care diversities and universalities in order to provide culturally congruent care to people of different cultures. (Leininger 2001). The theory is classified as a grand theory (Fawcett 2000, 1993).

2.5.2 Context of the Theory

Leininger (2001, 1988) rejected the widely used definition of nursing as the concepts of person, environment, health and nursing. Instead she proposed a metaparadigm comprising the concepts of human care, environmental contexts and well being. Leininger identified caring or the concept of care as being the central essence and unifying domain of nursing (Leininger 1988) with care being placed in a cultural context, since lay care practices can differ transculturally.

During the conceptualisation and development of The Theory of Culture Care, Leininger did not follow the conventional stages of theory development (Walker & Avant 1983) as she perceived these were grounded in the quantitative paradigm with the emphasis on hypo-deductive logical positivism (Leininger 2001). The theory of Culture Care was conceptualised using inductive emic views and not from Leininger's *a priori* hypotheses (Leininger 2001). In fact, Leininger does not describe the theory as 'grand theory', but instead identifies that Culture Care Theory has purposeful built-in action which minimises abstraction of the theory. She describes the development of the theory as a creative process of concept explication, reformulation and resynthesis (Leininger 1988). Leininger opposed the view that a theory was a set of interrelated concepts or hypotheses with measurable relationships which would predict and control the phenomena under study (Polit & Hungler 1997). Leininger maintains that such a definition arises from the quantitative paradigm and was inappropriate for qualitative enquiry. As a consequence Leininger deliberately sought to develop her theory without testing pre-conceived etic views (Sandelowski 1993). Leininger therefore defines theory as sets of interrelated knowledge with meanings and experiences that describe, explain, predict or account for a phenomenon through open, creative and naturalistic discovery methods (Leininger 1988). The theory of Culture Care is congruent with methods that support the discovery of emic perspectives, rather than methods that follow the preconceived views of the researcher.

2.5.3 Philosophical Claims

The fundamental philosophical claims underpinning the theory are Leininger's beliefs about nursing care and culture. From her anthropological study of the Gadsup, Leininger came to believe that care and beliefs about health and illness are embedded in a person's life patterns and values (2001a). Leininger defines caring as 'those assistive, supportive or facilitative acts towards or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway' (Leininger 2001, p 46). Leininger goes on to differentiate between professional caring and lay care and postulates that these are two different kinds of care: generic and professional care (Leininger 1997). Generic care relates to the lay or non-professional care developed by a culture to manage a specific health/wellness issue. Leininger argues that if professional care (nursing) understands and incorporates generic caring with professional care, clients would experience culturally congruent care. Leininger makes a

number of assumptions about caring and these are reflected in the theory of Culture Care. These assumptions have been summarised in Table 2.1

2.5.4 Conceptual Model

Leininger describes the person as an individual human caring and cultural being, as well as a family, a group, a social institution or a culture (Leininger 2001 p49-56, 1985a). This is the conceptual model on which her metaparadigm is based.

2.5.5 Antecedent Knowledge

As previously described, Leininger's experiences as a Psychiatric Clinical Nurse Specialist and her formal study of anthropology were the major influences on the development of the Theory. Ethno-nursing was developed by Leininger (1985) specifically to study the theory of culture care. It is a naturalistic and emic research method using open discovery, diverse strategies and enabling tools to understand people's meanings as applied to health care issues (Leininger 2001). The method is focused on learning from people through their eyes, ears and experiences. Leininger postulates that ethnomethods (ethnography, ethno-nursing, ethnohistory, ethnoscience) are the methods of choice when nurses only know some aspect of care or other phenomena from a professional (etic) perspective but do not know the client's emic views. Marked differences between emic and etic perspectives identify areas of cultural conflicts and potential non-compliance between health service and client (Leininger 1990). She states that ethno-nursing is the only research method uniquely developed for nursing (Leininger 1990), although it can be argued that given her anthropological background and the marked similarities between ethno-nursing and ethnographic methodologies, that in fact ethno-nursing has been developed from social science research methods used in anthropology and ethnography. This is not a direct criticism of Leininger's Sunrise Enabler or ethno-nursing methods; rather an acknowledgement of the appropriateness of the social science background which has strongly influenced its development (Vidich & Lyman 2000). In nursing and anthropological literature it is well established that the two disciplines have much in common because of their holistic view of human beings (DeSantis 1994). Recognition of this common ground has led to significant nursing developments; particularly the emergence of transcultural nursing, and the amalgamation of concepts from anthropology and nursing. It is considered to be entirely appropriate (Fawcett 2002). What is unclear from her writing is which concepts Leininger synthesized into transcultural nursing concepts from the disciplines of anthropology and ethnography. It would appear that this synthesis of concepts took place based solely on the assumptions made by Leininger. Whilst acknowledging the synthesis of constructs from anthropology it is important to clarify that anthropology primarily focuses on cultural knowledge whilst transcultural nursing is a professional practice focused on comparative cultural care, health and healing related human conditions.

Walker & Avant (1983) describe three approaches to theory development: analysis, synthesis and derivation. Leininger's work has been based for the most part on the use of concept synthesis, concept derivation and theory synthesis strategies (Cohen 1991). Cohen considers that concept derivation is evident in Leininger's selection of the anthropological concept and the methodology of ethnography (2001). Leininger has used ethnographic methodologies and made them applicable to nursing, naming it ethno-nursing. By using a concept from anthropology and ethnography and redefining it for nursing would fulfil the criteria of a concept derivation strategy in the development of Culture Care Theory (Walker & Avant 1983). The Sunrise Enabler is constructed using the anthropological concepts of world view and social structure based on the work of Redfield, a social anthropologist (1957) and is another example of concept derivation utilised by Leininger (Cohen 1991).

2.5.6 Content of the Theory

Within Leininger's publications (2001, 1988) it is stated that the concepts of the theory are care, caring, culture, language, ethnohistory, environmental context, holistic health, worldview, cultural care, care systems and culturally congruent nursing care. The concept of care has already been discussed. A review of Leininger's definition of culture is required to contextualize the concept. Leininger defines culture as 'the learned, shared, transmitted values, beliefs, norms and lifeways of a particular group that guides their thinking, decisions and actions' (Leininger 2001,p47). During the development of the theoretical conceptualization of Culture Care Theory, Leininger made a number of assumptive premises with regard to culture. One of these was that clients who experience nursing care that fails to be congruent with their beliefs, values and general lifeways will show signs of cultural conflict, noncompliance, stresses and slow recovery. The goal of Leininger's theory is to provide care which is culturally acceptable and beneficial to the client, family or culture group's health beliefs. The theory is congruent with the philosophical claims and conceptual model on which it is based.

In Leininger's personal work there are no examples of her use of the theory in anything other than distinct cultural groups (defined purely by race). However in the literature there are many examples of Leininger's Cultural Care theory, ethno-nursing and ethnographic methods being applied to cultural groups defined by sexuality (Gosner 2000), used in a hospital to identify nurses care concepts (Spangler 2001), to study the fate of health promotion in coronary heart disease families (Preston 1997), to understand the illness experiences of patients with congestive heart failure (Mahoney 2001) and to understand the perceptions of dying in hospice and hospital (Gates 2001).

Gosner (2000) identifies that historically, culture has been interpreted as the beliefs and lifeways of people related by race and ethnicity but that this definition is narrow in its perspective. Gosner argues that culture should now include relationships with an interlinking web of symbols, which can affect human choices, and can exist in both the mind and the person's environment (Spector 1996). Culture should be a tool which defines reality for its

members; it is not a finite and self-sufficient body of contacts, customs and traditions (Hall 1993). As a consequence of the expansion of the meaning of culture, Gosner postulates that individuals who identify as being lesbian, gay, bisexual and or transgendered can be classified as a cultural group. The unique health care needs of sexual minority groups are often ignored and gay men and lesbians have a higher rate of depression, suicide, alcoholism and breast cancer (Harrison 1996). Gosner identifies that Leininger's theory contains two operational definitions which support the development of culturally aware health care for persons who identify as members of sexual minority groups: Cultural Care and Cultural Care Diversity. Rather simplistically, Gosner suggests that using Leininger's model, the health needs of this minority sexual group could be better met and they would have the opportunity for their cultural symbols, values and belief needs recognized and met. Disappointingly, Gosner provides no practice or research examples to support this viewpoint. Nevertheless, I concur with Gosner's view on the historically rigid definition of culture being outmoded, and that by expanding the definition to include relationships with an interlinking web, sub cultures such as women with PFD can benefit from the tenets of Leininger's Theory of Cultural Care Diversity and Universality.

Preston (1997) used ethnographic methods to study the fate of health promotion in coronary heart disease families. The premise of her work was the proposal that each family can be regarded as a unique small-scale society or culture, with its own internal organization and view of the world. In her study, Preston identified that a crucial aspect of each family culture involved those beliefs, behaviours and habits that were either protective of health or pathogenic. Mahoney (2001), in a focused ethnography aimed at understanding the illness experience of patients with congestive heart failure and their family members, undertook 28 in-depth interviews (the informants were both Caucasian and African Americans). Data were analysed using an integration of recommendations from Leininger (1985) and Spradley (1979). Thematic analysis revealed that all patients and family members living with congestive heart failure experience a process that includes disruption, incoherence and reconciling. In her discussion, Mahoney outlines the need for health care providers to recognize that the resources of the popular and folk sectors are important aspects of the individual's experience. Given that the themes were identified equally in both racial groups with congestive heart failure, it is suggested that these common behaviours and practices derived from a 'disease' culture and not an ethnic culture.

Individuals who identify themselves as part of a subculture will have an implicit identity, have developed meanings and expressions of care and caring as part of their lived experience, have their own culture and behaviours, and that these guide their experiences and actions. It is argued that sub-cultures, not defined by race, have care needs which require insight and understanding if culturally congruent care is to be offered. Equally it can be argued that those who identify as having a medical problem will identify as a member of this subculture and learn and develop common lived experiences and care needs. A feature of transcultural nursing is the focus on comparative differences and similarities among cultures specifically in relation to lay

care, health, wellness, illness patterns, beliefs and values. Without including sub cultures in this work our comparative focus is limited and there would be risk of excluding subcultures from provision of congruent care.

2.5.7 Relational Propositions

The relational propositions are depicted in the Sunrise Enabler (Figure 2.1). The Sunrise Enabler is not the model as it now stands, but during the early evolution and development of Culture Care Theory Leininger originally referred to the Sunrise Enabler as a model. Leininger explained that the Enabler represents the sun; the upper portion of the Enabler depicts the world view, cultural and social dimensions which influence care. The lower part of the Enabler describes the care systems and dimensions of culturally congruent care (Fawcett 1993, Leininger 1985). Earlier in her work, Leininger developed the Sunrise Model (1985) to study different levels and phases of culture and healthcare. Leininger began work on the Sunrise Model in 1955 and continued to revise it in relation to the theory and the multiple holistic factors which she believes could influence cultural care until 1985. Initially Leininger described the 'Sunrise Model' but as her revisions continued and ethno-nursing methods became more formalised and tested she renamed the model the Sunrise Enabler. The Sunrise Enabler is a cognitive map or enabler to guide the researcher and not a conceptual model (Leininger 2001a, Fawcett 1989). The Enabler was originally developed by Leininger to support the transcultural nursing research process but it is equally appropriate for use in nursing assessment. When using the Enabler the nurse may start with any construct depending on the focus of the examination. The aim of the Sunrise Enabler is to facilitate the drawing of a comprehensive picture of the patient and their daily living practices and beliefs. It represents the historical, cultural and social context of human beings and as such clearly has its roots in anthropology. The Enabler is considered significant in that it combines both theory and method and distinguishes between different levels of abstraction (Cohen 1991, Leininger 1985). Included in the Sunrise Enabler are four levels of abstraction and analysis:

- Level one - focus on the structure of the culture of a group.
- Level two - focus on the specific meanings of health to individuals, families and groups.
- Level three - concerned with folk and professional systems of care.
- Level four - guides the development of care that is culturally acceptable.

The Sunrise Enabler also includes two phases for the generation of research knowledge. Phase one studies are substantive and generate new knowledge, whilst phase two studies test previously acquired knowledge (Higgins & Learn 1999). In relation to the Sunrise Enabler, the research described in this doctoral thesis is conceptualised as a level two phase one study, since it focuses on an individual, individuals and groups, means of living (coping) with PFD and its impact on health practices and help seeking behaviours, and generating new knowledge.

Ethno-nursing methodology utilising a Life Health Care History of an individual followed by individuals and then specific groups facilitates the process of abstraction.

2.6 The application of the Theory of Culture Care Diversity and Universality to nursing practice

Leininger herself has no doubt of the significance that Culture Care Theory has had on the nursing profession worldwide. She states that many nursing leaders hold that it has been the most significant breakthrough in nursing and health fields in the 20th century (Leininger 1997). This view is supported by Webber (2008), Seisser (2002) and McCance (1999), who consider Culture Care Theory and transcultural nursing to be one of the most significant and growing nursing developments influencing the discipline of nursing. The special significance of the theory lies in its contributions to understanding the influence of culture on people's experiences of health. Cohen (1991) considers that Leininger used her anthropological roots to provide nursing with a way to study caring that takes into account people's culture, beliefs and lifeways to provide culturally congruent care. It can be considered to have particular relevance as migration and world travel continue to escalate whilst the world appears to be growing smaller and cultural boundaries are becoming blurred and less defined. From a historical nursing perspective Leininger's beliefs and assumptions about the importance of care and culture must be viewed as forward thinking and innovative in a period when mainstream nursing remained focused on the medical model of care and the task orientated nature of 'nursing'.

It is postulated that Culture Care Diversity and Universality: a theory of nursing, and the research studies produced by the ethno-nursing methods, may not appear clinically relevant and certainly not clearly applicable to practice for nurses involved in direct patient contact. This perception has arisen primarily from the continued narrow application of transcultural nursing theory and research on ethnic groups defined by race. The ethnography which resulted from Leininger's studies of the Gadsup people (2001a) is a fascinating account of the culture and lifeways of the people, but unless the constructs described by Leininger are translated into the context of modern health care they may be considered irrelevant to modern nurses, whose likelihood of meeting a Gadsup villager in the course of their working life is minimal. If the methods described by Leininger are applied to cultures and sub-cultures not solely defined by race but by disease, then the research findings would be more clinically relevant in the practice setting.

Leininger has sought to make transcultural nursing care the exclusive remit of transculturally prepared doctoral students. Given that Leininger herself states that care (of which culture care is one part) is the central essence and unifying domain of nursing (Leininger 1988), a question can be raised as to how transcultural nursing is considered a new discipline and not part of the

discipline of nursing as a whole, with care as its unifying domain. Glittenberg (2004) suggests that transcultural nursing research has clearly increased nursing awareness of the importance of culturally competent care to the extent that cultural competence is now perceived as good nursing practice and competent healthcare (Dreher & MacNaughton 2002). Therefore it should not be viewed as a separate discipline of nursing, rather nursing itself. Leininger contends that all nurses and nursing must become transcultural by 2015 to be relevant, therapeutic and safe with people of diverse cultures (1995), which is an indication that this construct is central to nursing itself and not simply a new discipline.

With the development of ethno-nursing methods and enablers such as the Sunrise Enabler, Leininger promotes the use, testing and reproducibility of the theory by providing the practical research methods and tools to discover the meanings of culture care. Ethno-nursing methods allow application of theory to practice by providing tools to use the theory and a framework with which to do so. Summaries from the studies of 23 cultures conducted by Leininger and her students are presented by Leininger (2001); these identify the major research findings from Culture Care Theory:-

- There are far more cultural diversities and less universality among and between cultures.
- Culture care meanings and practices tend to be embedded in the social structure and are difficult to find.
- Marked differences between generic and professional care values and practices often lead to cultural clashes and cultural imposition with negative outcomes.
- High technology practices in Western hospitals tend to increase the distance between client and nurse.
- Generic (emic) practices provide the most credible and meaningful knowledge to guide professional nursing care practices (generic practices being the way in which a person /culture would care or mange a health problem, it encompasses the beliefs about cause, prevention and how the problem might get better).

These findings support nurses currently working in diverse clinical practice environments in their quest to develop nursing care strategies and have relevance and significance in the practice arena. The findings highlight issues of concern in the clinical arena and support the development of nursing strategies to empower, support and care for clients. These findings support the move away from technical, task orientated nursing role developments. Instead the focus is on incorporating laycare practices into the professional care provided by nurses. Previous studies have proven that the theory is broad enough to incorporate nursing care ideas and specific enough to develop culture specific care (Bohay 2001, Leininger 2001a, Rosenbaum 2001, Stasiak 2001, Wenger 2001). Further comparative studies of care from

diverse cultures and sub-cultures will be essential if nursing knowledge is to advance in order that clients receive culturally congruent personalised care.

2.6.1 Variety of settings in which Culture Care Theory has been utilised in published studies

As previously described in section 2.5.6, and to summarise, in the literature there are many examples of Culture Care Theory being utilised in studies of different cultural groups (i.e. those not defined purely by ethnicity). Gosner explored care needs of a group defined by sexuality (Gosner 2000), whilst Spangler used Culture care Theory in a hospital to identify nurses care concepts (Spangler 2001). Preston utilized the theory to study the fate of health promotion in coronary heart disease families (Preston 1997), whilst Mahoney has applied Culture Care Theory to understand the illness experiences of patients with congestive heart failure (Mahoney 2001). Gates used the theory to understand the perceptions of dying in hospice and hospital (Gates 2001). Miller explored the perceptions of politics and care amongst the Czech Americans (Miller 1997) whilst Finn described the care needs of Euro-American women during childbirth (Finn 1994).

Culture Care Theory has been used in a variety of settings from hospital, hospice, to long term care facilities. It has been applied to cultures defined by race, but also has been equally effective in discerning the care needs of sub cultures defined by sexuality and disease process. The theory has also be used within nursing academia to identify nurses care concepts and theoretical perspectives of care and care giving. It is therefore suggested that Culture Care Theory has utility and can be effectively used in any study setting when the emic care perspective of an individual or group is being explored.

2.7 Rationale for the utilisation of Shaw's Framework for the Study of Coping (1999)

Following a review of the literature, Shaw's (1999) framework for coping, illness behaviour and outcomes was identified as a model which facilitates identification of the determinants of health behaviour and outcomes. As such it was considered an appropriate framework to use to explore the coping and help seeking behaviour of women with PFD.

Chris Shaw is a Research Fellow in the Department of Epidemiology and Public Health, Leicester University, investigating help seeking behaviour in those people with urinary incontinence. Shaw undertook a review of the literature within health psychology to identify models of coping and health behaviour. From this review Shaw developed a theoretical framework to enable researchers to utilise psychosocial variables when investigating help seeking health behaviours (Shaw 1999). The studies undertaken by Shaw utilising this model are discussed in Chapter 4 (Shaw 2006, 2001, 2000).

Shaw's Framework of Coping is not a nursing theory and does not have the depth of literature or previous review and utilisation as does the work of Leininger. This is for the most part due to the relatively recent publication of Shaw's Framework of Coping. Despite this, it has been possible to analyse and evaluate the Framework to establish its appropriateness to be used as a tool for facilitating data collection and organisation of themes.

2.7.1 The importance of the Coping Framework

The Coping Framework is used in this study to aid data collection and organise themes arising from the data as it relates to coping and help seeking. The Coping Framework has been used to investigate the help seeking pathway of women with PFD and validate or refute the Framework in respect of help seeking behaviour in women with PFD. Whilst reviewing the literature on the four coping stages (event, situation, condition and cue) (Chapter 3), I utilised Shaw's framework to ascertain if the coping behaviours identified in the framework included all the potential variables that might be employed by a woman with PFD. Reviewing the data enabled me to draw comparisons between the data available on coping and help seeking behaviour. For each woman experiencing PFD symptoms the coping mechanism at each of these coping stages will differ as a number of variables will impact and interact with her coping mechanisms. It is essential that the four concepts: event, situation, condition and cue are seen as fluid states. A woman may progress through these four stages in a linear fashion, but equally may start her coping and help seeking pathway mid way through these concepts with, for example, condition.

According to Shaw (1999), an event begins with a situation that is influenced by health values, locus of control and the illness itself. This influences appraisal of the situation. What must be taken into account at this juncture is the individual's personality and previous experiences. These, along with impact on quality of life and perceived symptom severity, influence the precise perception of threat and the action a women may take in order to cope with that threat.

2.7.2 The Coping Framework

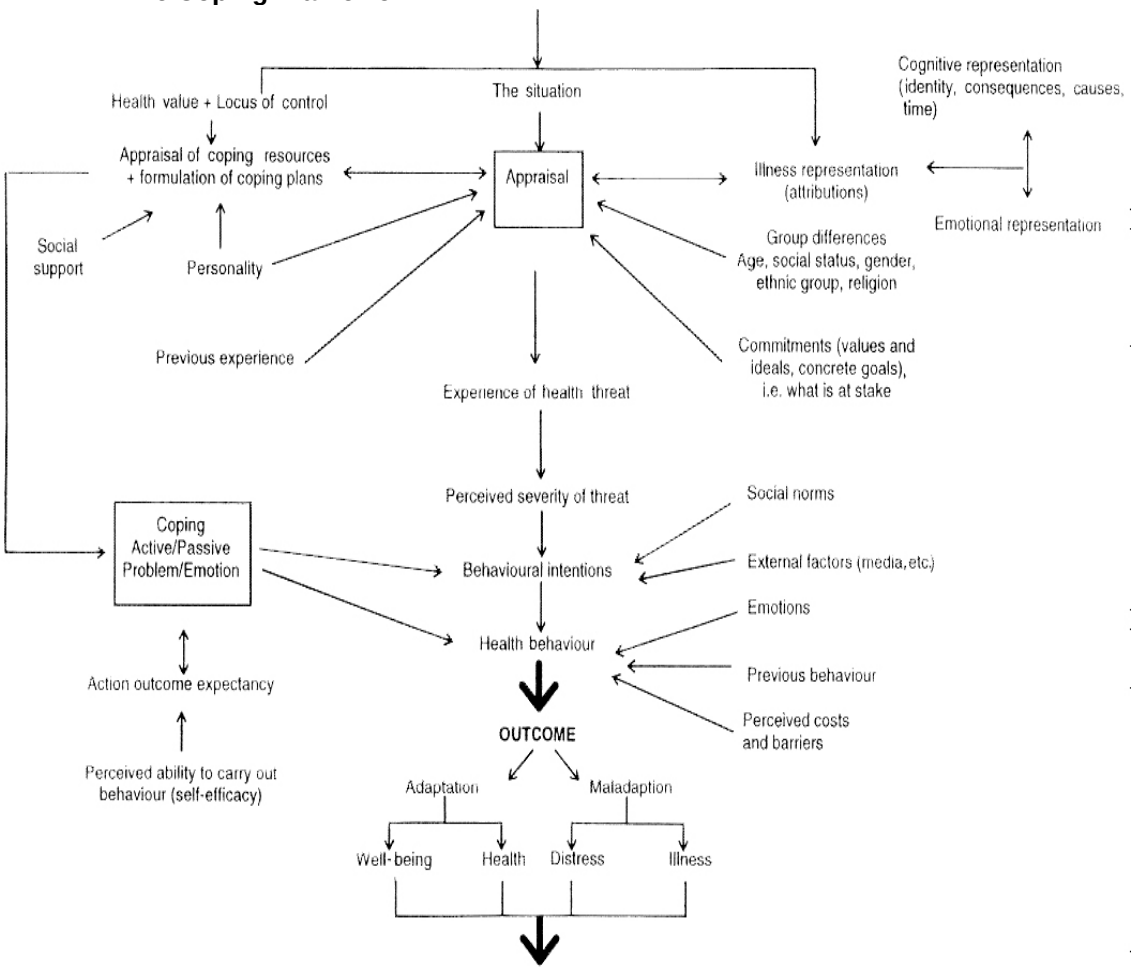

Figure 2.2 Framework for the Study of Coping, Illness Behaviour and Outcomes.
Reproduced from Shaw C (1999) A framework for the study of coping, illness behaviour and outcomes. *Journal of Advanced Nursing* 29: 1246-1255.

2.7.3 Methodology employed to develop the framework

Shaw reviewed a number of health psychology models, primarily the work of Folkman & Lazarus (1985), and identified three main phases which facilitate help seeking behaviour. These are: situation, appraisal and outcome. The work of Folkman & Lazarus and the stages that impact on health behaviour are discussed in Chapter 3. Having identified the main phases of help seeking behaviour, Shaw reviewed the literature on the variables which might impact on an individual's coping or help seeking. Shaw identified that coping styles, personality, health

locus of control, self-efficacy and social support where key barriers or facilitators of help seeking. These variables are discussed in Chapter 3.

2.7.4 Framework assumptions

Shaw (1999) developed a framework for coping, illness behaviour and outcomes, based on models developed in health psychology and views outcomes such as help seeking behaviour as dependent upon both situation and person (personality) variables. Shaw postulates that the framework is dynamic and changes over time subsequent to changes in any of the variables.

2.7.5 Analysis and evaluation of the Coping Framework

The framework has been tested with regard to help seeking behaviour in people with urinary incontinence (Shaw 2001). Shaw indicates that although severity of symptoms was found to be an important factor in predicting help seeking behaviour, illness and coping appraisal are important moderators of help seeking behaviour. Shaw identified that lay beliefs are important barriers to help seeking. The review of the literature, undertaken by Shaw, was limited in that it sought studies that examined associations between any of the variables previously identified by Shaw and stated in the framework.

Shaw (2001) undertook a study to examine why people do or do not seek help for their urinary incontinence. Thirty one people undergoing treatment for urinary incontinence were interviewed by 4 interviewers. Respondents reported two main reasons for seeking help: fear of a serious underlying problem and serious impact on quality of life. Lack of awareness about the condition and treatment options were the most common themes to emerge. It is difficult to apply the findings specifically to women with PFD as little information is given with regard to gender differences other than a statement that attitudes of men and women were very similar. However, it was noted that women were less likely to perceive urinary incontinence symptoms as a disease, whereas men considered urinary symptoms signified a disease process (prostate cancer) and were more likely to seek help. There are limitations to the study as the sample population were individuals who had sought help for their urinary incontinence problems. Consequently a respondent bias is probable. It is acknowledged that all research studies aiming to explore help seeking behaviour in people will have difficulty in accessing the population of non-help seekers and consequently transferability will be limited.

2.8 Summary

The Theory of Culture Care is a grand theory: ethnography is the utilized discipline, whilst ethno-nursing is the method employed to apply the Sunrise Enabler. The Theory of Culture Care Diversity and ethno-nursing has been widely used to explain the identity, meaning and expressions of care and caring in diverse cultures. It is an appropriate theoretical perspective

on which to underpin this study, which aims to understand the emic perspective of women with PFD, specifically in relation to coping and help seeking behaviour. The following premises based on Leininger's Culture Care Theory (Leininger 1988) have been used to guide this study:

- Care is the essence of nursing.
- Women with PFD have developed generic folk care values, beliefs, coping mechanisms and practices that can influence professional cultural care practices.
- Worldview, values, social structure and folk and professional health systems influence healthcare practices.
- Patterns and variability of health practices (or coping amongst women with PFD) need to be understood not only from the context of the women who express them but also from their social structure, worldview and cultural context in order that culturally congruent services can be provided for women with PFD.
- The culture care beliefs of women with PFD will influence women's well being, health status and use of health services.

Shaw's (1999) framework for the study of coping, illness behaviour and outcomes is an interactionist model, based on health psychology models, which facilitate identification of determinants of health behaviour and outcomes. This model has been utilised by Shaw (Shaw 2006, 2001, 2000) to inform studies of people with urinary incontinence (one of the symptoms of PFD). The Framework, alongside the Sunrise Enabler has been used to facilitate explanation and examination of the coping mechanisms and help seeking behaviour in women with PFD.

In the following chapter a review of the literature pertaining to coping and help seeking behaviour is presented. The aim of the literature review is to have an understanding, from previous studies, of the reasons why women with PFD may not seek help earlier and to elicit the coping mechanisms which they employ during this period.

CHAPTER 3: COPING AND HELP SEEKING BEHAVIOUR – A REVIEW OF THE LITERATURE

3.0 Introduction

The purpose of this literature review was to inform the study with regard to the constructs coping mechanisms and help seeking behaviour. A number of studies have demonstrated the negative impact of PFD symptoms (urinary and faecal incontinence, rectal evacuatory dysfunction and pelvic organ prolapse) on quality of life (Davis & Kumar 2003, Luber et al 2001, Norton et al 1998) and yet background evidence and clinical experience suggest that women with PFD do not seek help immediately when their symptoms occur unless they consider them very severe (Davis & Kumar 2003, Shaw 2001). Rather, women appear to cope with one symptom for many years and not seek help until the symptom worsens or an additional symptom develops. Another purpose of this literature review has been to have an understanding, from previous studies and literature, of the reasons why women with PFD do not seek help earlier in their symptomatology, to understand the coping mechanisms employed by women and the factors that impact on their coping mechanisms. Coping and help seeking are not opposites of a spectrum of constructs, but are the two constructs that are explored in this study with respect to women with PFD. The literature describes an individual woman's coping mechanisms as linked to, and part of, the help seeing pathway. The evidence from the literature predominantly pertains to coping and help seeking behaviour in women with urinary incontinence or general constructs with regard to coping with chronic illness and gender difference. There is an absence of data with regard to these constructs and variables in relation to women with PFD.

As is common in qualitative methodology, this literature review is a focused survey of the literature on the topic of coping and help seeking behavior. It is neither a systematic review nor a meta analysis. These methods, common in quantitative research, assess the quality of research according to pre-defined criteria and often exclude studies that do not match those criteria. Effective in reviewing randomized controlled trials and assigning statistical values to the analysis, a meta analysis is inappropriate in ethnographic research methods. In ethnographic methods (Lincoln & Guba 1985 p551-553), a literature review of the topic is considered to be the way in which the researcher 'becomes thoroughly acquainted' with the study constructs. Leininger (1990, 1995) describes the use of *a priori* fixed judgments of constructs under investigation to be contrary to the naturalistic, open discovery and inductively derived emic modes and processes of Culture Care Theory. Therefore, a literature review, prior to the research process, is designed to inform the researcher with regard to the constructs (coping mechanisms and help seeking behaviour) under emic enquiry. This is not unlike other qualitative research methods (Strauss & Corbin 1990) where a review of the literature is not undertaken prior to the study so as not to influence the work with *a priori* judgements.

3.1 Literature Search Strategy

The literature search involved both computerised and hand searching. The databases used were: Applied Social Sciences Index and Abstracts (ASSIA), The Database of Expercta Medica (Embase), Psychology Information (PSYC Info) and Cumulative Index to Nursing and Allied Health (CINAHL), Ovid for Nursing, AMED, Psychology and Behavioral Sciences Collection (ASSIA entered April 2005, CINALH 1982 to April week 2 2005, EMBASE (1996 to 2005 week 15, PSYC INFO 1985 to April week 2 2005). These were chosen as the most appropriate in relation to the topic area and were accessed via OVID, Ebcohost and Pubmed platforms. The keywords used to perform the database search were: help-seeking, help seeking, coping, wom$, psychometric$, tests, instruments, social support, ethnicity and quality of life. The above databases were searched using these keywords as a free text search. The literature review was not intended to be exhaustive, but was undertaken to identify the key and seminal published work pertaining to coping and help seeking behaviour. These key works are discussed in the review which follows.

3.1.1 Findings

A number of themes emerged when analysing the findings of the literature review. Coping mechanisms emerged from the literature and variations in definition have been described. Health related responses have been shown to be triggered by certain events termed event, situation, condition and cue. Primary (event, situation) and secondary (condition, cue) appraisal have been employed as the framework for presenting the themes which were explained in the review with respect to coping and help seeking behaviour. Themes relating to help seeking behaviour included: beliefs about illness, cognitive processes, health beliefs, Locus of Control, emotional processes, group differences, socio-economic factors, perceived severity of illness, raised awareness, knowledge, emotions, social support and coping behaviours. Finally it has been possible to delineate from the literature the barriers and facilitators of help seeking.

3.2 Pelvic Floor Dysfunction as a Stressor

Stress is generally viewed as a set of neurological and physiological reactions that serve as an adaptive or coping function, but few individuals define the concept of stress in the same way or identify the same life experiences as stressful (Selye 1982). A stressor is a psychosocial stimulus that is either physiologically or emotionally threatening with most common stressors represented within four broad categories: personal, social/family, work and the environment (Bernard & Krupat 1994). Prior to discussing the evidence from the literature with regard to coping mechanisms and help seeking behaviour it is necessary to identify how PFD might be identified by women as a stressor.

The literature describes a stressor as a phenomenon that precipitates a series of responses in an individual (Miller 2000, Rahe et al 1964). Stressors can be any environmental, social or

internal demand that requires the individual to readjust their usual behaviour patterns. The development of PFD symptoms would be likely to cause both social and internal demands on women.

Stress is a complex phenomenon during which an individual undertakes a series of thoughts in which they assess the potential threat and harm of the stress. The individual will then experience a number of stress emotions and coping responses prior to re-assessing the stressor (Lazarus and Folkman 1984). Resources or coping mechanisms are the social and personal characteristics upon which an individual may draw when coping with stress. These subjective stress phenomena may include such stressors as the threat of loss of body functions, personal relationships, body image or the threat of injury and/or pain. A woman with PFD symptoms will undergo a cognitive process in which she assesses whether these symptoms pose a threat to her well-being and quality of life.

Stressors can be classified as dimensions such as controllable versus uncontrollable, expected versus unexpected, chronic versus acute and positive versus negative. Within this theoretical paradigm of transactional theory, it is possible to identify that for some women PFD is an expected stressor that is perceived as a chronic stress that is controllable. Conversely for others it may be an unexpected stressor that occurs acutely and is uncontrollable.

From the perspective of transactional theorists (psychologists who use relational models to describe meanings constructed in communication or action), stressors are identified by the individual's response to the stressor. Lazarus & Folkman (1984) addressed the constructs of coping by developing a cognitive paradigm of stress and coping. This transactional model delineates the relationship between the individual and the environment as dynamic and reciprocal with different coping strategies being employed according to the context of the stressor. Cognitive appraisal of the stress is a two part process with primary appraisal identifying that the event is stressfull and a potential threat. Secondary appraisal occurs once the stress has been determined as a threat, and during this phase the individual evaluates their coping resources and options (Lazarus & Folkman 1984). It can be postulated that PFD only causes stress in a woman if she appraises it as relevant to her well-being and in order for a woman to view PFD as a stressor it must be personally relevant and there must be a perceived mismatch between the woman's ability to cope with PFD whilst continuing with her life situation.

3.2.1 The impact of PFD on Quality of life

PFD is not life threatening but it can significantly interfere with daily life and consequently influence perceptions of quality of life. PFD can be defined as a stressor which can impact on

the quality of life of a woman (Bernard & Krupat 1994). The degree of impact on quality of life depends on whether the individual woman perceives PFD as a problem and the coping mechanisms she employs to deal with the problem. For example, for some women PFD is an expected stressor that is perceived as a controllable chronic stress. Conversely for others it may be an unexpected stressor that occurs acutely and is uncontrollable. It can be postulated that PFD only causes stress in a woman if she appraises it as relevant to her well-being and that in order for a woman to view PFD as a stressor it must be personally relevant. There must be a perceived mismatch between the woman's ability to cope with PFD and continuing with her life situation. If a woman perceives that she has a high quality of life and is happy with the way things are, the woman is less likely to recognise that she has a health problem since it is not perceived to affect every day life (Shaw 2001). Increased severity in incontinence (urinary and/or facecal) has been found to be a significant predictor of impact on QoL (Huang et al, Monz 2007, Gasquet 2006, Yu et al 2003).

Until recently quality of life outcomes have been measured using generalized health related quality of life instruments such as the Medical Outcomes Survey Short Form 36 and the Sickness Impact profile (Hunskaar & Vinsnes 1991, Wyman et al 1987). These generalized instruments allow comparisons across groups but lack sensitivity to the unique aspects of PFD and how it affects women's lives. Condition specific QoL measures have been developed for female lower urinary tract disorders and faecal incontinence. These condition specific instruments demonstrate higher face validity and more in-depth assessment of condition specific issues (Rockwood et al 2000, Jackson et al 1996, Lee et al 1995, Shumaker et al 1994). The majority of evidence from the literature relates to either QoL outcomes measured using generalized QoL tools or those designed specifically for urinary or faecal incontinence. Given the frequent coexistence and complex interaction of pelvic floor disorders, a comprehensive condition-specific QoL instrument is needed to assess the impact on a patient's quality of life from all aspects of PFD (urinary and faecal incontinence, prolapse, sexual dysfunction and obstructed defaecation). Until the work of Barber et al (2001), no condition specific instrument was available to measure QoL in women with PFD; consequently there is little specific QoL evidence in women with PFD. The PDF specific QoL instrument was designed to assess life impact and symptom distress in women with PFD. Given the comprehensive nature of this instrument it took over 30 minutes to administer, making it impractical for use in many busy clinical areas. Consequently a short form version has been developed and validated for use in the clinical setting (Barber et al 2005). In the literature a number of studies have demonstrated the negative impact of PFD symptoms on quality of life (Davis & Kumar 2003, Luber et al 2001, Watson et al 2000, Bump & Norton 1998, Brown et al 1998, Grimby et al 1993, Macaulay et al 1991).

The majority of evidence with regard to impact on quality of life relates to specific symptoms such as urinary incontinence, and not PFD in its entirety. The quality of life of women with urinary incontinence is significantly lower than for women with no urine loss (Huang et al, Monz 2007, Gasquet 2006, Yu et al 2003). Women with urinary incontinence report more physical discomfort, more worries about their health, are more hindered in their social activities, and more restricted in their daily activities (Vandoninck et al 2004). These findings are replicated in other studies which have identified that women suffering from urinary incontinence have an impaired quality of life (Monz 2007, Gasquet 2006, Grimby et al 1993), poorer life satisfaction (Herzog et al 1988), poorer health status (Roe & Doll 2000) and more depression and anxiety (Valvanne et al 1996) than those who are continent. The severity of symptoms appears to impact considerably on quality of life measures, with more severe symptoms causing greater restriction on social activities (Lam et al 1992, Lagro-Janssen et al 1990). Loss of self esteem, social isolation, curtailment of aspects of social activity, occupation and role difficulties and depression are all reported as key impacts on psychological and quality of life measures in faecal and urinary incontinence (Goldstein et al 1992).

3.2.2 The stigma, embarrassment and feelings of disgrace associated with PFD

The literature provides evidence to support significant under-reporting of symptoms such as faecal and urinary incontinence (Shaw et al 2006, Hunskaar et al 2004, Shaw et al 2001, Johanson et al 1999, Lafferty 1996). Commonly cited in these studies is the fact that women felt that they could not or did not want to talk about their problem with a health professional due to the embarrassment they felt about having incontinence (Wilson 2007, Roe et al 1999, Reymert & Hunskaar 1994). It can be speculated that fear of reproach or disgrace might prevent a women from raising the subject with a health professional, if a women perceives that her PFD symptoms might be a cause for shame or disgrace it is probable that she will choose to mask these symptoms rather than risk disgrace. Embarrassment, depression, frustration and feelings of disgrace (da Silva et al 2009, Gasquet 2006, Monz et al 2006, Horrocks et al 2004, Oh & Park 2004, Mason et al 2001, Roe et al 1999, Goldstein et al 1992) are associated with urinary and faecal incontinence symptoms. Embarrassment alone accounts for between 11 and 47% of women with urinary incontinence not seeking help (Goldstein et al 1992, Norton et al 1998). Embarrassment often stems from women finding it difficult to know what the correct terminology or language is to use to describe their symptoms (Brittain et al 2001). Faecal or urinary incontinence, the lack of control over bodily functions taught as a child, is seen as a taboo subject and a socially unacceptable topic of conversation (Ashworth & Hagan 1993). The subject is avoided not only with health care professionals but family and friends as well, possibly because of the fear of disgrace or shame that might follow from such a disclosure. It is postulated that it is the fear of shame or disgrace, rather than an actual negative response (opprobrium appropriation) which is a negative trigger or barrier to help seeking for many women.

Nevertheless written or verbal information and direct questioning from the health care professional can enable women to talk about what they considered to be an embarrassing or shameful problem. In a study undertaken by Mason et al (2001) women suggested that health professionals should enquire about incontinence type problems as a matter of routine at each consultation, as if asked directly, the sufferers felt they would respond as permission had been given to discuss what they had perceived to be a taboo subject.

Despite the variation in theoretical paradigms evident amongst stress theorists, it has been possible to clearly identify PFD as a stressor which impacts on QoL and is associated with stigma. However, it is evident that there is no standard way of coping that is uniformly effective in dealing with different stressors and therefore, however defined, the coping mechanisms employed when managing stress need to be extrapolated from the literature.

3.3 Coping mechanisms

There are varied clinical and research traditions related to coping; each having a slightly different emphasis with as yet no agreed-upon classification of coping behaviours. Psychologists view coping as a personality based emotional and behavioural mode of responding, whereas social-psychologists would view coping as a context specific behavioural and emotional process (Miller 2000). For example: Folkman & Lazarus (1980) distinguish 'problem-focused' from 'emotional-focused' coping, whilst Jalowiec (Miller 2000) identifies confrontive, emotive and palliative coping behaviours.

Despite the large number of papers addressing coping theory, there appears to be little coherence in theory or understanding, with confusion as to what is meant by coping and coping impact on the process of adaptation. Focusing specifically on illness, coping is defined as the cognitive and motor activities a sick person uses to preserve bodily function, with coping strategies being the specific techniques that an ill person selects to deal with an illness and its consequences (Lipowski 1970). Women have been found to use more strategies than men in all coping dimensions in order to minimise the impact of disease (Bogg et al 2000, Sutherland & Jensen 2000, Barker et al 1990). In a study by Barker et al (1990) data were collected within one of the regular surveys conducted by the Broadcasting Research Department of the BBC. A large national sample of the UK adult population was surveyed to find out how informants would cope and whom they would turn to for help if they experienced psychological problems. From the study paper it is not possible to identify how the sample was derived but it is reported that a quota sampling procedure was used to ensure representativeness. Face to face interviews were carried out with over 1000 informants. The most highly favoured coping methods were two cognitive strategies: try not to worry and think about ways of overcoming the problem; and two behavioural strategies: keep busy and watch television. There were gender differences in coping methods with women employing coping strategies such as keeping busy, praying,

drinking more tea and coffee and eating more, whilst men coped by taking exercise and drinking alcohol. Differences in help seeking, with women turning to relatives and friends may reflect women's greater intimacy with those outside the home and the workplace. The findings on help seeking behaviour identify the need for directing research and resources beyond traditional clinical interventions, as most people bring their problems to informal rather than professional helpers. Kinchen et al (2003) suggest research is needed into the structure, function and chronological unfolding of informal helping. This premise is supported by the work of Leininger (2001a, 1990, 1985a, 1978) which stresses the importance of understanding and incorporating the lay care beliefs of practices of an individual if culturally competent care is to be offered.

It is suggested that stress and health-related responses are triggered by certain events that are termed: event, situation, condition and cue (Shaw 2001). Lazarus & Folkman (1984) classify these events as primary and secondary appraisal. In primary appraisal both event and situation are included as the individual assesses the event and situation to see if they are a threat. Once this appraisal has taken place secondary appraisal of the condition and cue takes place where the individual identifies actions that can be taken. Lazarus & Folkman (1984) define eight coping strategies which individuals employ in stressful situations: confrontation, seeking social support, planned problem solving, self control, accepting responsibility, distancing, positive re-appraisal, and avoidance. These coping strategies are further divided into two: the emotion focused strategy, and the problem solving strategy. Studies have shown that emotion focused strategies tend to be used in situations where the individual has little control such as when experiencing health problems (Lazarus & Folkman 1984). Folkman & Lazarus (1985) indicate that each strategy has its own merits and neither coping strategy is superior. This view is contested by some psychologists who postulate that emotion coping strategies are not as efficient as problem solving ones, as individuals may use avoidance to 'not deal' with the stressor and consequently may suffer ill health problems (Sorlie & Sexton 2001, Holahan & Moos 1987). Given the lack of data there is speculation as to the exact role that opprobrium, shame, disgrace, reproach or imputation (of shameful conduct) plays in the development of emotional coping strategies such as avoidance and masking and the negative impact these might have on help seeking in women with PFD.

Primary and secondary appraisal have been used as a framework to guide this literature review as they mirror a woman's pathway from recognising a health problem arising from PFD to seeking help.

3.3.1 Primary Appraisal – Event

An unexpected event such as an episode of faecal or urinary incontinence or a realisation that something has changed such as the symptoms getting worse, may trigger women with PFD to

recognise that something is not right. This initial trigger event may lead to the woman asking 'Do I have a health problem?' Before being able to answer this question, the women go through a complex process of cognitive appraisal about their wellbeing (Lazarus and Folkman 1984), with this primary appraisal leading to a decision about whether indeed PFD is a threat or is challenging to their well-being.

Shaw (1999) identified that at each of the four coping phases (event, situation, condition and cue) variables can occur. The literature confirms that at this initial 'trigger' phase, beliefs about the illness, cognitive processes, health beliefs and locus of control, emotional processes, group differences and socioeconomic factors are variables which impact on the woman's appraisal of this trigger event. The event, such as an episode of urinary incontinence may only occur once, or may occur on a number of occasions prior to the woman considering that there is something wrong.

3.3.1.1 Beliefs about the illness

PFD and the symptoms it may cause are viewed by some women as inevitable and normal after having children (Swanson et al 2005, Facione et al 2000), in which taboos and shame (Okojie 1994) regarding disease or certain parts of the body may hinder the realisation of a health problem and cause social isolation (Godfrey & Hogg 2007). Furthermore the understanding of the causes of the problem (Porrett & Cox 2008, Horrocks et al 2004, O'Neill & Morrow 2001, Shaw 1999), whether the illness is curable (Oh and Park 2004, Facione et al 2000) and misperceptions about the consequence of delay (O'Donnell et al 2005, Facione et al 2000) have been identified as impacting on a woman's perception of illness.

3.3.1.2 Cognitive processes

Cognitive processes are needed to perceive a health threat (Shaw 2001, 1999).The four factors involved in the cognitive process are: identity, consequences, causes and time line. A woman experiencing PFD symptoms will at first identify the symptom. The knowledge or lack of knowledge about consequences of the illness will have an impact on her perception of the problem and consequent response (Shaw 2001). Attitudes toward health ('this is probably nothing because I have never been sick in my life') or ageing ('this is what happens when you get older') (Moos et al 2006, O'Donnell et al 2005, Horrocks et al 2004, Brittain et al 2001, Mason et al 2001, Shaw 2001) may also affect the woman's illness representation. Some women perceive PFD is normal and to be expected after having children (Mitteness 1990). Mitteness (1990) considers that laypeople have vague understandings of the causes and parameters of incontinence and that there is consistent evidence that elderly people often consider urinary incontinence to be an inevitable part of the normal ageing process. Linking incontinence and normal ageing may protect the self esteem of the sufferer. Horrocks et al (2004) undertook a qualitative inquiry on a small sample of informants who had identified

themselves as suffering from urinary incontinence in a previous General Practitioner postal survey which had investigated the prevalence of urinary incontinence in older people. Interviewees had reported urinary incontinence and had volunteered for interview. The study identified that informants' responses to their incontinence seemed to be closely associated with their attitude about ageing. The informants normalised their urinary incontinence symptoms as a consequence of ageing and most accepted the daily restrictions of urinary incontinence as an inevitable fact of ageing. The authors suggest that health care professionals contributed to older peoples' reduced help seeking for incontinence symptoms by their own attitudes to, and simplified explanations of, the cause of urinary incontinence. The importance of this paper should not be underestimated with respect to help seeking in the elderly as it targeted informants who had urinary incontinence but did not seek help for the problem, however caution needs to be considered when reflecting on the transferability of the findings as these informants chose to volunteer for interview. The views of those elderly informants who have urinary incontinence but did not seek help, nor volunteered for interview, are unknown and may differ from the informant population. The data are reported as a whole and no gender specific observations are made, reducing the study's ability to inform issues pertaining specifically to women and their attitudes to ageing and help seeking behaviour. A prolonged condition, such as longstanding mild stress urinary incontinence may become a normalised condition and therefore not perceived as a serious problem (Swanson et al 2005, Currie & Wiesenberg 2003).

3.3.1.3 Health beliefs and Locus of Control

The concept of Locus of Control Reinforcement was developed by Julian Rotter in the 1960s, and is considered an important aspect of personality in psychology (Rotter 1966). Locus of control refers to an individual's perception of the main causes of events in life, as determined by their own behaviour vs. fate, luck, or external circumstances. Locus of control can be understood as a bipolar construct, ranging from external causes to internal causes:

- External locus of control: the woman believes that her behaviour is guided by fate, luck or other external circumstances.
- Internal locus of control: the woman believes that her behaviour is guided by her personal decisions and efforts.

Rotter's concept of Locus of Control has been utilised in nursing research to explore the association between locus of control and help seeking behaviour. However, findings identified that locus of control may not be a useful predictor of help seeking behaviour in specific health or disease situations (Ruiz-Bueno 2000). Consequently the theory was expanded to include health outcomes (Wallston & Wallston 1981). The Health Belief Model postulates that in order for individuals to undertake disease prevention measures they must believe that the disease may have a serious impact on their life and that taking actions will be successful to avoid them (Holm et al 1999, Wallston 1992). A woman's readiness to take action is related to concepts such as

controllability, susceptibility, causability, seriousness (Currie & Wiesenberg 2003), family health history and general health (Porrett & Cox 2008, Brittain et al 2001).

Health beliefs together with personality attributes (Porrett & Cox 2008, Oh & Park 2004, Shaw 2001) and social support have been identified to impact on the recognition of a health threat. An individual may ask herself: Can I cope or how will I cope? Personality attributes influence decision-making style (Facione et al 2000). A view of fatalism, as opposed to optimism (Facione et al 2000), and philosophies about altruism/opportunism and a cultural heritage (Brittain et al 2001) will impact on the individual's recognition of the health threat and their ability to manage the problem, with women either expecting that health outcomes are the result of their own actions (internal locus of control) or the actions of others (external locus of control) (Holm 1999).

Women differ greatly in the extent to which they seek and utilise information. It is perceived that seeking information is one step in a chain of behaviours that ultimately might lead to the woman seeking help (Wallston & Wallston 1981). In the context of locus of control a woman will seek information about PFD if she values the outcome (health) and believes that her behaviour will influence her health (Horrocks et al 2004, Currie & Wiesenberg 2003, Henly et al 2003, Brittain et al 2001, Facione et al 2000, Goldstein et al 1992).

3.3.1.4 Emotional processes

From the literature it is evident that emotional representation is an important factor in recognising a health problem. If a woman perceives that she has a high quality of life and she is happy with the way things are, she is less likely to recognise that she has a health problem since it is not perceived to affect every day life (Shaw 2001).

3.3.1.5 Group differences and Socio-Economic factors

Age, social status, gender, ethnicity, family dynamics and religion may impact on recognition of a health problem and seeking help. For example, it is a common belief that urinary incontinence is a normal condition in older women (Lefler & Bondy 2004, Mason et al 2001, Facione et al 2000, Herzog & Fultz 1990). This belief has been connected to a lack of information (Brittain et al 2000, Goldstein et al 1992) about the condition, leading to an inability to react to symptoms (Horrocks et al 2004). In addition there is a historical view of women taking aches and pains for granted (Currie & Wiesenberg 2003), which may explain why some women do not recognise a health problem. In a review of the literature O'Neill & Morrow (2001) examined studies published between 1990-1999 which addressed women with chronic health problems in which symptom perception was evaluated. Thirty two papers met the inclusion criteria and the analysis identified gender differences. O'Neil & Morrow describe five constructs which emerged: physical functioning, coping, self care, roles and relationships and socio-cultural issues. Women

described a lack of knowledge of symptoms which meant they were unaware of what was happening, and consequently based their perception of the severity of the problem on whether they could carry on with their daily roles and responsibilities. The review also identified that there were detrimental effects of poverty on women's health and that lack of money negatively influences symptom response. Of the 32 studies reviewed most samples predominantly included middle class Caucasian women over 50 years, and the data were retrospective; studies were for the most part descriptive, and the wide variety of measurement tools used made comparisons difficult. Caution is required in interpreting the general application of the five constructs proposed by O'Neill & Morrow but the review is a useful tool to frame thinking on gender specific issues surrounding coping and help seeking behaviour in women.

Van Wijk & Kolk (1997) undertook a literature review on the biopsychological explanation of physical symptoms. They identified that evidence for women's higher rates of physical symptoms were derived from three different research bodies: health surveys, studies on symptom reporting and registration of health complaints by doctors. Uniformly, a female excess of physical symptoms was identified but it is stressed that all these studies took place on healthy men and women. In illness the converse is true with men more likely to over-report clinical symptoms (van Wijk & Kolk 1997, Macintyre 1993). This difference is important, and may impact on help seeking behaviour.

Ethnic and minority racial groups in the UK have traditionally been less successful in gaining access to health care than the indigenous population; further, some of their needs have been neglected (Lanceley & Cox 2007, Hopkins & Bahl 1993). The 'Black Report' published in 1980 highlighted inequalities in health between different social classes (Whitehead 1992). Since the 'Black Report' there have been a number of reports on the relationship between gender, age, race, unemployment and inequalities in health (Oppenheim & Harker 1996). The report suggests that: addressing social and economic factors; reducing barriers to the adoption of healthier ways of living; improving the physical environment; and improving access to appropriate, effective health and social services will reduce inequalities. There is an increasing cultural diversity and range of ethnic backgrounds of individuals accessing health care in the UK (OnLine Public Access Catalogue 2003, OnLine Public Access Catalogue 1992). There has been a strong link made between ethnic background and social class, with studies identifying difficulties in the accessing of healthcare for non-English speaking ethnic groups. (Lancley & Cox 2007, Cancer BACUP 2004, Lazenbatt et al 2001, Twinn 1997, Spector 1996, Benzeval et al 1995, Anderson et al 1991).

Low educational levels (Lefler & Bondy 2004, Facione et al 2000), low income (Kelley et al 2006, Lefler & Bondy 2004, Facione et al 2000,) and living alone (Lefler & Bondy 2004) are

associated with delays in seeking help. Link & Phelan (2002, 1996) maintain that a person's health is as much a product of education, financial resources and social status as it is genetic make-up and exposure to disease.

In summary, event is the first step towards realisation of a health problem. There are many factors that influence a woman's perception of the event. If the trigger event is not identified as a problem the woman will continue with her lifestyle and will take no further action. The trigger event may occur on a number of occasions before it is identified as a problem. Once the woman is able to articulate the question 'Do I have a health problem' she will be able to proceed to the next sub concept, situation. Once this occurs primary appraisal of the situation is undertaken. At this primary appraisal stage numerous variables impact on the process of threat appraisal and consequent recognition of the health problem including, beliefs about illness, emotional processes, cognitive processes, health beliefs, locus of control, personality attributes, social support, group differences and socioeconomic factors.

3.3.2 Primary Appraisal - Situation

Primary appraisal of the situation happens when a woman has perceived that an event or trigger means that she may have a health problem. Primary appraisal is a term used in transaction-theory (Lazarus & Folkman 1984), with a PFD stressor being the result of a transaction between a woman and her environment. Primary appraisal is the consideration of the possible effects of PFD on wellbeing and an assessment of available resources to deal with the situation. If the demands of the situation are greater than the resources available, the woman may assess that PFD is a potential or actual threat.

At this appraisal stage the severity of the condition has a major effect on the woman's perception as a health problem (Shaw et al 2006, Reymert & Hunskaar 1994, Jolleys 1988). For example in urinary incontinence, the severity of the condition depends on the frequency and amount of leakage, and need and use of aids (Burgio et al 1994). If the problem is perceived by the woman as a medical problem, the woman is more likely to take action (Shaw 2006, 1999).

3.3.2.1 Perceived severity of illness

A health threat comprises symptom appraisal and the expected effect of the condition on the woman's health. In symptom appraisal the woman may not perceive the health problem if it has continued for a long time and therefore feels it has become a normalised situation (Henly et al 2003). Furthermore women may not have the knowledge to recognise their symptoms (Facione et al 2000). In a qualitative survey using semi-structured interviews in women with urinary incontinence, Mason et al (2001) identified lack of knowledge as a barrier to seeking help with many informants identifying the need for information, feeling that written information and

advertising of problems in clinics gave them permission to ask and seek help. The study identified that 62% of the women had received no information about stress urinary incontinence during pregnancy or following delivery. Women suggested that the health professional should inquire about incontinence type problems as a matter of routine at each consultation. Women felt that if they were asked directly about continence issues they would respond but if asked a general question about whether they were fine, would not raise the issue themselves. The asking of a direct question by a healthcare professional was perceived by women as giving them permission to talk about the problem (Porrett & Cox 2008). This study highlights clear information needs and clarifies the importance of the role of the health care professional in facilitating help seeking. It is postulated here that for some women the perceived shame or disgrace associated with PFD symptoms may be a greater perceived threat to their well being than the PFD symptom itself and as a consequence help is not sought.

As discussed previously, women perceive that PFD symptoms are normal following childbirth (da Silva et al 2009, Azuma et al 2008, Teunissen et al 2005, Margalith et al 2003, Goldstein et al 1992, Holst & Wilson 1988, Jolleys 1988). In addition, some women may have a fear of surgery and medical intervention and therefore hope that the symptoms will improve on their own (Norton et al 1998, Goldstein et al 1992). Social determinants such as whether symptoms have an impact on leisure, social activities or on other people may affect symptom appraisal processes (Kinchen et al 2003, Shaw 2001). Kinchen et al (2003) undertook a two-stage survey of adult US women. In Phase one, 45,000 households received a questionnaire to identify women with incontinence, with a 66% response rate. The second phase of the study involved a stratified random sample of the previously identified incontinent women, of whom 2310 received a detailed questionnaire from which there was an 85% response rate. A total of 38% of informants had initiated a conversation with a health care professional about incontinence. A multivariate logistic regression analysis identified factors associated with help seeking. Having symptoms for longer than 3 years, having a history of noticeable accidents, and worse disease-specific quality of life scores were found to be significant. Symptom severity is known to be associated with help seeking (Burgio et al 1994); however Kinchen et al identified that although severity is important, help seeking could not be explained by this alone. The proportion of women who discussed incontinence with a health care professional increased as the impact on quality of life increased. Kinchen et al (2003) concluded that women reported urinary incontinence due to concerns that incontinence was not normal and could get worse signifying a more serious condition. This study does have a number of limitations, the major being that there may have been a nonresponse bias in the first questionnaire and that this would limit the generalisability of findings. The study is cross-sectional and therefore cannot show a cause and effect relationship between various factors and help seeking, but associations are clearly demonstrated. It is thus reasonable to suggest that educating both health care professionals and the public about the factors associated with help seeking as well as the available treatment options may aid women seeking help.

3.3.2.2 Raised Awareness

Some women with PFD may have built up an understanding about the condition through the media (Horrocks et al 2004, Brittain et al 2001), relatives, peers or health care professionals in order to make a decision about whether to seek help, treatment or further advice. Mason et al (2001) reviewed 112 (54 men, 58 women) patients who had been identified from a Local Authority patient register as having urinary incontinence. These patients were receiving treatment at a nurse led continence service and as part of their assessment were asked five open ended questions relating to help seeking triggers. The most frequently cited trigger was raised awareness. The study does not describe how patients came to be aware of service or treatment options but suggests that health promotion campaigns could be effective in raising awareness. The study findings were reported as a whole but comparisons were made between men and women, and overall there were few marked differences. Women however reported more personal triggers for seeking help such as emotions and hygiene, rather than raised awareness triggers. Consequently health promotion and raised awareness may not be as important in women in promoting help seeking behaviour as it is in men. As with many other studies, this addresses patients who have sought help; therefore the views of those currently not seeking help are unknown. In addition, the study was investigating triggers in those patients experiencing urinary incontinence only, and therefore does not address the triggers for help seeking in women with multiple symptomatology. In general a lack of knowledge of health services available impacts negatively on help seeking (Twinn 1997, Benzeval et al 1995). The literature has not demonstrated any evidence of health promotion activities related to Pelvic Floor Dysfunction and is thus silent with respect of the efficacy of raising public awareness of PFD services in relation to help seeking behaviour.

3.3.3 Secondary Appraisal - Condition

Secondary appraisal takes place when a woman has identified that a problem exists and has assessed that the problem poses a potential or actual risk. Secondary appraisal is the process of asking 'What can I do about this situation?' (Lazarus et al 1985, Lazarus 1966). In this process the woman undertakes an appraisal of her coping resources and formulates a coping plan. The literature suggests that a woman's intentions and behaviour have a major impact on the decisions they make about what to do. A woman may consider and weigh up a range of support mechanisms in order to look for answers to questions such as, can I cope and/or how will I cope?

Prior commitments, values and goals such as what is at stake if help is not sought may influence a woman's decision to seek help (Shaw 2001). Traditional gender role patterns and gender responsibilities may influence coping and a delay in help seeking (Kristofferzon et al 2003). In a meta-analysis of the literature on coping and gender differences relating to myocardial infarction, Kristofferzon (2003) and colleagues reviewed 41 articles and concluded that women used more coping strategies than men and tended to minimise the impact of the

disease, delayed seeking help and did not wish to bother others with their health problems. Kristofferzon et al (2003) concluded that traditional gender roles may influence the recovery of patients who have experienced myocardial infarction, and that care-givers needed to be more sensitive to gender specific needs with regard to social roles and the patient's own role identity. There was no consensus on the measurement of coping and social support and this limits generalisation of the findings. Given this limitation, all studies identified differences in coping between men and women which supports the suggestion that gender specific health promotion and gender specific support programmes be considered valuable when considering PFD services. It is also recognised that cultural heritage (Lefler & Bondy 2004, Shaw 2001, Hunskaar 2000), extreme modesty in physical examination (Facione et al 2000), attitudes toward the female body (Berman et al 2003, Currie & Wiesenberg 2003) and religious beliefs influence help seeking and coping.

3.3.3.1 Emotions

The literature provides evidence to support the embarrassment that women with symptoms such as urinary incontinence feel, and the depression, frustration and distress this causes (Horrocks et al 2004, Oh & Park 2004, Mason et al 2001, Watson et al 2000, Roe et al 1999, Goldstein et al 1992). The referenced research above indicates that a proportion of women felt they could not or did not want to talk about their condition with a health professional, mainly due to the embarrassment and shame they felt about having the problem. It is reasonable to expect that such feelings may have a negative effect on help seeking behaviour. In addition, perceived confidence in doctors and the treatments available may also influence decision making (Holst & Wilson 1988, Jolleys 1988).

3.3.3.2 Social Support

Social support is closely related to coping and is often seen as a coping resource (Schereurs and de Ridder 1997, Broadhead et al 1983). Research indicates that family dynamics have a major contribution toward help seeking behaviour (Facione et al 2000). Furthermore spouses, significant others, children, friends and health care professionals are most frequently mentioned as a main source of social support (Shaw 1999, Broadhead et al 1983). However it is also acknowledged that spouses or significant others may not always provide a positive support system, for example due to alcohol abuse, or that they may provide victimising support, or no support at all (Schereurs & de Ridder 1997). Equally there may be a difference between actual and perceived social support.

3.3.4 Coping behaviour

Coping behaviour seeks to manage or alter the source of stress (problem focused coping) or to regulate the emotional response (emotion focused coping) (Lazarus et al 1985). The coping mechanisms employed by a woman will change over time; once she has coped with the initial trigger event and situation a reappraisal of the situation is undertaken. During reappraisal her

feelings about the situation are reviewed and new coping strategies developed (Lazarus & Folkman 1984). Some women will attempt to 'normalise' their condition; this negatively impacts on help seeking behavior (Gulec 2008). Maladaptive coping can adversely affect both physical and emotional health. Denial, anger, minimisation and avoidance (Kristofferzon et al 2003, Pikler & Winterow 2003) can be perceived as maladaptive coping mechanisms and these strategies are associated with poorer outcomes (Moos et al 2006, McCrae & Costa 1986). Humour, acceptance and self-efficacy (Pikler & Winterow 2003) engender the use of rational action and positive thinking, and are strategies that are associated with better outcomes (McCrae & Costa 1986).

3.3.5 Secondary Appraisal - Cue

At this stage women are in a position to decide to seek help or to self treat the PFD symptom. If the intention is to seek help, the woman may not actually carry out this behaviour. This intention behaviour gap is well documented and believed to occur because individuals carry out a cost-benefit analysis in relation to carrying out the behaviour (Oh & Park 2004, Becker 1974). The behavioural intention to seek help may not translate into actual behaviour if the perceived benefits are outweighed by the costs or other barriers to seeking help, such as the perceived risk of shame or disgrace. At this point the woman undertakes a re-appraisal process and may await a further trigger event prior to beginning this coping process again.

3.3.5.1 Barriers to help seeking

Literature reflects that women with chronic illnesses and with conditions such as PFD may encounter several barriers in seeking help. The accessibility or perceived access to health care can be considered a barrier. Issues such as transport (Kelley et al 2006, Moss 2002), mobility (Currie & Wiesenberg 2003) and whether a health care service is provided during the day or evening (Kelley et al 2006, Lefler & Bondy 2004, Currie & Wiesenberg 2003) may be crucial to some women in order to access health care. Awareness of the availability of health services (Melville et al 2006, Roe et al 1999, Holst & Wilson 1988, Jolleys 1988), language (Cox & Lancley 2003), expectations of prejudice or paternalistic services, gender and the maturity and gender of health care practitioners (Christensen & Hewitt-Taylor 2006, Facione et al 2004, Currie & Wiesenberg 2003, Brooks & Phillips 1996) may all negatively impact on help seeking. In addition, immigration issues (i.e. fear of deportation), economic constraints (Facione et al 2004) and low health expectations (Horrocks et al 2004, Walters et al 2001, Anderson et al 1991) have been recognised as barriers in help seeking.

A lack of knowledge on the part of health care providers can actively reduce help seeking behaviour with statements such as 'don't worry its normal'; reinforcing the myth that PFD is normal and inevitable in women who have undergone vaginal delivery (Teunissen et al 2005, Tunink 1988, Simons 1985). Several studies identified 'normal as part of being a women' as a

frequent reason for not seeking help (da Silva e al 2009, Azuma et al 2008, Margalith et al 2003). A wide variety of factors may be perceived as a barrier to help seeking, and for each individual woman these factors may or may not impact on her help seeking (Table 3.1). These factors often overlap and can be placed amongst multiple headings. In Table 3.1 the descriptor heading assigned by the referenced authors is presented. These are not amalgamated into larger umbrella descriptors.

Table 3.1

Table 3.1

3.3.5.1.1 Evidence with respect to women who do not seek help

There is a lack of knowledge with respect to the number of women who do not seek help for their PFD problems. Accurate figures on the prevalence of women with PFD in the UK are not readily available, however in the USA they are (Neimark 2006). There is estimated data on the prevalence of Urinary and Faecal Incontinence only (Royal College of Physicians 1995), which estimates that at age 65 and over, 10-20% of women have urinary incontinence and up to 15% of those over 85 years with have faecal incontinence. A MORI poll from 1993 reported a general prevalence of one in three women in the UK having a continence problem at some time during their life (Brocklehurst 1993). Koch (2006) in an integrative literature review of help seeking behaviours in women with urinary incontinence, identified four studies only, in which study subjects were recruited randomly from large cross-sectional databases (Kinchen et al 2003, Yu et al 2003, Hagglund et al 2001, Mason et al 2001). In only one of these studies (Mason et al 2001) was data presented from women who had not sought help. Mason (2001) did not consider that severity of symptoms explained help seeking, as women with both 'occasional' and 'daily' incontinence sought help, and women with 'severe' symptoms did not. It is apparent from these studies that few women sought help for their urinary incontinence symptoms with the rate varying between 14% and 38%. It is important to consider that not all women with PFD symptoms may need or wish help for their problem.

It was the purpose of this study to look at the coping and then help seeking behaviour of women with PFD who did seek help. Understanding more clearly the variables that impact on the help seeking behaviour of those women who did wish help for their problems, will enable further service design and research to address the barriers which these help seeking women encountered.

3.3.5.2 Factors which promote help seeking

The literature provides little evidence to support positive opportunities in help seeking (Table 4.2), but it is thought that good contacts and previous experience with Primary Care may promote help seeking behaviour. Equally there is evidence that increasing exposure in advertising and magazines influences attitudes and knowledge about incontinence (Horrocks et al 2004, Brittain et al 2001). Fear of a serious underlying disease such as cancer and a serious impact on quality of life seem to actively promote help seeking (Shaw et al 2001). Duration of symptoms longer than three years, a noticeable trigger event, poor quality of life scores and lack of embarrassment have been identified as trigger factors associated with help seeking behaviour (Kinchen et al 2003). Zola (1973) identified five triggers to seeking help which are: interpersonal crises, perceived interference with social or personal relations, sanctioning or pressures from others to seek help, and temporising of symptoms. The work of Brittain et al (2001) organised the findings of their study into 'triggers for help seeking in patients with urinary symptoms' into these five trigger headings. The study contained almost equal numbers of male

and female informants and the identified triggers were not broken down into gender specific responses. Interestingly, embarrassment was identified as a trigger rather than a barrier to help seeking.

O'Donnell et al (2005) undertook a large cross-country study using the same survey instruments in France, Germany, Spain and the UK to explore help-seeking behaviour in women with urinary incontinence. A representative sample of nearly 30,000 women received a postal questionnaire to identify those with urinary incontinence (58% response rate); a randomly selected sub-sample of 3000 women with urinary incontinence received a more detailed questionnaire (response rate 53%). The study found that 31% of women had consulted a doctor about their incontinence symptoms, with more women consulting in France and Germany than Spain and the UK. Willingness to take long-term medication and having spoken to others about urinary incontinence were found to be strong predictors of help seeking in all four countries. Given the cross-sectional nature of the study a cause and effect relationship cannot be shown, rather associations between different factors and help seeking are described. Of concern are the low response rate and the issue of differences in health care systems between countries which were not addressed. Whether countries have a fee paying service may impact on women's help seeking behaviour. Despite the low response rate the study reported a consultation rate of 31% which is in line with many other studies (Herzog & Fultz 1990). Consequently findings could be considered transferable to other populations.

Trigger	**Reference**
Symptom duration of more than 3 years	Melville et al 2006, Teunissen et al 2005, Kinchen et al 2003, Brittain et al 2001
Having a history of a noticeable accident/ temporising of symptoms/ hygiene issues	Melville et al 2006, Kinchen et al 2003, Brittain et al 2001, Zola 1973
Not being embarrassed to talk to a physician about urinary incontinence / being embarrassed, being depressed	O'Donnell et al 2005, Kinchen et al 2003, Brittain et al 2001
Interpersonal crises	Teunissen et al 2005,Zola 1973
Keeping regular routine/preventative check ups	Kinchen et al 2003, Brittain et al 2001
Poor quality of life scores and interference with social life	Teunissen et al 2005, Kinchen et al 2003, Shaw 2001, Zola 1973
Good contacts and previous experience with a Primary Care Trust or GP	O'Donnell et al 2005, Horrocks et al 2004
Exposure to advertising and magazines influenced attitudes and knowledge about incontinence	Horrocks et al 2004, Brittain et al 2001
Cultural trigger	Rudell et al 2008, Brittain et al 2001
Fear of a serious underlying disease such as cancer	Shaw et al 2001
Pressure from others to seek help	Zola 1973

Table 3.2 Factors Which Promote Help Seeking Behaviour

The evidence from the literature predominantly pertains to coping and help seeking behaviour in women with urinary incontinence or general constructs with regard to coping with chronic illness and gender difference. Age and ethnicity were identified in the literature as affecting the illness appraisal process but little evidence was found that assessed the help seeking behaviour of different ethnic groups. Equally little evidence was found that fully explored the stigma and taboos attached to PFD. Further exploration of this area is essential for supporting the development of public service information and self help or support groups.

3.4 Summary

In order to seek help women progress through four distinct processes: event, situation, condition, and cue (Lazarus & Folkman 1984). This help seeking pathway is necessary in order for women to reach the decision that their PFD symptom is a problem which has the potential to cause harm, and for them to actually seek help. For some women the pathway will stop after the trigger event when costs or other barriers prevent further progress. For others, progression will continue further down the pathway, but the potential for maladaptive coping mechanisms and barriers to prevent further progress exist at each stage. The maladaptive coping strategies and barriers to help seeking will vary for each individual; however clarification of those barriers which are specific to women with PFD is essential if services are to be developed to meet the needs of service users. Further exploration of these specific topics, coping mechanisms and help seeking behaviour in women with PFD, is warranted so that specific information needs, health promotion, health professional training and education and service promotion can take place to offset barriers to help seeking.

Evidence identifying coping and help seeking behaviour is available for individual symptoms such as urinary incontinence or faecal incontinence. However little data have been found relating to PFD incorporating the range of potential symptoms that women might experience. PFD is a syndrome in which women may experience a number of symptoms simultaneously. Little data can be extrapolated from the literature with regard to coping behaviours and help seeking in PFD; hence the importance and value of this research. Equally the literature is silent with regard to the construct of opprobrium and its impact on coping and help seeking behavior.

It has been possible to delineate the barriers to help seeking for women with incontinence problems (Table 3.1). Help seeking is a complex process. It is apparent that a combination of personal attitudes and practical barriers prevent women with PFD seeking help. Personal attitudes and the fear of stigma and shame appear to play a negative role in help seeking behavior. It is speculated that an individual woman's perception of opprobrium may impact on the development of coping mechanisms to delay or avoid help seeking.

Studies have identified women who do not choose to seek help for their PFD symptoms, although the true numbers of those living with PFD is unknown in the UK. For those women who perceive PFD to be a 'normal part of ageing or of being a woman', not seeking help is an informed decision (Azuma et al 2008, Margalith et al 2003). Equally for women who perceive PFD as a personal rather than a health issue, help seeking is not an option that is chosen (da Silva et al 2009).

Evidence articulated in this review has been used to formulate themes for discussion with women who have PFD to discern if these themes are reflected in their life experiences. The development of interview guides incorporating the themes reflected in the literature is discussed in the research methodology chapter that follows on from this chapter.

CHAPTER 4: METHODOLOGY

4.0 Introduction

Grounded within the naturalist paradigm, this research employs an exploratory descriptive design using ethnographic methods as described in ethno-nursing research by Leininger (2001, 1997, 1990, 1988, 1985). As a micro-ethnographic study, it focuses on the emic perspective of a defined group: that being women with PFD who present to a London Hospital for treatment. This chapter presents the research methods chosen to approach this study, discusses the rationale for the methodologies chosen, describes each stage of the study design and address the qualitative criteria for trustworthiness employed in the study. This chapter begins with a description of the study question, aims and assumptions.

4.1 Research question – What are the reasons for women with Pelvic Floor Dysfunction not seeking help earlier in the course of their symptomatology?

4.1.1 Study aims

- To understand the underlying reasons why women with PFD don't seek help earlier in their symptomatology.
- To understand the coping mechanisms that women with PFD employ to compensate for or mask their symptoms.
- To understand the 'triggers' for women seeking help.
- To delineate cultural universality and diversity in women with PFD from different cultural backgrounds.
- To develop a conceptual model that can facilitate understanding of coping and help seeking in women with PFD.
- To make recommendations for how services can be targeted and developed to more adequately meet the needs of women with PFD.

4.1.2 Study assumptions

- Women with PFD seek help once coping mechanisms fail, rather than on their knowledge of the health services available to them (Davis & Kumar 2003, Norton et al 1998, Royal College of Physicians 1995, Shaw et al 2006, Hunskaar et al 2004, Shaw et al 2001, Johanson et al 1999, Lafferty 1996, Harris 1999, Ashworth & Hagan 1993, Grimby et al 1993).

- There are 'triggers' which affect help seeking behaviour in women with PFD.

4.1.3 Inclusion criteria

- Women with a diagnosis of PFD over the age of 18 years.
- Women able to give informed consent.

4.1.4 Exclusion criteria

- Women requiring urgent surgical intervention for their PFD.
- Women with PFD who have a diagnosed or previously treated pelvic neoplasm.

The study question and aims will be addressed through the use of Culture Care Theory and ethno-nursing methods (Leininger 2002, 2001, 1997, 1990). The rationale is described within this chapter. An explication and critique of Culture Care Theory can be found in Chapter 2. Shaw's (1999) framework of coping and health behaviour also informs the study in relation to data organisation for analysis and categorisation of coping and help seeking behaviour. Shaw's (1999) framework is described as it relates to the research data collection in this chapter and more extensively critiqued in Chapter 2.

4.2 Rationale for the use of Leininger's Culture Care Diversity and Universality: a theory of nursing and ethnographic methods to underpin this study.

This study has aimed to learn from women with PFD, to understand their world view (the emic perspective) as they define it and to reveal the tacit knowledge within the group in relation to coping and help seeking behaviour. The methods chosen to address this study facilitate understanding from the perspective of women with PFD and allow identification of the lay care beliefs that impact on their coping and help seeking behaviour. The central tenet of Culture Care Theory is that culturally congruent care is essential for clients for their wellbeing or to become and remain healthy. The basis of this theory is that the knowledge, beliefs and experiences of a culture (or group) are important factors in maintaining health (Leininger 1985a). Culture Care Theory is grounded in the naturalistic paradigm and was developed using selected culture constructs from both anthropology and nursing (Leininger 2001). The Sunrise Enabler combines both theory and method and distinguishes between different levels of abstraction (Cohen 1991, Leininger 1985). Included in the Sunrise Enabler are four levels of abstraction and analysis: Level one - focus on the structure of the culture of a group, Level two - focus on the specific meanings of health to individuals, families and groups, Level three - concerned with folk and professional systems of care and Level four - guides the development of care that is culturally acceptable. .

Given that this study has aimed to identify specific behaviour patterns for a clearly defined group (women with PFD), methods used in ethnography and specifically within ethno-nursing were applied (Hodgson 2000, Savage 2000, Agar 1997, Gold 1997, Polit & Hungler 1997,

Baillie 1995, Sanday 1979). In this research study the term culture refers to culture in its broadest sense, not purely defined by race or ethnicity (Gosner 2000), and incorporates those women (a sub culture distinct from men) with PFD. In the sub-culture of women with PFD, women from different countries and religions have been included, to accurately represent the ethnic mix of the local population served by the East London Hospital. Ethnography sits within the naturalistic paradigm (Guba & Lincoln 1988) and is used by many disciplines to address questions that concern how cultural knowledge, norms and values influence patients' behaviours (Boyd 1990). It is being utilized more frequently in nursing research (Mulhall 1996). Ethnographic methods facilitate examination of the health beliefs and practices of women with PFD and allow the views of women with PFD to be understood from their perspective and context (Savage 2000, Gold 1997, Carter 1993).

There is much literature to support the notion that women's experiences of chronic illness cannot be subsumed under those of men, as there are specific issues e.g., women's roles inside the home, which influence their experience of illness (Lambert et al 2004, O'Neill & Morrow 2001, Anderson et al 1991, Anderson 1987, Anderson 1985, Verbrugge 1985). Therefore a woman from any cultural background will potentially react differently from men when dealing with specific health issues; consequently it is asserted that women have already been identified as a cultural group (van Wijk & Kolk 1997). Equally the majority of research, healthcare delivery and economic support have focused on illnesses that tend to afflict the male gender (Lambert et al 2004). It has only been within the last twenty five years that a limited number of countries have begun to recognize and address health care issues that are specific to women (Evangelista et al 2001, Williams 1995). Women are already perceived as a specific cultural group with unique health care needs (van Wijk & Kolk 1997) and as a consequence women with PFD can be defined as a sub-group of the cultural group 'women'.

In ethnographic methods, 'micro-ethnographies' study narrowly defined cultural groupings, such as 'Women with PFD'. It is postulated that Leininger's Culture Care Theory can legitimately be applied to the cultural understanding of a group who have a shared disease process (PFD); particularly when the disease process is a common, female predominant chronic problem which is known to be socially stigmatizing (Vandoninck et al 2004, Davis & Kumar 2003, Roe & Doll 2000, Bump & Norton 1998, Norton et al 1998, Ashworth & Hagan 1993, Goldstein et al 1992).

Ethno-nursing was developed by Leininger (1985) specifically to study the theory of culture care. It is a naturalistic and emic research method using open discovery, diverse strategies and enabling tools (such as the Sunrise Enabler) to understand people's meanings as applied to health care issues (Leininger 1991). The Sunrise Enabler identifies potential influences that might explain care needs or practices. It is a holistic depiction of the theory and facilitates

comprehensive exploration of the phenomena. Leininger postulates that ethno-nursing is the method of choice when nurses only know some aspect of care or other phenomena from a professional (etic) perspective, but do not know the client's emic views. Marked differences between emic and etic perspectives identify areas of cultural conflicts and potential non-compliance between health service and client (Leininger 1990). This encapsulates and addresses the aims of this study: to understand the emic perspective of women with regard to coping and help seeking behaviour in order that etic advice and service provision may be culturally congruent. A summary of the study paradigm is depicted in Figure 4.1.

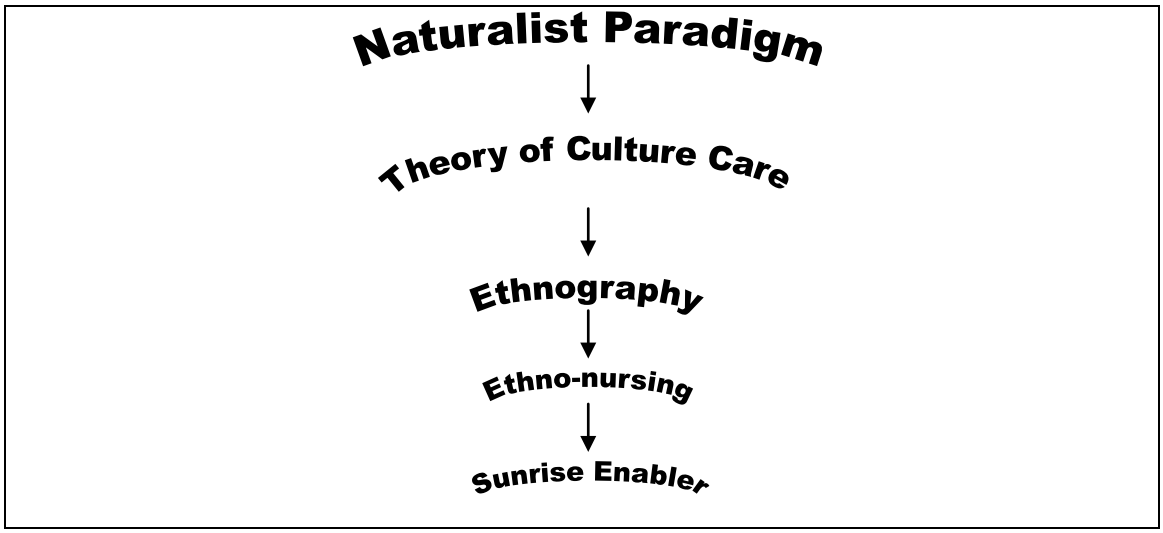

Figure 4.1 Study Paradigm and Theoretical Perspective

Ethno-nursing has within it specific methodological processes beginning with a Life Health Care history of one individual, then examination with individuals and subsequently with specific groups, to discern similarities and differences associated with the phenomenon being studied within the defined group (women with PFD).

4.3 Rational for the use of Shaw's framework of coping

Whilst undertaking a review of the literature pertaining to coping and help seeking behaviour (Chapter 3), the framework developed by Shaw (2006, 2001,1999) was found to facilitate the identification of determinants of health behaviour, outcomes and coping behaviour in people with urinary incontinence. This model has been extensively utilised to inform studies of people with urinary incontinence (one of the symptoms of PFD). Shaw developed this framework (1999) based on models developed in health psychology. As noted previously, the framework is described and critiqued in Chapter 2. Shaw's (1999) framework has been utilized to ascertain whether the coping behaviours identified in the framework include all the potential variables that might be employed or exist in a woman with PFD. Event, situation, condition and cue are employed to evaluate the help seeking process and pathway in women with PFD. Shaw's

Coping Framework (1999) has been used in this study to aid data collection and organise themes arising from the data.

4.4 Dual role of nurse and researcher

My professional role is that of Nurse Consultant in Coloproctology. One aspect of the clinical services I provide, is working alongside a multidisciplinary team in an integrated PFD service. It was during my clinical practice that the questions underpinning this study arose. Due to my clinical involvement in the services offered to women with PFD it was not possible to detach myself from the hospital environment and community in which I work, but in the context of ethno-nursing methods this reflexivity signifies my part in the social world and context of women with PFD. It is postulated that this reflexivity is invaluable in understanding the phenomena observed and allows contextual meanings to be identified in the context in which they are explored. It is postulated that this reflexivity is invaluable in understanding the phenomena observed and allows contextual meanings to be identified in the context in which they are explored (Leininger 2001, Hodgson 2000, Agar 1997, Hammersley & Atkinson 1995, Boyd 1990).

I was aware of a potential tension between my clinical role and the image I expected to portray as a researcher, and I was concerned about separating my research role from my identity as a clinician. Despite my knowledge of some of the women informants (as a clinician responsible for an aspect of their clinical care), I felt supported during the interview process by the semi-structured interview guide. I felt able to detach myself from the clinician role and focus on my role as researcher. Although I acknowledge that there was the potential for tension between my clinical role and my research role, the ‘support’ and focus I felt at each interview from the semi-structured interview guide, enabled me to focus on my research; not clinical role.

It can be argued that in-depth interviewing provided a legitimate way to gather data on the coping and help seeking behaviour of women with PFD, allowing me to talk and interact with women with PFD (some known to me, some unknown) and to gain access to their accounts of coping and help seeking. Gaining their trust was important; it could be argued that my clinical role was beneficial in this respect. I am aware that my background as a clinician, together with my personal values and beliefs, has contributed to the interest I have developed in wishing to better understand coping and help seeking behaviours in women with PFD. Reciprocity (the practice of sharing things with others) ensured the development of a close personal rapport and a mutually beneficial relationship, between myself and the informant’s, that was both honest and morally sound. Despite knowing some of the informants in a clinical capacity I had no preconceived ideas about what the informants might choose to disclose to me. As a reflexive practitioner, I was aware that by going with the informant(s) in their disclosure of coping and

help seeking behaviours I would discern knowledge that would ultimately enrich my practice and provide a framework for culturally congruent service provision.

By asking open-ended questions from the interview guides I could increase my focus on aspects of coping and help seeking behaviours that could otherwise be taken for granted or overlooked. By using semi-structured interview guides as cues, where needed, I could go with the informant(s) story and maintain my focus upon the meaning of the event/situation to the informant(s) (L'Aiguille 1994).

4.5 Research study phases

This study took place in three distinct phases, these phases did not overlap. Each phase informed the next stage of the study. Table 4.1 summarises the Research Study Pathway according to the ethno-nursing process.

Phase 1	Life Health Care History (Leininger 1985a) through use of the Life Health Care History Enabler. 1 patient with longstanding PFD.
	Thematic analysis of Life Health Care History
Phase 2	Development of semi-structured interview guide utilising findings from literature review of coping and help seeking behaviour and the themes derived from the Life Health Care History(Leininger 2001, 1997, Strauss & Corbin 1990 p52)
	Eight semi-structured interviews with women with PFD (interviews continued until saturation was achieved) (Strauss & Corbin 1990). All informants were given a copy of their interview transcript to allow member checking/verification/validation (Leininger 2001, 1997, Strauss & Corbin 1990).
	Concurrent thematic analysis. Themes derived from interviews were included in future interviews to validate/refute themes
Phase 3	Three Focus groups: purposeful sampling, of Turkish women, Orthodox Jewish women and African women. These groups closely represent the local population which the hospital serves.
	Semi-structured interview guide used to verify and validate second phase 'member checking', validation of themes identified in Phase 2 as reflective of their life experiences as well (Lincoln & Guba 1985).

Table 4.1 Research Study Pathway

4.5.1 Phase One – One Life Health Care History (longitudinal case study)

The Life Health-Care History, as described by Leininger (1985a), is an adaptation of anthropological methods which commonly use oral and written life histories. In essence a Life Health Care History is an in-depth case history which aims to generate longitudinal data from the informant regarding their health history. I modified Leininger's Life Health Care History Enabler to incorporate case study research methods and designs (Yin 2003, Stake 2000, Boyd

1990, Stake 1978). Case studies are common in qualitative inquiry and in fact the Life Health Care History can be described as an instrumental case study (Stake 2000), with its primary aim being to gain a better understanding of this particular woman and her life health history and provide insight into the coping mechanisms and help seeking behaviour she developed. An understanding, in an in-depth way, of a woman's Life Health Care History can advance the understanding of coping and help seeking behaviour in women with PFD generally. This form of Life Health Care History was utilized as it was considered that the longitudinal nature of the data would be valuable and might not be obtained by using questionnaire/survey techniques, as these tend to emphasise the present time only. Equally, although general questions were formulated using Leininger's Life Health Care History Enabler, the focus was also on the individual telling her story. In instrumental case studies, the case is still appraised in-depth (the Life Heath Care History) but specific questions are used to add data about the specific area of interest (coping and help seeking behaviour in PFD). Consequently the Life Health Care Enabler (Leininger 1985a) was used but additional questions were added to specifically address coping and health care beliefs with regard to the informant's PFD. These themed questions were used at the end of Leininger's guide of proposed questions to ensure that a general and longitudinal health care history was obtained initially and then specific issues with regard to PFD were included. Asking questions in this way is a widely accepted method of gathering information about subjective variables such as beliefs, attitudes and personal actions that cannot be measured directly, and is not considered to be 'leading' the informant (Yin 2003, Stake 2000). A number of the questions in the Life Health Care History Enabler were originally written in a closed format and so were restructured in an open question format to facilitate the collection of rich data. The Life Health Care History interview guide can be found in Appendix 1. The interview guide was formulated to guide the interviewer. The interviews spanned seven hours in total, but the semi-structured interview guide did not preclude the informant from discussing other issues she considered appropriate, equally not all questions were formally asked as the informant answered many of the questions during her conversation and during answers to other questions. In the ethnographic ethno-nursing methodology described by Leininger (1985a) this form of semi-structured interview guide is described. Leininger does not describe un-structured interviews. There was specific information I wanted to know. Open questions were used to explore these issues, using the semi-structured interview guide as an *aide memoire*. The use of open questions is considered neither inappropriate nor leading but rather a mechanism for allowing a 'richer and fuller perspective on the topic of interest' (Polit & Beck 2004 p350). Interviews were open-ended, semi-structured, in-depth and audio-taped.

4.5.1.1 Sampling methods in general and for Phase One specifically

The general study sample was the population of women who attend the PFD service at an East London Hospital. Leininger describes study informants as being key or general informants (1991, 1988, 1985a, 1978, 1970). The Life Health Care History informant was a key informant as she had coped with longstanding PFD. In Phase 1, a woman (key informant) was purposefully selected from the PFD database. This key informant displayed an insight into her

PFD problems and was chosen because she was typical of the women seen in my clinical practice with PFD, in that she had multiple symptoms arising from her PFD but presented for help for one symptom only. This informant's story was illuminating; yet disturbing. She was articulate, wanted to participate in the study and verbalized that she valued the opportunity to talk about her experience. To gain general informants for interview from the general population of women with PFD, consecutive sampling from patients presenting to the PFD clinic took place. These women were the participants in Phase 2 of the study. To verify/validate the findings of the interview process in Phase 2, purposeful sampling from the database took place to allow sub-group specific focus groups to be held (i.e., Turkish women, African women and Orthodox Jewish women). These groups represent the ethnicity mix of the local population served by the East London Hospital. The general study sample is the population of women who have attended the PFD service at the East London Hospital. At no point during the study did sampling involve specific presenting symptoms; rather it was considered that if women had been referred and treated in a designated PFD Service they met the criteria of 'women with PFD'.

4.5.1.2 Data analysis methods used throughout the study

Thematic data analysis took place through three overlapping phases of open coding (identification of general themes), axial coding (exploration of the thematic categories and their relationships to other categories), and selective coding (organization of the data around a core category selected on account of its critical importance) (Burnard 1991, Strauss & Corbin 1990). Interview transcripts were read and re-read and annotations made in the right hand margin of general themes arising from the data. The transcripts were then scrutinized again and in the left hand margin annotations were made exploring the relationship of the general themes (noted in the right hand margin) with all aspects of the content. The list of categories was then analysed and reviewed by both of my research supervisors to ensure that no omissions had been made in the grouping of categories under higher order headings. Leininger's (1990, 1985, 1985a) Sunrise Enabler was used as the organisational framework to organise the categories. It is acknowledged that organising the general themes into categories proved complicated as a number of categories could have fitted under several category headings (for example age) and the decision about how to organise higher order categories within the Sunrise Enabler was made following a return to the interview transcripts for clarification. Shaw's Framework (event, situation, condition and cue) was useful in organising the themes arising from the data.

The core category (selective coding) is the central concepts that relates to all the main categories and appears frequently throughout the transcripts. There were strong interrelating concepts such as 'embarrassment, stigma, shame, lack of knowledge, low position in society. Through abstraction of the concepts, *Opprobrium* appeared to describe the key factor in the coping and help seeking behaviour of women with PFD. The extent to which women appropriated opprobrium will vary due to variables (the central concepts) such as knowledge,

shame, role and position in society and their coping mechanisms will reflect the extent to which women perceive opprobrium. Opprobrium and its key impact on coping and help seeking behaviour is described in Chapter 8.

4.5.1.2.1 Life Health Care History

Two Phase 1 interviews with the informant were fully transcribed for analysis. This thematic content analysis of the data (as described above), from the transcribed Life Health Care History was undertaken manually (Roper & Shapira 2000, Agar 1997, Leininger 1985a, Spradley 1979). The name Ann is a pseudonym used to protect the identity of the research informant. The biographical life history informed the background to the study, has been written as a narrative ethnography and is presented in Chapter 5. What surprised me was the informant's response to her stress urinary incontinence and the way she coped with it. This reinforced for me the difference between my etic perspective and her emic perspective.

4.6 Modification of Shaw's Framework of Coping

Shaw presents coping constructs in a linear fashion in the framework (Figure 2.2), suggesting that women progress through these stages in sequence. Completion of Phase 1, personal observation and an extensive review of the literature, specifically the work of Lazarus & Folkman (1984), led me to believe that women may enter this coping cycle at any stage and may progress or regress through the process, dependant on other factors occurring in their life at that given time. It is possible to speculate that variables such as a woman's feeling of self worth and perception of the potential for personal stigma or disgrace will impact on her personal help seeking process. Consequently the Shaw framework has been adapted to demonstrate the fluid nature of these concepts (Figure 5.2). A detailed description of the modified circular framework is presented in Chapter 5, where the results of Phase 1 are presented.

4.7 Modification of Leininger's Sunrise Enabler.

The Sunrise Enabler is a conceptual picture and holistic depiction of the diverse components of Culture Care Theory. The Enabler facilitates the discovery of potential and actual influencers on care and health phenomena and relates them to historical, cultural, religious and other social structure factors. Leininger does not identify that personality might have an impact on an individual's lay care beliefs and practices. Personality was identified in the literature pertaining to coping and help seeking behaviour as an important variable in health care behaviour (Oh & Park 2004, Brittain et al 2001, Shaw 2001, Facione et al 2000, Rotter 1966). The Life Health Care History informant identified that her 'pragmatic personality' impacted significantly on the management of her PFD symptoms and consequently coping and help seeking behaviour. As a result of these findings the Sunrise Enabler was modified to include personality as a significant influence on lay care beliefs and practices and aided data collection in Phase 2. It also

facilitated the generation of evidence relating to the relevance of personality in coping and help seeking behaviour. An example of the modified Sunrise Enabler (Figure 5.1) is presented in Chapter 5, where the results of Phase 1 are presented.

4.8 Phase Two – semi-structured interviews

In Phase 2 data were collected from women using in-depth individual interviews to identify key themes such as those related to coping behaviours used by women with PFD and the triggers and barriers to them seeking help. The second phase of the study aimed to:

- Understand why women with PFD don't seek help earlier in their symptomatology.
- Understand the coping mechanism that women with PFD develop to compensate for their symptoms.
- Understand the 'triggers' for women seeking help.
- Understand what would have facilitated help seeking behaviour.

Ethnographic interviews are designed to discover cultural meanings (help seeking behaviours/coping mechanisms) which exist within a social group (women with PFD). Leininger's Life Health Care History Enabler was used to facilitate the interview design as was the work of Spradley (1979), which identified three elements which help informants verbalise their thoughts and beliefs: explicit purpose, ethnographic explanations and ethnographic questioning. Examples of these elements are found in the semi-structured interview guide (Appendix 2). The questions are specific in nature but the majority do not force the informant to answer either yes or no or to respond from a list of alternatives (closed questions) (Polit & Beck 2004). Rather the questions are deliberately specific to focus the informant and also seek to alleviate issues of memory recall and embarrassment.

Phase 2 interviews continued until saturation was achieved. In total 8 in-depth semi-structured interviews with women with PFD were undertaken. These Phase 2 interviews verified/validated the themes obtained from the Phase 1 interviews and also those themes identified from the review of the literature pertaining to coping and help seeking behaviour.

4.8.1 Thematic development of questions and question format

The themes identified from the literature with regard to coping mechanisms and help seeking behaviour and the themes identified from the Life Health Care History have informed the development of the Phase 2 semi-structured interview guide (Appendix 2). The key themes included knowledge, health care beliefs, coping mechanisms, perception of severity of the problem, role obligations, emotions, locus of control, trigger, financial and personality. Phase 2 interviews followed a semi-structured format using the questions as a guide whilst allowing the

researcher freedom to insert other questions into the interview to capture elaborations. Interview questions sought to clarify:

- Time from realization there was a problem (first symptoms) to seeking help.
- If delay between realization of problem and seeking help – why?
- If delay between realization of problem and seeking help what coping mechanisms did the women employ?
- If a delay in seeking help, what the 'trigger' was that prompted help seeking?
- If women sought help immediately – why?
- Anything that would have made the help seeking process easier.
- Any barriers that prevented help seeking.

There was no defined order of the questions and open questions to promote discussion were used where possible. Questions were formulated using the adapted Sunrise Enabler (Figure 5.1). A number of the questions substantiate or refute the evidence and stages of Shaw's framework (Figure 2.2). Given that these questions are targeting specific areas related to coping and help seeking (as identified in the literature) they were more focused and specific.

The questions were also formulated to address the issue of memory. It is known that memory processes illness and organizes it into certain concepts, such as pain, visits to the doctors, medication and symptoms. If broad questions are asked such as 'tell me about your PFD problem', it is difficult for the informant to answer viewing the episode as a whole; consequently under-reporting is possible as the question does not stimulate adequate recall. It is suggested that several questions are asked that aid the informant to recall information (Foddy 2003). The semi-structured interview guide provided a framework of associations to aid informant recall.

The closing part of the interview placed the informant in an 'ideal world' situation, giving them permission to speak freely about what they would have liked to have known about their condition, the things that might have made it easier for them to cope, and the services they would have liked to receive. The 'ideal world' scenario was used to facilitate free and open comment by the informant as it lessens the psychological stress of the question by allowing the informant to respond either in 'an ideal world scenario' or as another person. Consequently it lessens the informant's concern that they may be seen as criticizing the care they have received. As the interviewer, I knew some of the informants and played a part in their professional care and support. The use of the 'ideal world' strategy allowed suggestions of how services might be developed to be raised without the informant feeling they were criticizing me or the hospital services in any way.

PFD and issues such as incontinence are often perceived as embarrassing and stigmatizing conditions. There is evidence to suggest that subjects that are sensitive or embarrassing tend to be under reported (Locander & Burton 1976, DeLamater 1974). By raising these issues and framing the topic in subtly different questions, the modelling effect was employed [('if the interviewer can talk about this embarrassing issue so can I.' (Foddy 2001 p49)] to allow informants to feel able to discuss such issues. This is consistent with the findings of previous studies which found women felt more able to talk about 'embarrassing' subjects when the question was raised specifically by the healthcare professional (Mason et al 2001), giving them permission to discuss the subject.

4.8.2 Sampling methods for Phase Two

Phase 2 interview informants were general informants. That is women with a relatively short history of coping and living with PFD. To gain general informants for interview from the general population of women with PFD, consecutive sampling from patients presenting to the PFD clinic took place. In the context of this study interviews continued until no new data were uncovered. Saturation was further confirmed by member checking (Strauss & Corbin 1990). The demographics of Phase Two informants, alongside their PFD symptom spectrum are found in Chapter 6, Table 6.1.

4.8.3 Data analysis

The data analysis was conducted as per description in 4.5.1.2. Each interview was transcribed and analysed prior to commencement of the next interview. Such overlapping of the data collection phases is a principal element of naturalistic research. Thus, in this study, themes from each individual interview were identified and validated in the following interview (Strauss & Corbin 1990).

4.9 Phase Three Focus Groups - the emic perspective of women with PFD from diverse cultures

In Phase 3, focus groups were used to verify/validate/refute those themes explicated from Phases 1 and 2, identify universality and diversity amongst differing cultural groups of women with PFD (Agar 1997, Miles 1994, Leininger 1985, Spradley 1979) and identify what cultural values beliefs and practices impact on women with PFD, from these specific cultural groups.

The aims of the focus groups were:

- To understand why women with PFD from different cultures do not seek help earlier in their symptomatology.
- To understand the coping mechanisms that women with PFD from different cultures develop to compensate for their symptoms.

- To identify universality and diversity amongst differing cultural groups of women with PFD.
- To verify/validate/refute themes identified in Phase 1 and 2 (Strauss & Corbin 1990, Lincoln & Guba 1985).
- To build trustworthiness into the study (Polit & Beck 2004).

4.9.1 Sampling methods for Phase Three

To validate the findings of the interview process in Phase 2, purposeful sampling from the database took place to allow sub-group specific focus groups to be held (i.e., Turkish women, African women and Orthodox Jewish women). As stated previously, these groups represent the ethnic mix of the local population served by the East London Hospital. The general study sample is the population of women who have attended the PFD service at the East London Hospital. Data from the 2001 Census identifies that approximately 60% of the population of Hackney is white (British, Irish, other). Other white includes both the Turkish/Kurdish population and the Orthodox Jewish population. Black African constitutes approximately 12% of the population with the Chinese and Indian populations being relatively small at approximately 5% in total Census (ONS 2001). The chosen focus groups thus reflect the demographic population of Hackney.

4.9.2 Thematic development of Focus Group questions and question format

The themes relating to coping and help seeking behaviour have been identified from the literature and from Phase 1 and 2 of the study. Phase 3 focus groups followed a semi-structured format using the questions as a guide whilst allowing the freedom to ask other questions in the focus group to capture elaborations (Appendix 3). The closing part of the focus group again placed the informants in an 'ideal world' situation, giving them permission to speak freely about what they would have liked to have known about their condition, the things that might have made it easier for them to cope, and the services they would have liked to receive.

4.9.3 Data analysis

Phase 3 focus groups were fully transcribed for analysis. Thematic data analysis took place through three overlapping phases of open coding, axial coding and selective coding (Strauss & Corbin 1990) as described previously in section 4.5.1.2. The thematic content analysis of the data from the transcribed Focus Groups was undertaken manually (Agar 1997, Miles 1994, Leininger 1985, Spradley 1979).

4.10 Qualitative criteria for trustworthiness used throughout the study

The robustness of the research findings have been assessed according to widely accepted criteria appropriate to qualitative research (Polit & Beck 2004, Lincoln & Guba 1985). Leininger (1990, 1985a) and Lincoln and Guba (1985) identify that the conventional positivist criteria for measuring trustworthiness (internal and external validity, reliability and objectivity) are

incompatible with qualitative research methods. Trustworthiness in qualitative research relates to the ability to demonstrate both rigour in the research process and the relevance of the project itself (Sandelowski 1993). The trustworthiness of the study has been documented and proven using the four criteria for naturalistic research proposed by Lincoln and Guba (1985): credibility, transferability, dependability and confirmability (Ballinger 2004).

4.10.1 Credibility

Credibility relates to the truth or accuracy of the study findings. In this study the accuracy of interview data have been substantiated by means of the informants verifying the transcribed interview account as accurate. By this member checking, the informants were given a copy of their Life History Care History interviews or semi-structured interview, and they confirmed the accuracy and true reflection of their experience. In addition aspects of the data collected through the interview process were triangulated with information from the informants' medical notes. The original interview tapes were reviewed for transcription accuracy by both the researcher and independently by the research supervisors. Member checking occurred after every interview, when transcripts were reviewed; equally a review of the audio-taped transcriptions and researcher's reflective diary also took place. The use of focus groups in Phase 3 of this study effectively acted as member checking of the themes identified from the previous stages, undertaken by members of the study group themselves (Lincoln & Guba 1985).

Credibility has been enhanced by my prolonged engagement (Pars 1999, Lincoln & Guba 1985) with each informant, with follow-up clarification interviews undertaken when identified as necessary. This allowed the development of a trusting relationship between the informant and myself. Persistent observation (Parse 1999) also added a dimension of depth to the study and over time allowed me a level of understanding of the issues surrounding women with PFD and their coping behaviour. Equally persistent observation facilitated focus on the issues identified by thematic analysis as relevant and recurring.

4.10.2 Confirmability

Confirmability is the reaffirmation of what the researcher has seen or heard with respect to the phenomena under study. This study has triangulated information from ethnography, interviewing and focus groups. Confirmability has been achieved by repeated accounts from informants, in which they restate and reaffirm ideas and themes, and through mutual agreement of the findings. The informants have reviewed the transcription of their interviews to ensure accuracy and true meaning. Confirmability also took place by constant peer review of the process and data, with my first research supervisor ensuring that the transcriptions were accurate.

4.10.3 Dependability

The dependability of a study can be assessed if a clear audit trail is provided and the documentation of data, methods and decisions about the research are laid open to allow external scrutiny. All phases of the study have a proven audit trail from interview guides (Appendix 1, 2,4) through to the interview transcripts (these are available on request) which alongside the triangulation methods also ensures both dependability and confirmability of the study. The study process is visible and therefore auditable (Polit & Beck 2004). Finally data collection methods used in this study are consistent, stable, and repeatable. Interview outlines were produced for each informant and reflect the incorporation of the previous interviews thematic analysis.

4.10.4 Transferability

Although generalisability is not the goal of this study, given the wide range of contexts in which the help seeking behaviour and coping mechanisms of women with PFD are identified, triangulated and validated, it has been possible to develop a theoretical model (Figure 8.1) which has been adapted from the Sunrise Enabler, (Leininger 1985) of coping and help seeking behaviour in women with PFD. Themes identified from the literature with regard to coping mechanisms and help seeking behaviour and the themes identified from the Life Health Care History have informed the development of the Phase 2 semi-structured interview guide (Appendix 2).

Transferability was increased by purposeful selection of the informants in Phases 1 and 3. In Phase 1 the woman was known to the researcher (who had facilitated her care for 12 months). The informant was eloquent and had insight into her medical problems and coping strategies. These facts strengthened the context of the research and as consequence transferability. In Phase 3 of the study women were purposefully selected from the hospital database of women attending the PFD service and specifically from the women identified as being Turkish, African or Orthodox Jewish. These women were keen to discuss their culture and cultural beliefs.

4.11 Ethical considerations

Ethical approval was obtained from the East London and The City Research Ethics Committee (05/Q0602/49). The purpose of the study was explained to each informant and written consent obtained. Patients were invited to participate in this study by the use of both a written information sheet and verbal explanation from the researcher (Appendix 4). Written consent was obtained by me. Confidentiality was maintained and if patients did not wish to participate in the study their treatment continued uncompromised.

4.11.1 Data protection

Medical records were used to identify the PFD symptom spectrum of informants. These medical records were stored in established Trust medical record holding facilities. Computerized data were stored on a password protected pre-existing Trust computer facility. In the analysis and recording of interviews measures were put in place to prevent direct reference to individual informants. Data were encrypted and only known to myself. The audiotapes from the interviews and focus groups were destroyed once the transcription had been verified by the informant and my research supervisor.

4.12 Summary

The research design employed for this research is exploratory and descriptive. It uses ethnographic ethno-nursing methods within a micro-ethnographic approach to focus on the emic perspective of a defined group (women with PFD) who present to an East London Hospital for treatment. The design of this study, using ethno-nursing methods, has facilitated identification and understanding of the cultural values and social structure factors which influence the health, wellness and illness behaviour of women with PFD. Traditionally nurses focus on biomedical and psychological factors to plan care and services but this approach is limited as it uses primarily etic perspectives. The methodology used in this research has facilitated the emic perspective of coping and help seeking behaviour in women with PFD to be described and laid the foundation for development of the conceptual framework and construct (opprobrium appropriation) articulated in this thesis. The strength of the study design is that it took place in three distinct phases, these phases did not overlap and each phase informed the next stage of the study.

The chapter that follows presents the results of Phase One - The Life Health Care History. The ethnography is presented with an explication of the arising themes and resultant modifications to both Leininger's Sunrise Enabler and Shaw's Framework of Coping.

CHAPTER 5: RESULTS OF PHASE ONE – THE LIFE HEALTH CARE HISTORY

5.00 Life Health Care History

This Life Health Care History, as described by Leininger (1985a), is an adaptation of anthropological methods which commonly use oral and written life histories. Case studies are common in qualitative inquiry and in fact the Life Health Care History can be described as an instrumental case study (Yin 2003, Stake 2000), with its primary aim being to gain a better understanding of this particular woman by obtaining a personalized and longitudinal account of her health, care and illness experiences from a lifetime perspective (Carter 1993). The Life Health Care History semi-structured interview guide may be found in Appendix 1. In keeping with Leininger's description of Life Health Care History informants, the woman is referred to throughout as 'the informant' (Ann).

5.1 Background history of the Life Health Care History informant

The woman, in her 30s, lives with her partner (the father of her children) and her two children. She is university educated; and holds an important and responsible well paid job. Her partner works away from home, returning only at the weekend. She has a severe nut allergy and almost died as a child from an allergic reaction. Her PFD symptoms include obstructed and painful defaecation and urinary incontinence.

This Life Health Care History provides insight into the coping mechanisms and help seeking behaviour the woman developed. The ethnographic narrative below is constructed from the informant's two interview transcripts. The themes relating to this woman's particular story have been used to portray her life with PFD and the associated stressors she encounters in her daily life. This form of narrative ethnography, telling the story of the informant, is common in ethnographic methods. The ethnography below comprises of reconstructive narrative and the thematic analysis which follows provides direct quotes to support the analysis and discussion.

5.2 Ethnography – 'Juggling aspects of my life to cope with Pelvic Floor Dysfunction'

PAIN - that was my introduction to this problem you call pelvic floor dysfunction. It began with the delivery of my first child and continues even today. I had a second degree tear. The tear was sewn up but it was extremely painful. Initially this pain only created a problem in my sex life with my partner. Intercourse was really, really painful but I just lived with it and either abstained from sex which created difficulties in the relationship or I went ahead with sex and created difficulties for myself, which I lived with. I just got on with my life; I enjoyed looking after my child; I went back to work, began to get my life in order; I NEVER sought help. During the birth of my second baby I had a third degree tear. After the birth of my second baby the treadmill of coping with my baby and the pain really began. My baby had reflux. He vomited his feed from the very beginning, so all my attention went on keeping him healthy. I had to cope.

I didn't seek help, but at a routine appointment with the Gynaecologist to review the healing of the third degree tear, I was very emotional; I did lots of crying. I was embarrassed and ashamed to admit I couldn't cope. When I saw the Colorectal Nurse Consultant, I was in pain, constant pain. There was the build up to going to the toilet; the aftermath of going to the toilet; the anticipation of going to the toilet; the anxiety about not having sex; the result of everything that was going on with my bottom and the pain that resulted from it. The whole thing was just absolutely ghastly. The pain was excruciating. The sexual problems I've been experiencing started following the birth of my first child and I think was related to the sewing up of the tear. Sex was very painful but I didn't ask for any help for this. It really only became apparent after the second birth, that I had problems in this area because I had sensation difficulties. I really didn't explore this problem because I probably used it to avoid doing things I didn't necessarily want to do. So I didn't try and sort it out. I felt vulnerable but knew I had to succeed as a wife and mother. The problems with my bottom allowed me to tell my partner that he ought to be a bit more understanding and not try and make me have nooky when my backside was hanging out. It wasn't the sexual problems that stopped me having intercourse. I used my bottom problems as an excuse.

I suppose I coped because the pain of childbirth was so much greater in its immediate impact. I thought I'd be a bad mother if I gave in to the pain. It probably entered my head every two seconds, but I never voiced it. I didn't tell anybody. I don't give in much.

It was only once I sought medical help, once I'd seen the Colorectal Nurse Consultant that my problem was something concrete that I was able to share with people. It made it real for them and it made it real for me. I wasn't imagining this terrible pain anymore. Before that I'd been really stoic and keeping a lot to myself, but then it gave me permission to go and tell everybody that what I'd got was really serious. It gave me permission to be ill and to be upset, to be angry, and it gave me permission to have the attention on me. I was angry with myself; angry that I hadn't sought help earlier, but then I did have extenuating circumstances with my baby. I was pre-occupied, but – yes – I was angry with myself.

But how did I get to this situation? The pelvic floor – it's a really abstract concept. Before this problem started, I'd never heard of pelvic floor dysfunction. I didn't know that a woman could have urinary, faecal and sexual problems related to childbirth or delivery. I knew I had to do pelvic floor exercises after my deliveries. I still don't really understand how to find my pelvic floor; how to pan and tilt and lift. It's a very euphemistic concept. I'm an intelligent person, but I still really don't understand pelvic floor exercises. I certainly didn't do them after my two deliveries. I knew I should, but I just didn't do them. I know people say pelvic floor exercises are easy. I could do them waiting for a bus, but I didn't do it.

I'm quite a pragmatist in life and generally that's how I cope with many things. I have a severe nut allergy, with severe allergic [anaphylactic] reactions. This started when I was a child and I've learnt, with the help of my family, to live with it. I've nearly died on a number of occasions, but I have adrenalin and antihistamine, and I know how to treat myself. I suppose I throw caution to the wind at times but I'm not being a risk taker, just a pragmatist. I think that probably sums me up medically. I think maybe the way I've learnt to come to terms with and manage my nut allergy, has impacted on how I coped with the pain of my pelvic floor dysfunction problems.

I think that part of my reluctance to acknowledge that there was a problem, was my feeling that there just wasn't any time. My partner works away from home. When I wasn't at work or preparing to go to work, I was travelling to and from work. Then I was back at home, bathing the children; feeding the children; stroking them to sleep; reading them bedtime stories. Then I'm shovelling food in my own mouth, and then I'm in a coma on the sofa, and really that's my life. That's the life I've chosen to have, but there isn't any room in there for any time of my own. I think I have a great capacity to cope and I just can't give in. That's just the way I'm built. I've also got a high tolerance of pain and a tendency to be a martyr, which makes me think that it's my lot and this is what I have to do. I just have to get on and do it and put up with it. If I let these chinks of vulnerability seep through, then maybe I couldn't keep juggling all these balls in the air, and keep going. I think the momentum has to be kept going in life. I realise now I was on a treadmill, just trying to cope.

I think my personality leads me to being far more likely to internalise things and to try and crack on with things and not talk about it. I don't go out and seek help very much. I did spend money on various pills and potions to try and solve the problem.

Knowledge, knowledge is a key issue here. Knowledge or lack of knowledge; lack of information and lack of understanding. It's part of the reason why I'm in this position now. I'd never heard of pelvic floor dysfunction. When you're pregnant, you're excited. You're also a bit terrified, because all you think about is that you want to give birth to a live healthy baby. I don't know how much I'd have been able to take in if somebody started telling me about fissures, anal pain, faecal incontinence, urinary incontinence; all of these things that can happen to you after you've had a baby. I probably wouldn't have been able to take it in. I was just thinking about having babies. So throughout the course of my two pregnancies, in reality nobody really discussed with me the potential problems that I could encounter. I had no knowledge of how pregnancy and having children would change me as an individual. After my children I expected to be the same as I was before. I had no idea about the loss of autonomy I would feel; the fact that you can't do anything on your own ever again, or at least that's how it feels sometimes. At ante natal classes nobody talks to you about the responsibility that will impact on you. The focus

was on breast feeding. If someone had started talking to me about it at antenatal classes, I'm not sure I would've wanted to listen. I just wanted to talk about babies; not talk about me. But, if I'd been provided with something that was readable, that I wouldn't have to read at the time, but I could keep and, in a private moment if I was anxious afterwards, I could've read, then I would have realised.

I used joking or humour to help me get through. I mean, you can do nothing but joke about it, surely. I'd joke with the nurses and doctors about it, because it makes it OK to talk about it. If you've got a smile on your face, it makes it easier. It's a deeply embarrassing problem, to allow people to go to places that you don't even go to yourself; to examine you. Well humour, joking gives you some sort of protective distance or a barrier to mask the shame. This sort of problem lends itself to that sort of humour, doesn't it? I have been particularly open and jokey about it. I think more so than a lot of people might have been. There's a possibility that presenting my problems to my friends and family in such a jokey way was my way of trying to prove to myself that the problem wasn't really that serious.

The pressures of my life directly affect my health. If you've got a job and a partner and children, these are three balls that you can keep in the air but you can't be selfish. The fourth ball is your health, but you can't juggle four balls. I'm not a selfish person although I have been when I was single. I was able to then, but not now.

I'd never told anybody until I went to the hospital and was asked directly, that I have problems with my bladder. Sometimes I leak urine, but don't we all suffer that type of thing after childbirth? Apparently, I have a slightly prolapsed bladder. I only really mentioned the bladder problem in passing because I was asked, but it's true I do wet myself. I did it the other day, running to the car because there was somebody putting a parking ticket on my car and I ran. I actually evacuated the whole of my bladder all down my leg. It was really embarrassing, but I just couldn't stop it. I was mortified. The disgrace in public. I found an old babygrow in the back of the car and rammed it through my legs, and drove at breakneck speed. It doesn't happen very often, but when it does its spectacular. I think it's just something that one gets and has to live with. I mean to put it into perspective, I suppose if I'd only had the bladder problem with no bottom problem; no severe pain, it might not be something I'd be particularly upset about now. But in comparison to the severe anal pain, it's minor. It's like a spot on the end of my nose that I can cover up.

I often wonder what might have helped me seek help earlier. I think if all new mothers were given a routine appointment, a sort of compulsory appointment where there was childcare

available. Then you could go and sit on your own and talk to the health care professionals, without having to look after your baby. Then all sorts of things might come to light. Definitely having more knowledge about the potential problems and what can be done to treat them would have helped as would having more time; not feeling so exhausted. Exhaustion, never addressed or dealt with was probably the worst thing; the most detrimental aspect of my life; the thing that prevented me seeking help.

5.3 Themes extrapolated from the Life Health Care History

Data analysis took place through three overlapping phases of open coding (identification of general themes), axial coding (exploration of the thematic categories and their relationships to other categories), and selective coding (organization of the data around a core category selected on account of its critical importance). The two interview transcripts were read and re-read and annotations made in the right hand margin of general themes arising from the data. The transcripts were then scrutinized again and in the left hand margin annotations were made exploring the relationship of the general themes (noted in the right hand margin) with all aspects of the content. The list of categories was then re-analysed to ensure that no omissions had been made in the grouping of categories under higher order headings.

Leininger's Sunrise Enabler was used as the organisational framework to organise the categories. The framework guided what narrative was included in the Life Health Care History. The major themes that were extrapolated from the Life Health Care History are presented under the headings of the Sunrise Enabler. Each theme is presented with informant quotes to elucidate the theme. The quotes are directly from the interview transcripts and presented in italics. If the informant did not articulate factors as being of importance or relevant to her help seeking and coping behaviour the factor is identified as adding no new data. It is acknowledged that organising the general themes into categories proved complicated as a number of categories could have fitted under several category headings (for example age) and the decision about how to organise higher order categories within the Sunrise Enabler was made following a return to the interview transcripts for clarification. An example of the thematic analysis process is shown below in Table 5.1. In response to *'You describe time or rather lack of it as a key factor that prevented you from looking after yourself as much as you'd like to, so I was wondering if you could explain this in more detail for me? And 'You described very articulately about juggling balls in the air and about three balls you could do, I'm interested in learning more about how you manage to juggle these three balls and keep everything going when at times you haven't felt very well'.* The fully transcribed answer is seen in the centre of the table with annotations made in the right hand margin of general themes arising from the data. Following further scrutiny annotations were made in the left hand margin exploring the relationship of the general themes (noted in the right hand margin) with all aspects of the content.

Relationship of themes	**Question and response**	General themes
	You describe time or rather lack of it as a key factor that prevented you from looking after yourself as much as you'd like to, so I was wondering if you could explain this in more detail for me?	
Social support Societal pressure Women in society Role and status of women	Well there isn't any time. I mean. But when I'm not at work or preparing to go to work, I am travelling to and from work, and when I'm back I'm putting people in baths and feeding them and stroking them to sleep and reading them bedtime stories, and I'm shovelling some food in my gob. And then I'm in a coma on the sofa, and really that's my life. That's the life I've chosen to have, but there isn't any room in there for any time on my own.	Lack of time Role obligations Chosen life Career Mother
	You described very articulately about juggling balls in the air and about three balls you could do, I'm interested in learning more about how you manage to juggle these three balls and keep everything going when at times you haven't felt very well.	
Coping mechanisms Personality Role obligations Coping/control Perception of vulnerability Personality Role obligations Society/culture Role obligations Role and status of women Permission Fear of being a bad mother – role obligations	I don't know really. I think I have a great capacity to cope and cannot give in. Not in a noble way, just that is the way I'm built. I also have a high tolerance of pain, and a tendency to being a martyr, which makes me think that it's my lot and this is what I have to do, and I just get on and do it. But it is my way of coping to be controlling. If I let chinks of vulnerability seep through, then maybe I couldn't juggle any of them or keep anything going. I think the momentum has to be kept going, but also my personality lends itself to being rather, I'm more likely to internalise and crack on with those sorts of things, even though I'm a talkative person and everything. I don't go out and seek help very much. I live with a level of tiredness which I can continue with and do the juggling that I need to do, but the minute somebody wants something a little bit more from me, and I can't deliver, that's when it snaps. I think I was going slightly do-lally over it, but at the same time, all that time I had a very sick baby. So all of this period he was a very unwell baby and I was pumping milk every three hours I would have to pump. Because I wouldn't give in. I wouldn't feed him on bottles. I was stupid actually. Somebody should have said "Don't be so ridiculous. Stop breast feeding, give him a bottle. You're destroying yourself". But nobody did. And I thought I would be a bad mother if I gave in. It probably entered my head every two seconds, but I never voiced it and I never gave in. I don't give in much.	Don't give in Being a martyr Control Don't let vulnerability seep in Juggle to keep everything going Tiredness Role as mother Sick baby Wouldn't give in Fear of being bad mother Detriment to self Wanted to give in

Table 5.1 Example of Thematic Analysis

5.3.1 Kinship and Social Factor

The informant had a lifelong severe nut allergy which she initially leant how to manage by the example and teaching of her parents. However since adulthood has learnt to manage her nut allergy in a more pragmatic way. The informant's learned health care beliefs are discussed in section 5.3.7.

5.3.1.1 Kinship - Knowledge

The informant indicated that she had no knowledge from her mother or National Childbirth Trust classes or others that PFD problems could occur following childbirth. She perceived that the focus during the childbirth classes was on breastfeeding. Furthermore the informant had no knowledge of the cause of the problem and displayed a lack of insight into her problem. It is postulated that her lack of insight was in fact denial. It is a negative coping mechanism which she developed to avoid the shame of admitting there was a problem for which she needed help.

'*The pelvic floor – it's a really abstract concept. Before this problem started, I'd never heard of pelvic floor dysfunction.'*

'Knowledge is a key issue here. Lack of information and lack of understanding. It's part of the reason why I'm in this position now.'

5.3.1.2 Kinship – Social Support

The informant has a limited social support network. She works part time and her partner is only at home at weekends. His job takes him away from home Monday to Friday. She expressed many time constraints due to her work and family commitments which prevented her from seeking help. The role obligations and time constraints articulated by the informant are discussed in section 5.3.3.

'I live five days a week on my own. My partner lives in Birmingham. I'm bringing up two children and holding down a part time job, and I don't have much of a social life.'

5.3.1.3 Societal Pressure

The informant elucidated the social pressures she felt as a woman: to be a wife, mother and career woman. These pressures and fear of failure are discussed in section 5.3.3.

5.3.2 Political and Legal Factors

The informant did not articulate any political or legal factors in relation to her coping or help seeking behaviour or experience of living with PFD. Consequently no new data are described.

5.3.3 Cultural Values, Beliefs and Lifeways

5.3.3.1 Women in society

The informant was a working mother who wanted to be able to have a challenging and fulfilling career but also to enjoy the bringing up and nurturing of her family. This ideal placed pressure on the informant. She describes very clearly the *'juggling'* of the roles of career woman, mother and wife and the resultant exhaustion. Society and its cultural view that women can work, be a mother and a wife led to a fear *'of failing. It's really bad, this time when you're really vulnerable.'* The informant felt very strongly that she should be able to be a partner, mother and career woman. She articulated the societal pressure she felt to succeed in all these roles and felt strongly that to seek help would show vulnerability and possibly shame and a form of 'disgrace' that she was failing as a woman. The fear of failing was a significant contributing factor to her delay in help seeking.

'I think living in London and having a tough job and maintaining a family and attempting to maintain a relationship – all those sorts of things, puts very great pressure on the woman in the household.'

'Career, job and the responsibilities and stresses that come with that are another drain on your ability to look after yourself.'

5.3.3.2 Role and status of women

The informant identified that lack of time, exhaustion, juggling commitments, lack of social support and the obligation to care for her children impacted on her. She describes *'the treadmill of coping.'* She experienced guilt that her health problem was affecting her family and job commitments. The need to be a good mother and wife and maintenance of a sexual relationship with her partner were paramount. The informant perceived she would be seen as a bad mother if she sought help, *I thought I'd be a bad mother if I gave in.'* That to the informant would be a disgrace.

'There is an expectation that you are the same person, when in fact you are just shattered and you're being required to be a mother and pulled upon, and responsible, and difficulties result from that.'

'When I wasn't at work or preparing to go to work, I was travelling to and from work. Then I was back at home, bathing the children, feeding the children, stroking them to sleep. Then I'm shovelling food in my own mouth and then I'm in a coma on the sofa.'

'In hindsight now I realise that even at this stage I had begun to juggle aspects of my life in order to live with PFD.'

5.3.4 Religious and Philosophical factors

5.3.4.1 Religious beliefs and health

The informant did not have any formal religious faith but had a philosophy of not giving in, *'I have a tendency to be a martyr, which makes me think that it's my lot. I just have to get on and do it and put up with things.'* The informant considered these attributes as part of her personality rather than a religious or philosophical belief. This is discussed in more detail in section 5.3.5.

5.3.5 Personality Factors

5.3.5.1 Personality traits

The informant identified herself as a pragmatist and considered that this had an impact on how she dealt with many stressors in her life.

'I'm quite a pragmatist in life and generally that's how I cope with many things.'

'I think my personality leads me to being far more likely to internalise things and to try and crack on with things and not talk about it. I don't go out and seek help very much.'

5.3.5.2 Emotions

The informant experienced a range of emotional responses whilst coping with her PFD symptoms: guilt, blame, embarrassment, anxiety, the need to be selfless and anger that she was ill and had not sought help earlier. These emotions also raised her need to be valued as an individual not just a mother; potentially this need to have her self-worth re-affirmed was her attempt to negate the fear of failure which she was experiencing.

'If you've got a job and a partner and children, these are three balls that you can keep in the air but you can't be selfish. The fourth ball is your health, but you can't juggle four balls.'

'My reluctance to cause further anxiety to my family impacted on the way I have dealt with this problem. It makes me not want to involve them because I don't want to worry them. My behaviour has changed in a more protective way towards them because I'm perfectly capable of dealing with my own health.'

'I was also quite angry. I was a bit angry with myself that I hadn't sought it earlier, but then I did have extenuating circumstances. I was a bit pre-occupied.'

5.3.5.3 Permission

The informant coped by not giving in, but she felt that someone should have taken control of the situation for her. She clearly articulated her need for permission to be ill and acknowledge the

severity of the problem. She only discussed her longstanding PFD symptoms at a routine hospital outpatient appointment when she was asked directly about urinary and sexual problems.

'*It was only once I sought medical help that my problem was something concrete that I was able to share with people. It made it real for them and it made it real for me. It gave me permission to go and tell everybody that what I'd got was really serious.'*

'It gave me permission to be ill and to be upset and to be angry; gave me permission full stop. It gave me permission to have attention on me.'

5.3.5.4 Coping Mechanisms

The informant articulated the coping mechanisms she had employed to cope with her PFD symptoms. The informant used humour, palliation, denial and avoidance to help mask the embarrassment and shame she felt with regard to her PFD and the possibility that she was failing in her role as wife, mother and career woman.

'I use joking or humour to help me get through, as a means of coping, I mean; you can do nothing but joke about it, surely.'

'If you've got a smile on your face, it makes it easier, it's a deeply embarrassing problem, I'm ashamed so humour/ joking gives me some sort of protective distance; a barrier.'

'I suppose I coped because the pain of childbirth was so much greater. All this time I'd just been coping, coping with a sick baby, not giving in. It probably entered my head every two seconds, but I never voiced it. I didn't tell anybody, I don't give in much.'

5.3.6 Educational Factors

5.3.6.1 Knowledge

Although university educated, the informant had little knowledge of PFD and therefore her perception of the severity and nature of the problem initially negatively impacted on her help seeking behaviour. The pelvic floor was thought to be quite a difficult concept to understand.

'It's a very euphemistic concept, and I would think I would be the sort of person who would be able to get it, and I still don't really. It's a really abstract concept. Before this problem started, I'd never heard of pelvic floor dysfunction. I didn't know that you could have urinary, faecal and sexual problems related to childbirth or delivery. I knew I had to do pelvic floor exercises after my deliveries.'

5.3.6.2 Communication and language

As an articulate individual with good communication skills, the informant did not feel that communication issues or language were a barrier to help seeking. She did not have a problem in explaining what her problems were. The issue was of not wanting to volunteer the information. The informant did not articulate this factor as being of importance or relevant to her help seeking and coping behaviour and consequently adds no new data.

5.3.6.3 Perception of the problem

The informant realised there was a problem but went through stages of denial and avoidance. Her perception was that the symptoms were manageable and therefore *'not a problem.'*

'I'd never told anybody until I went to the hospital and was asked directly, that I have problems with my bladder. Sometimes I leak urine, but don't we all suffer that type of thing after childbirth?'

'There's a possibility that presenting my problems to my friends and family in such a jokey way was my way of trying to prove to myself that the problem wasn't really that serious.'

5.3.7 Technological Factors

5.3.7.1 Health Beliefs

The informant's experience of managing her severe nut allergy impacted on how she dealt with her PFD symptoms. She had developed clear strategies of avoidance and occasional risk taking behaviour when dealing with her nut allergy and naturally employed these learnt behaviours in managing her PFD symptoms. Potentially the informant compares the life threatening nature of her nut allergy with her PFD symptoms, and judges them to be minor in comparison.

'I have a severe nut allergy, with severe allergic [anaphylactic] reactions. This started when I was a child and I've learnt, with the help of my family, to live with it.'

'I suppose I throw caution to the wind at times but I'm not being a risk taker, just a pragmatist. But I have nearly died on a number of occasions. I think that probably sums me up medically. I think maybe the way I've learnt to come to terms with and manage my nut allergy, has impacted on how I coped with the pain of my pelvic floor dysfunction problems.'

'I know how many accidents I really have, which are lots, and so if I was ever to admit that to my family they would be seriously worried.'

'The pressures of my life directly affect my health.'

5.3.7.2 Knowledge of services

The informant did not articulate any concerns about not knowing who to discuss her PFD symptoms with; she was aware of her GP services but chose not to use them. This decision was related to her not 'giving in' rather than any distrust of the services.

5.3.8 Socio-Economic Factors

The informant addressed the issue of the cost of pads, cost of pills and the cost of time off work, as factors which did have an impact on her ability to cope with her PFD. Although the greatest issue was the inconvenience of time off work and potential stresses this might cause rather than a direct financial burden from unpaid time away from the workplace.

'I'm spending a fortune on pills and potions. Its extra money.'

5.3.9 Care Influencers

5.3.9.1 Trigger to help seeking

The informant indicated that pain was a trigger factor in her seeking help but in fact it was at a routine hospital follow up appointment, when directly questioned that she first described the problems she was experiencing. So although the pain was severe, it was not a worsening of the pain which facilitated her seeking help, rather the direct questioning of a doctor which was the trigger.

'It was a regular check up because I had had a third degree tear. It was the first time I had said anything and it was a very emotional period for me, and there were lots of tears.'

5.3.9.2 Barrier to help seeking

The exhaustion of juggling her role obligations presented the major barrier to help seeking, with lack of time being seen as the major barrier. Lack of knowledge and insight into the problem compounded the barrier to help seeking. In conjunction with the fear of failure the informant experienced, role obligations and lack of knowledge became significant barriers to help seeking.

'Exhaustion was probably the most detrimental aspect of my life, the thing that prevented me seeking help.'

'I think that part of my reluctance to acknowledge that there was a problem, was my feeling that there just wasn't any time.'

'Throughout the course of my two pregnancies, in reality nobody really discussed with me the potential problems that I could encounter. I had no knowledge of how pregnancy and having children would change me as an individual.'

5.3.9.3 Facilitator of help seeking

The informant identified the importance of 'permission' as a facilitator of help seeking. She felt that post delivery all women should have routine follow-up appointments where PFD issues would be discussed routinely. The informant would have found active questioning by the midwife and health visitor helpful and she felt this would have facilitated her discussing the problem much sooner. Equally the informant described how useful a written information booklet, given to her following delivery, would have been, like a check sheet of symptoms or problems which could occur following childbirth. This form of written information would give written rather than verbal permission for the woman to raise the subject with a health practitioner.

'If I'd been provided with something that was readable, that I wouldn't have to read at the time, but I could keep and, in a private moment if I was anxious afterwards, I could've read, then I would have realized, I would've known I'd got a problem and I would have sought help'.

'Definitely having more knowledge about the potential problems and what can be done to treat them would have helped.'

'I think if all new mothers were given a routine appointment, a sort of compulsory appointment where there was childcare available, so that you could go and sit on your own and talk to the health care professionals about yourself, without having to look after your baby, then all sorts of things might come to light.'

5.3.10 Summary of thematic analysis

The informant articulates the cultural pressure she perceived to be successful as a wife, mother and career woman and the fear and shame she felt would be associated with failure or asking for help. The fear of failure and the perceived shame associated with this, is related to both her incontinence and her failing to cope in the mother/career woman role. The disgrace and fear of failing, not coping, and the part it plays in this woman with PFD, is related to both her role as a woman (in her culture), what it says about her as women in her culture, and the perceived stigma associated with the medical condition itself. This re-enforces the importance of 'culture' and the perceived shame that is associated with failing within cultural role obligations. If PFD contributes to the women's inability to cope and function as her culture expects, then this reproach or shame is felt. It is suggested that PFD impacts on a woman's ability to fulfil/live up to her role obligations in her society. Not coping within her cultural role alongside the nature of her PFD symptoms are entwined, the two appear to coincide. If the woman had no inability to function as a woman in her society she would not experience this perception of shame and

failure (this issue is discussed further is Chapter 8 where examples from different ethnic cultural groups support this hypothesis).

A pragmatic personality who does not ask for help or 'give in', elucidated the perceived disgrace '*if I let these chinks of vulnerability seep through, then maybe I couldn't keep juggling all these balls in the air, and keep going.'* Lack of knowledge was identified as a barrier to help seeking and the need to be asked directly about the problems associated with PFD was seen as essential in facilitating help seeking.

5.4 Expositional Analysis

5.4.1 Sunrise Enabler

The Sunrise Enabler facilitates the discovery of potential and actual influencers on care and health phenomena and relates them to historical, cultural, religious and other social structure factors (Leininger 1988). Leininger does not identify that personality might have an impact on an individual's lay care beliefs and practices. Personality was identified in the literature pertaining to coping and help seeking behaviour as an important variable in health care behaviour (Oh & Park 2004, Brittain et al 2001, Shaw 2001, Facione et al 2000, Rotter 1966) and the Life Health Care History informant identified that her pragmatic personality impacted significantly on the management of her PFD symptoms and consequently coping and help seeking behaviour. Consequently the Sunrise Enabler was modified to include personality. This is an example of the strength of the design of this study, in that it took place in three distinct phases. These phases did not overlap and each phase informed the next stage of the study. After Phase 1 of the study it was apparent from both the literature and the Phase 1 informant, that personality influences lay care beliefs and practices, and it is apparent that decision making style and personality traits impact on help seeking behaviour. Therefore the modification of the Sunrise Enabler as identified in Figure 5.1., facilitated the data collection in Phase 2 of the study and generated evidence to validate or refute the role of personality (Personality traits, emotions, permission and coping mechanisms) in the coping and help seeking behaviour of women with PFD. Including personality in the Sunrise Enabler is not isolating personality from a cultural perspective but is providing the framework to explore the construct further in the following two research phases. This is discussed in detail in Chapter 8. Culture, or cultural expectation impact on help seeking behaviour and the impact of role obligations are explored in Phases 2 and 3 of the study. Modification of the Sunrise Enabler to explore the construct of personality is justified, using data from both an in depth Life Health Care History informant and the literature. This is an acknowledged trait of exploratory research: if you don't pose the question you can't explore the construct (Leininger 1991).

The Sunrise Enabler has also been expanded to include factors delineated from the literature and from Phase 1 of the study which are known to impact on help seeking behaviour in women

(Figure 5.1). The factors are written on the appropriate segments of the Sunrise Enabler and the added segment for Personality Factors is identified by dotted line shading. The described adaptation of the Sunrise Enabler makes it a specific tool for use in exploring coping and help seeking in women with PFD. This new perspective and approach has been derived from the research process. Phases 2 and 3 of the research enable the delineation of the emic perspective of women and discovery of the variables which impact on coping and health behaviour.

Adapted sunrise enabler figure 5.1

5.4.2 Shaw's Framework of Coping

Shaw's (1999) Framework of Coping presents the four coping constructs in a linear fashion, suggesting that women progress through these stages in sequence (Figure 2.2). Personal observation, an extensive review of the literature and the work of Lazarus & Folkman (1984) has led me to believe that women may enter this coping cycle at any stage and may progress or regress through the process dependant on other factors occurring in their lives at that given time. By using Shaw's framework when reviewing the literature and results from Phase 1, I was able to ascertain whether the coping behaviours identified in the framework included all the potential variables that might be employed or exist in a woman with PFD. The informant in Phase 1 did not use the terms event, situation, condition and cue. These are the etic terms used by Shaw to describe a help seeking pathway. As a consequence of this application of the framework to women with PFD (not urinary incontinence alone), the framework has been modified specifically for use in exploring the help seeking and coping behaviour of women with PFD. The Phase 2 semi-structured interview guide (Appendix 2) was developed specifically to identify the individual women's perception of what the event, situation, condition and cue were for her. In Appendix 2 after each question in brackets the specific themes/topics are shown that the question is wishing to address. This aided analysis of each interview transcript. For example the question '*Did you think that this condition/problem was a normal occurrence which was to be expected or was it an abnormal occurrence/problem which you had not expected to happen?* aimed to identify coping, perception of problem, cue, condition, threat, and knowledge.

It is possible to speculate that variables such as a woman's feeling of self worth and perception of the potential for personal stigma or disgrace will impact on her personal coping and help seeking process. Consequently the Shaw framework has been adapted to demonstrate the fluid nature of these concepts (Figure 5.2) and to validate or refute help seeking behaviour in women with PFD. The framework is presented in a circular fashion and the barriers to help seeking are shown surrounding the framework ensuring that it is a specific tool for use in exploring coping and help seeking in women with PFD. The data that were derived from using the modified Shaw framework are summarised in Chapter 6, Table 6.2 (Synthesis of Primary and Secondary Appraisal).

Figure 5.2 Adapted Shaw framework

5.5 Conclusion

This informant's Life Health Care History advances understanding of coping and help seeking behaviour in women with PFD. The themes extrapolated from the Life Health Care History and the modified Sunrise Enabler alongside Shaw's (1999) Framework of Coping have been used to inform the development of the Phase 2 semi-structured interview guide. The knowledge generated provides a foundation for the development of clinical services, in both primary and secondary care settings, which meet the needs of women with PFD.

Chapter 6 presents the results of Phase 2 of the study; identifying opprobrium as a significant construct which impacts on help seeking and coping behaviour.

CHAPTER 6: RESULTS OF PHASE TWO

6.0 Introduction

In the previous chapter a woman's Life Health Care History was presented. It advances understanding of coping and help seeking behavior in women with PFD. The themes extrapolated have been used to inform Phase 2 of the research which is described in this chapter. Phase 2 comprised eight in-depth individual interviews of women with PFD (Informants 2, 3, 4, 5, 7, 8, 9 and 10). The informant registered as number 6 had agreed to participate but a serious accident left her unable to do so. A semi-structured interview guide (Appendix 2) was used during each interview, to identify key themes related to the barriers, triggers, facilitators to seeking help, and coping mechanisms. This chapter describes the thematic data arising from the in-depth interview process and demonstrates the different ways that the phenomenon of coping and help seeking has been seen.

6.1 Demographics

All informants engaged in this phase of the research were English speaking and had sought help for their PFD problem and referred to a PFD Outpatient Service. The median age of informants was 43 years with a range of 32 – 82 years. The median duration of PFD symptoms as reported by the informants was 3 years with a range of 3 months to 15 years. Many women had multiple compartmental problems and these are outlined in table 6.1. The fact that few women in this study complained or discussed sexual dysfunction issues reflects the sampling methods employed and is discussed in section 4.5.1.1. At no point during the study did sampling involve specific presenting symptoms; rather it was considered that if women had been referred and treated in a designated PFD Service they met the criteria of 'women with PFD'.

Participant	Age (years)	Marital Status	Number of children	Working or retired	PFD Symptom spectrum
1	38	Co-habiting	2	Employed	Stress urinary incontinence. Sexual dysfunction Rectal Evacuatory Dysfunction
2	67	Widowed	2	Retired	Urinary incontinence Prolapse
3	43	Married	2	Employed	Rectal Evacuatory Dysfunction
4	47	Co-habiting	1	Employed	Prolapse Urinary incontinence
5	63	Divorced	3	Retired	Rectal prolapse Urinary urge incontinence
6	Non-participant	Non- participant	Non-participant	Non-participant	Non-participant
7	35	Married	1	Employed	Urinary Incontinence Cystocele
8	32	Single	2	Disability Allowance	Urinary Incontinence Rectal Evacuatory Dysfunction
9	82	Widowed	4	Retired	Urinary Incontinence Faecal Incontinence
10	42	Single	6	Employed	Stress Urinary Incontinence Vaginal prolapse

Table 6.1 Informant Demographics

6.2 Thematic analysis of interview transcripts

Following transcription, thematic analysis took place through three overlapping phases of open coding, axial coding, and selective coding. The analysis is structured using Leininger's modified Sunrise Model, with the themes being organised under the eight categories of the model (Figure 5.1); technological factors, religious and philosophical factors, personality, kinship and social factors, cultural values, beliefs and lifeways, political and legal factors, educational factors and socio-economic factors. Figure 6.1 depicts the thematic categorisation as applied to the Sunrise Enabler.

In Leininger's Sunrise Enabler the lower third section incorporates the influences that impact on care expressions and practices. Figure 6.2 depicts the influences that impact on help seeking behaviour. Thematic categories and their relationships to other categories are described in this section, with particular reference to the four stated aims of the study; the barriers, triggers and facilitators to coping and help seeking behaviours.

Figure 6.1

Figure 6.2

6.2.1 Synthesis of Primary and Secondary Appraisal

Following transcription and analysis, a synthesis of primary and secondary appraisal was completed; this included situation, event, condition and cue. The synthesis is presented in Table 6.2 and is then followed by the narrative of the thematic analysis and detailed data from the interview transcripts. Informant quotes are presented in italics and the informant identified by their participation number only.

Life Health Care Informants	Primary Appraisal		Secondary Appraisal	
	Situation	***Event***	***Condition***	***Cue***
2	Worsening of incontinence		Death of husband and noticing a new symptom - a bulge	
3	Intermittent symptoms 1 yr post delivery-thought it was constipation	Reading article on PFD, the symptoms identified were the same as her problem	Reading the article, although her symptoms were worsening the cue was realising the nature of her problem	
4	Immediately post delivery had prolapse, was treated immediately	Realised the prolapse was the same as before	Increasing severity of problem	Increasing impact on QoL
5	Noticed a bulge and thought it was piles		Confirmation of friends it must be piles	Worsening symptoms
6	Non Participant	Non Participant	Non Participant	Non Participant
7	Initially thought it was heavy periods, sought help and had treatment		Despite treatment no symptom improvement	Worsening symptoms
8	Already diagnosed with medical problem, thought it was due to medical problem	Slow continued change in symptoms	Long term health problems	Frustration with chronicity of symptoms
9	Urinary urgency	Slow deterioration of symptoms	Worsening of symptoms	Increasing impact on QoL
10	Pain started during and continued after pregnancy	Continuation of symptoms	Worsening of symptoms	Increasing impact on QoL

Table 6.2 Synthesis of Primary and Secondary Appraisal

6.3 Thematic Exposition

As stated previously Leininger, in her published works, does not describe or define the categories of The Sunrise Enabler (technological factors, religious and philosophical factors, personality, kinship and social factors, cultural values, beliefs and lifeways, political and legal factors, educational factors and socio-economic factors) but rather suggests questions which the researcher might use to explore these areas (Leininger 1995). Leininger envisages that these cultural and social structure dimensions refer to the dynamic features of the interrelated structural and organisational factors of a particular culture or subculture (Leininger 2001, 1990, 1988, 1985, 1985a). All the dimensions may, to varying degrees, impact on human behaviour and influence help seeking and coping behaviour in women with PFD in different environmental contexts.

Analysis of the interview data identified a strong overlapping of themes within three of Leininger's Sunrise Model Dimensions: Kinship and Social, Political and Legal, and Cultural Values, Beliefs and Lifeways. The themes arising from each of these dimensions relates to society and women's role in society.

6.3.1 Kinship and Social Factors

Leininger suggests that Kinship and Social factors can be explored by questioning how friends and family have influenced the individual with regard to their life, particularly their caring or healthy lifeways. She suggests discernment of how family and friends have cared and supported an individual during illness (Leininger 1995).

6.3.1.1 Kinship – knowledge

Women described the ways in which they learnt and gained knowledge from their friends and family and how this enabled them to cope or seek help. Conversely they also described trying to support friends, who also had a problem, with the knowledge they had gained during their help seeking pathway.

'A friend of mine, who's a Nurse, gave me an article to read that she was reviewing, on rectoceles, I'm a Nurse and she wanted me to read it through just to see what I thought of it, and I said "Oh my God, I think this is what I've got". She told me to go to my GP.' **3**

'A couple of friends, they were quite open about it and said if they laughed too much, they'd notice the wetness. It made me feel better in myself to know that I'm not the only one.' **10**

'My sister is a Health Visitor; I mentioned all the things that were happening. She was like "Oh, you might have this problem" and she said "go and see a doctor". So I did.' **7**

'When I started to talk about it, I discovered that lots of people had it. Everyone was popping out of the woodwork. My Mum had it as well, and she was the one who actually bought a box of Tena (urinary incontinence pads for women) *for me.'* **7**

6.3.1.2 Kinship – Social Support

Women described the value of the support they received from their family and friends. Just talking to their family or friends was beneficial and helped them to cope. It was clear the women limited the number of people that they confided in about their problems as many of them had no knowledge of the problem and could not fully comprehend the issues they were experiencing.

'They are 100% behind me, and they do push me quite a lot. They say "now, Mum, come on, I hope you're doing this and I hope you're not doing that", and I am because I'm doing it for me, but I'm doing it for them.' **2**

'There are certain people, my mother, my partner and my neighbour who have constipation problems, but they understand this as being different. I feel better if I talk to them when I'm having a crisis with it 'cos it changes how I cope with it. But I just stick to a few people. I think there's one other woman that knows about it.' **3**

'I mean my daughter's brilliant, and I even spoke to my son, but not in depth of how it was.' **5**

'With my sister I talked about it, 'cos it's really easy to talk to her. So, I was able to say to her I have to use my daughter's nappies because ordinary pads won't do.' **7**

It was considered that PFD services have low priority in society. It was postulated that this was because it was a medical problem impacting for the most part on women only. Given the low priority and status associated with this condition women were reluctant to ask family or friends for support, which put added pressure on the women to cope.

*'It's so low in terms of societal priorities, if we've developed effective nappies for babies, we could certainly have developed effective incontinence (*aids*), technologically it would surely be possible, and we haven't. There's not been that sort of investment 'cos it's not a priority for society to sort out. I think it's partly societal attitude to older women as being sort of asexual and irrelevant.'* **4**

'I'm not saying that it's not being taken as a serious problem. I think there is an element of concern that is invested into it but there's a lot more factors that could be addressed.' **8**

6.3.1.3 Social - Societal Pressure

The over arching theme which arose under this conceptual heading was that of societal pressure. All informants clearly articulated the perceived stigma, shame, degradation and embarrassment associated with PFD. They described a negative response from society (friends), which resulted in them not wishing to discuss PFD and this generated feelings of isolation. It was a hidden problem. The women perceived that they were not being understood. It is speculated that this reaction or feeling is in part due to the women's perception of the fear of shame and disgrace they might feel if their PFD problems were common knowledge.

'I'm a Sexual Health Nurse. I'm used to all sorts of difficult things. I did find it really difficult to talk about. Only a few people in my life know I have this problem. It's a big issue. I thought they'd just look at me as though I was describing something rather revolting and they didn't really want to know.' **3**

'It's bowels. Mainly I just don't want to tell them because I'm frightened of what they might say. They haven't actually been horrible. You're frightened of what someone says that's why you don't say it, and people aren't actually that horrible.' **2**

'*It's a sort of very basic feeling of gone wrong. It makes people feel out of control. It re-stimulates feelings of being a child and being incontinent. So very early that total loss of control, physical disintegration, is very embarrassing, I felt ashamed.'* **4**

'In society it's a taboo subject and there are friends who you can't talk to, because they don't really want to be involved. They're not experiencing it.' **5**

'I suppose if you feel awkward about it, then you are saying you're embarrassed about it. It's just not something that you can bring up in conversation "I've got a leaky bladder" as opposed to, "I've got a broken leg". I would say there's an element of awkwardness about it; it's not something that you can see. If you've got a scratch or bandage, it comes up in conversation naturally. With a bladder problem, unless you mention it to somebody no-one's ever gonna say anything to you because they're not aware.' **7**

'It's just too embarrassing to talk about, what I did was stop going out, *it's a bit degrading.'* **10**

Some informant's articulated feelings of 'Feminist' pressure; with women they knew equating having a vaginal delivery (whatever the problems) as being a good mother. Women expressed a fear of being judged by their peers, particularly if they didn't have a caesarean when advised to do so. These women also expressed their personal lack of insight (prior to development of PFD problems) to women with urinary incontinence and were saddened by their response in the past to women experiencing PFD and to those who may not be receiving help.

'I feel it's a bit my own fault. I was very determined to have a natural birth. I felt that it was something that my body could do, and it did in the end. I don't want to go back and say "well, I should not have done it." I pushed for five or six hours, and I think that's what did it.' **3**

'I remember when I worked in the Nursery there was a worker there and she was quite young, in her twenties, and she'd had two children, and she'd lost control of her bladder. She needed an operation, she was a very young woman, and was a very outgoing person and a positive person. I never even gave it a thought, I never really saw the depths of it for her, and she was working. So, it's just sad really isn't it?' **5**

'When I received all the continence aids, they are just so helpful, the pads and those things that go along with it. They did make that improvement and I think it's quite sad because people aren't aware, people don't know that these things exist.' **7**

Informants considered that PFD was perceived by society as a problem of the elderly, a physical disintegration, with continence being perceived as integral to being an adult. This was articulated by a number of the informants and it contributed to their help seeking behavior.

'I just thought it was an old age thing, and I didn't seem to think I had a problem.' **2**

'It makes me feel old. I associate it with being an old person, and I hate that. I do have big mental issues about it, associating it with being old, which depresses me.' **3**

6.3.2 Political and Legal Factors

Leininger postulates that our world is full of ideas about politics and political actions which can impact on health. She suggests exploring ways in which the individual feels political or legal problems might influence health and well being (Leininger 1995). Despite the fact that the NHS is partly a reflection of the political view/bias of whichever political party is in power, politics and its impact on women with PFD was not raised. Instead women focussed on our society and culture and its associated impact on women with PFD.

Exploration of the political and legal dimension offered little data with respect to help seeking behaviour in this sample and the findings could be appropriately included in the Kinship and Social dimension. None of the informants raised issues regarding legal issues which impacted on their help seeking for PFD, and as such, this factor added no new data.

6.3.3 Cultural Values, Beliefs and Lifeways

An understanding of cultural values are important for health care providers to understand and particularly in relation to what an individual considers to be good caring practices (Leininger 1995). Leininger suggests asking individuals what values and beliefs they feel health care providers should know in order to help them regain or maintain health.

6.3.3.1 Women in Society

A common theme which arose under this conceptual heading was that of gender issues and role obligations of women. Women described issues such as lack of time, juggling commitments, the obligation to care for children and the need to be a good mother as issues which impacted on their coping and help seeking. Narrative examples of women in society are articulated in the following section, Role and status of women.

6.3.3.2 Role and status of women

Women coped with their role obligations by subjugating their needs and experienced guilt that their health problem was affecting their family and job commitments. This is the reality of the lifeways of women with PFD and impacts greatly on coping and help seeking behaviour. Women perceived that if they were unable to perform in their role as mother or wife they would have somehow failed. In essence fear of failing in their cultural role impacted significantly on women's help seeking behaviour.

'Sometimes you push it to the back. He was my priority (terminally ill husband) *and I wanted to give him the best.'* **2**

'You just get on with it. In most situations when you're ill, you just get on and do what you have to do. I've got a young daughter. I think I was just working, started working part time, and stopped doing full time for part time work. You just got on with life.' **7**

'Didn't have much time for myself running around and looking after the kids and plus I was looking after Mum and Dad and I was not taking care of myself generally really.' **10**

6.3.4 Religious and Philosophical Factors

Leininger (1995) posits that when people are ill or anticipate problems they often pray or use their religion or spiritual beliefs as a support mechanism. The rationale for exploration of this dimension is to ascertain how religion/spirituality has impacted on an individual's health care needs and how religion /spirituality can be incorporated into health care services.

6.3.4.1 Religious beliefs and health

All of the informants identified either a formal religious faith or a personal philosophy and belief in themselves. These religious or spiritual beliefs were perceived as positive coping mechanisms and they employed them during their PFD journey to enable them to cope.

'I am a practicing Roman Catholic, and it helps me through all I've been through. I have great faith and I think it's very important in today's society. I think without my faith I wouldn't have got through what I've been through.' **2**

'*I don't have any religious faith. I am a great believer that I need to be in control of my life. I believe I am in control of myself and I need to be in control of the situation.'* **3**

'I had an escape where I could go and meditate and get my peace and, feel more comfortable. I've always meditated for many years; it drops my level of anxiety. I have my own philosophy and I think meditation did help, because I feel that the philosophy I have is that I've got to take care of myself.' **5**

'I get peace and I get relief through prayer.' **9**

6.3.5 Personality Factors

Leininger does not include personality as a dimension which can impact on an individual with respect to their help seeking behaviour or coping mechanisms. Equally personality is not identified in Leininger's Sunrise Enabler as a factor that might impact on lay care practices. There is some evidence from the literature that personality is a factor in coping and help seeking behaviour (traits such as Locus of Control, decision-making style, fatalism, optimism, altruism and opportunism) (Oh & Park 2004, Brittain et al 2001, Shaw 2001, Facione et al 2000, Rotter 1966). Phase 2 of the study has assessed personality to validate or refute the construct of personality with regards to its role in coping and help seeking behaviour. It was considered important to assess personality as a construct in coping and help seeking behaviour in order to attempt to characterize a women's expectations, perceptions and experiences of her illness/coping experiences.

6.3.5.1 Personality traits

There were four overlapping themes which arose under this conceptual heading. These were the impact that personality, emotion, and permission seeking had on the women and their coping strategies. Informants clearly articulated the impact that their own personality played in their PFD journey. They described numerous personality traits which they believed either positively or negatively impacted on their ability to cope, these included: decision making styles, being a realist, pragmatist, stubbornness, fatalism, optimism and pessimism.

'I'm sensitive, maybe it's me, I'll be honest, but it really bugged me. It really upset me and I thought no, I am not going to be beaten.' **2**

'I felt very positive that I was going to be able to manage it.' **3**

'*I just stubbornly carried on. I just behaved as if everything was normal.'* **4**

'I like to think I'm helping myself to maintain the best I can get from myself, I'm very positive, it's just a sort of a blip, and I'm working towards getting better.' **5**

'I've got the lazy mode now, when I was going to the physio, I had to keep doing it to show improvement. Now I'll just chance my arm, I'm not leaking so much, but I am still leaking, so I've got to go back to do my exercises and not sit back and think I can't be bothered because there's no-one to chase me.' **10**

6.3.5.2 Emotions

Discussing their experience of PFD aroused numerous emotions in the informants; the range of emotions tended to be negative in nature and ranged from guilt, blame, anxiety and fear, to sadness, self consciousness, agitation and frustration.

'I think I worry about it more than its real though.' **3**

'I am upset that because I didn't know I delayed seeking help.' **2**

'I need advice and support. I like to know somebody's there. I feel very fearful. If I could sometimes just relax and get on with it, it's all right.' **3**

'I thought I'd rest myself into a coma and then my self esteem went low, my self-worth, depression heightened, and I found myself just on a slippery scale.' **8**

6.3.5.3 Permission

The need for permission to discuss their PFD symptoms was voiced by some informants, who despite having an internal locus of control with regard to self help strategies, had an external locus of control with regard to speaking about the subject and felt the need to be asked directly regarding their symptoms.

'The only times I really go to my GP is in relation to my lungs. So, I'm sure she probably did ask "how's it going?" but I would've just said "oh, fine." Because it's insignificant, but you know it wasn't.' **4**

'*Fair enough the GP would have an expectation that someone would come forward themselves and, in fact, I did eventually, but I can see that for some people they might never go back. Actually I think if the hospital had approached me and asked, I might have responded.'* **5**

6.3.5.4 Coping strategies

Women described numerous coping strategies that they had developed to enable them to live with their PFD. For the most part these coping mechanisms involved containment, avoidance, alteration of life style and meticulous planning.

'It was just too embarrassing; what I did was stop going out, stop doing anything strenuous and just basically stayed at home and ate as much as I could. Well, comfort eating and not dealing with issues or the problems.' **10**

'*I'd kind of squeeze my legs in closer when sitting down or standing up and I wouldn't partake in activities which involved aerobics, because I knew that there'd be a lot of leakage.'* **8**

'*I always bring some special toilet bag with my pads in it, a bag like a nappy bag to put into it, and some smelly stuff, and if I can't dispose of them there, I take them home and dispose of them when I come indoors.'* **9**

'Where there are public toilets I can go in and change my pad, which I do, when I go out. So I've got to plan all that, because that's part of your life isn't it really.' **5**

'You carry around a spare pair of knickers, or make sure, if you're going out, you know the toilet spots, but you just have to plan ahead.' **7**

6.3.6 Educational Factors

Education and knowledge potentially contribute to an individual's ability to stay well (Leininger 1995). Leininger suggests exploration of education and knowledge alongside the beliefs an individual may hold about what knowledge is important for them to remain well and healthy.

Women articulated the desire to have known more about their PFD problem as they felt this would have impacted on their help seeking. The desire to understand more about PFD and have knowledge to empower themselves was equally demonstrated amongst the spectrum of informants, some of whom were from a nursing background or held degree qualifications. The educational background of the women did not appear to affect their knowledge base or their subsequent desire for further knowledge with regard to their PFD problem.

Women clearly articulated that their lack of knowledge regarding their bodies, particularly following childbirth, contributed to their delay in help seeking. They described knowledge or lack

of knowledge before childbirth but also described more generally how they had acquired knowledge.

6.3.6.1 Knowledge

A major theme from the older informants was the lack of pre delivery education and support. This particularly impacted on their undertaking of Pelvic Floor Exercises (PFE) and/or their understanding of the importance of the pelvic floor in keeping them healthy.

'In the years we had babies, in them days you didn't get anything, no information. And in them years, you came out of hospital and that was it. You got on with it.' **2**

'I think I did recall hearing something about the bladder and the impact of pregnancy.' **8**

'If I knew then what I know now, I wouldn't probably be in this situation.' **2**

'37 years down the line, you don't sort of refer back to that but if I look back now, I should have been taught to do something (PFE), *and unfortunately I wasn't, and I didn't do anything to be honest.'* **2**

*'There were no ante natal classes (*when she had her children)*, within three months of the baby coming, you'd go to the clinic and just they'd tell you what to do and that was that.'* **9**

Despite being available to younger women, some either did not attend Antenatal classes or attended alternative pregnancy yoga classes.

'Never attended antenatal classes. No, I always wanted to, but I never did.' **10**

'I did pregnancy yoga classes where we did a lot of work on pelvic floor and about doing it for life. I think it was mainly about urinary incontinence. I don't think faecal incontinence was ever mentioned.' **3**

Younger informants described using the internet to access information, some described the knowledge they had gained from reading or from their mother but ultimately felt a lack of knowledge had impacted on their behaviour.

'I think the internet's made a huge difference, in terms of people accessing information, some of which, isn't terribly accurate. I used the internet, it was quite helpful, but I'm used to being able to distinguish what probably isn't very good and what is more reliable. So, I wouldn't have just accepted anything that I was reading.' **4**

'I did look up on the internet all about surgery, and there's a lot of stuff on American sites, with frightening surgery.' **3**

'No-one said that you might have bladder problems, if I'd been given that information I would've sought help a lot sooner had I known that.' **7**

'I mean I tore and had stitches, I did, know that there might be a level of incontinence and things resulting from childbirth.' **4**

6.3.6.2 Communication and Language

Women described their lack of knowledge impacting on how they could describe their problem but also on their ability to understand information they were being given.

'As a Nurse you know most illnesses, I had no idea, I'd never heard of it. I'd heard of people being faecally incontinent following birth, but I'd never heard of this. It was only when somebody told me there was an illness that I thought I could go (to see the doctor)*. And I then went straight to my GP and told her about it.'* **3**

'He just started spouting words, and I just looked at him and I said can we just stop a minute because I don't understand what you're saying, can you make it a bit simpler.' **7**

'To be honest, I just went and told him that I couldn't stop weeing myself. And when I need to go to the toilet, I couldn't hold it.' **9**

'I needed to know what it was before (she went to the doctor)*, I think that's common, but because it's not a problem we talk about very much, we're not aware of it, so we don't know it exists so we don't go.'* **3**

6.3.6.3 Perception of the problem

The woman's perception of the problem, from her knowledge base, impacted on her help seeking behaviour. It appears that those women who considered it a medical problem perceived that they sought help promptly.

'I knew immediately it was a prolapse. I didn't understand what had happened, exactly, technically, but I knew what it was.' **5**

'The actual birth had been so straight forward that I hadn't anticipated any difficulties really.' **5**

'I wondered what was the problem, and if I coughed I'd have an accident and due to the fact that I've had so many kids, it just seemed like they tended to say oh, well wear and tear of the body.' **10**

'I kept running to the loo and having accidents, then I noticed this bulge, which I hadn't noticed before and I'm sure I would have noticed it. So the minute I noticed it, I had a feeling that it was something to do with my womb.' **2**

'It may sound quite bizarre, but I was sexually abused from the age of 6-15 years. I've always, psychologically, emotionally been concerned or worried of the impact it may have had internally on my bladder.' **8**

6.3.7 Technological Factors

Technology and modern equipment and appliances are a factor of modern life. Leininger (1995) suggests exploration of an individual's perception of technology and its ability to help or hinder health and health care practices. The themes arising from this dimension overlap to some degree with women's perceptions of their PFD problem. They describe their beliefs about the illness the treatment and services available and their service expectations.

6.3.7.1 Health beliefs

Some women initially considered the problem to be age related and therefore assumed nothing could be done.

***'**I just thought it was old age, and in the beginning it wasn't bad. But as it went on and on it got worse.'* **9**

One woman initially thought the leakage a result of her periods and as a consequence did not seek help: *'If I sat down or stood up, I'd feel leakage. If I coughed or laughed and walked or just trotted a little bit for a bus, I'd find that I was leaking. I'd always think I was on my period, and then I'd find that I'm not on my period, but I'd just leaked.'* **8**

Others did not seek help because of their assumption that surgery would be the only treatment option offered: *'I assumed I would have to have a hysterectomy. I didn't actually know but I assumed it was a hysterectomy.'* **4**

A woman who had a serious medical problem since her 20's felt that her other medical condition was far more serious and in relation to that her PFD problems were more insignificant: *'I've had to learn how to cope* (with severe asthma)*, that's been massively more serious implications of that and series of sort of lung, pneumonia and pleurisy. So, managing that has felt a much bigger issue than managing this actually.'* **4**

6.3.7.2 Knowledge of services

A good and longstanding relationship with a GP appeared to enable women to seek help once they considered they had a problem.

'I had a really good relationship with my GP for 19 years, it felt very straightforward actually.' **4**

'It made it easier, he wasn't like a doctor. He was like a friend. He knew the whole family with my six kids, my Mum, my brothers and sisters.' **10**

'I was attending the HRT clinic, I mentioned it to the doctor there who was very nice, I could talk to her, and she checked me and said she thought I should go and see my own GP about it. I felt better because I thought a woman would know more about those parts.' **5**

'When I found out I was pregnant, I moved from a male doctor to a female doctor. I just thought, if they're going to be prodding me around I would prefer to have a lady doctor. It was easier because she'd seen me throughout my whole pregnancy.' **7**

Unfortunately some women did not have such a positive relationship or experience on consulting their GP.

'I didn't want to waste his time, and it was such a big surgery but he was always busy.' **5**

'When I first started having the problems, I wasn't taken seriously by my previous GP, and apparently the GP is like the gate keeper, so once you go through the GP, you've got access to so much more and that was really frustrating, so, here I am trying to do a lot of stuff again.' **8**

6.3.8 Socio-Economic Factors

Leininger, with her background rooted in the American Health Care system, believes 'money means health or survival' (Leininger 1995 p138). She perceives that money may influence health and access to health services and as such will impact on home care and coping behaviours. The UK NHS currently provides health care free at the point of delivery. However it is reasonable to assume that financial issues such as those incurred with time off work may impact on women's help seeking behaviour.

Women articulated a need to juggle work commitments around hospital treatment and needed to consider the financial implications of time off work for surgical treatment. Economic factors did not seem to be a major factor in women's decision making with regard to help seeking and neither did it appear to impact on their coping mechanisms.

'Well, if I had the money, I would be going privately.' **2**

'I was a director of a company and I was moving on to another job, so I only had a certain amount of cover for sick pay, and I had to take at least four weeks unpaid. So it had hugely serious implications financially. I had a complete choice really in terms of when it was. They let me choose exactly (when her operation date would be) *when it was, which meant it was manageable.'* **4**

6.3.9 Care Influencers

From the data it has been possible to delineate the Care Influencers on help seeking in women with PFD. These Care Influencers are organised under the headings help seeking barriers, help seeking triggers and facilitators of help seeking. The knowledge articulated as Care Influencers is knowledge discerned through this research and has not been discovered previously through research. It enhances understanding of the coping and help seeking behaviour of women with PFD. Table 6.3 presents a summary of the findings in relation to Care Influencers and identifies the key dimensions of the Sunrise Enabler which impact on help seeking. It is evident from the thematic analysis, abstraction and summary of care influencers (Table 6.3) that the key dimensions which impacted on women's coping and help seeking were Kinship and Social Factors, Cultural Values, Beliefs and Lifeways, Technological Factors and Educational Factors.

To a lesser degree Socio-Economic Factors, Personality and Religion impacted on help seeking. These eight dimensions influence the lower section of the Sunrise Enabler, as described in Figure 6.2.

6.3.9.1 Trigger to help seeking

Each informant identified her personal help seeking trigger. These triggers centred on worsening symptoms and fear that there might be a serious cause for their problem.

'It was becoming severe and I didn't know what it was and that was starting to worry me, because my brother had had bowel cancer.' **5**

'I waited until it was so bad that I had to. I started going to the hospital over it.' **9**

'The conversation came up with my sister again. She was like "what are you doing? You need to go back it's been such a long time, it could be something else". Then she really started my mind off, going off on a little trip.' **7**

6.3.9.2 Barriers to help seeking

Each woman had her individual perception of the barriers that prevented her seeking help. The majority of informants identified the impact society played with respect to the shame associated with the problem and the role obligations of women in modern society. The perceived impact of the perception in society significantly impacted on their help seeking behaviour. Equally lack of knowledge, a poor relationship with their GP and fears about surgery were also seen as major barriers.

'It was a matter of getting to the doctor's. I should've made one a long time ago, it's just that you get into that comfort zone it was just the timing and getting it right.' **10**

'Oh God, that area, it's really hard for you to go (to the Dr)*.'* **2**

'But it was still mainly the disgrace, why it was happening to me?' **5**

'It was absolute horror because I've never had a general anaesthetic. I've never slept a night in hospital in my life, so I think I was quite resistant initially.' **4**

'I knew exactly what delayed me doing it, was my own sort of feeling of "I just can't face this." You know, I don't want surgery, I think I probably delayed it by at least a year if not eighteen months.' **3**

6.3.9.3 Facilitator of help seeking

Each woman had a slightly different perception of the things which facilitated her seeking help, but the two overarching themes that arose were having the knowledge and having a trusted relationship with their GP. These were key in facilitating help seeking behaviour.

'My GPs were good, I knew they would help. They wouldn't just fob me off.' **10**

'When you go in there she listens, I know that I'm not gonna get mucked around when I go in to see her, and I know that she's gonna listen, so for me that made it easier.' **7**

Life Health Care Informant	Barriers	Trigger Event	Facilitator of help seeking
2	Role obligations Stigma, embarrassment and taboo Perception of cause Lack of knowledge	Perception of change from social to medical problem	Trusted relationship with Dr
Sunrise Enabler Categories	***Cultural values, beliefs and Lifeways., Kinship and Social Factors, Educational Factors, Technological Factors***	***Educational Factors***	***Technological Factors***
3	Initially not having the language to describe the problem, lack of knowledge. Thought it was a social not medical problem. Taboo subject- revulsion at the problem. Stigma and embarrassment	Having the language and knowledge to seek help after reading magazine article	Knowledge gave her permission to seek help
Sunrise Enabler Categories	***Educational Factors, Technological Factors, Kinship and Social Factors***	***Educational Factors,***	***Personality***
4	Stigma and taboo Fear of treatment Lack of knowledge Perception of the severity of the problem	Pain	Threat to her well being Good relationship with GP
Sunrise Enabler Categories	***Kinship and Social Factors, Technological Factors, Educational Factors***	***Educational Factors***	***Cultural values, beliefs and Lifeways, Technological Factors***
5	Stigma, embarrassment and taboo Lack of knowledge Isolation Fear of wasting Dr's time	Already had appointment with trusted female Dr so told her	Worsening QoL Trusted relationship with Dr
Sunrise Enabler	***Kinship and Social Factors, Educational***	***Technological Factors***	***Technological Factors***

Categories	***Factors***		
6	Non-participant	Non-participant	Non-participant
7	Stigma, embarrassment and taboo Lack of knowledge Isolation Fear of wasting Dr's time	Knowledge from a poster Discussions with her sister Fear of seriousness of problem	Desire to gain knowledge of the problem Good relationship with GP
Sunrise Enabler Categories	***Kinship and Social Factors, Educational Factors, Technological Factors***	***Technological Factors***	***Technological Factors***
8	Stigma, embarrassment and taboo Lack of knowledge Not being taken seriously by GP Poor relationship with GP	Worry that previous sexual abuse had caused problem	Perception of medical nature of the problem
Sunrise Enabler Categories	***Kinship and Social Factors, Educational Factors, Technological Factors***	***Technological Factors, Educational Factors***	***Technological Factors,***
9	Role obligations Lack of knowledge Need for privacy – intimate nature of problem	Death of husband Worsening symptoms	Worsening QoL Trusted relationship with Dr
Sunrise Enabler Categories	***Cultural values, beliefs and Lifeways, Kinship and Social Factors***	***Cultural values, beliefs and Lifeways , Technological Factors, Educational Factors***	***Technological Factors, Educational Factors***
10	Stigma, embarrassment and taboo Role obligations Lack of social support	Death of daughter Impact on QoL Financial need to work Fear of seriousness of problem	Trusted relationship with Dr Desire to be a positive role model to her children
Sunrise Enabler Categories	***Cultural values, beliefs and Lifeways, Kinship and Social Factors***	***Cultural values, beliefs and Lifeways, Socio-economic Factors, Educational Factors***	***Technological Factors, Cultural values, beliefs and Lifeways***

Table 6.3 Summary of Care Influencers

6.3.10 Ideal world comments

Leininger does not use the term 'ideal world' in the Sunrise Enabler but does suggest exploring the perceptions of individuals about the health care they have received, what has been most helpful for them (Professional and Generic Care Beliefs) and identifying the barriers to good nursing care (General and Specific Nursing Care Factors). The closing part of the interview placed the informant in an 'ideal world' situation, giving them permission to speak freely about what they would have liked to have known about their condition, the things that might have made it easier for them to cope, and the services they would have liked to receive. The 'ideal world' scenario was used to facilitate free and open comment by the informant as it lessened the psychological stress of the question by allowing the informant to respond either in 'an ideal world scenario' or as another person. As stated previously, the use of the 'ideal world' strategy allowed suggestions of how services might be developed to be raised without the informant feeling they were criticising me or the hospital services in any way.

The knowledge arising from an 'ideal world' scenario has not been discerned in research before and gives the reader an understanding of some of the issues which would have improved the coping and help seeking pathway for these women. It also elicits their beliefs and hopes for the future with regard to PFD.

6.3.10.1 Aids to help seeking

In an ideal world women considered that having more time or support in their role obligations would aid help seeking. Women felt that if there was more knowledge in society about PFD, it would help to lessen the taboo and stigma which they felt was currently associated with the problem. Raised awareness and knowledge about the problem and information about the services that are available would lessen the fear of stigma.

'Having more time would have made it easier to cope; it would be nice to have all the time.' **10**

'I think more knowledge in society, then it's not a taboo subject, there is no disgrace. It's very much like sex isn't it? It's supposed to make things more knowledgeable and that people do get these things.' **5**

'It's about breaking the taboo, making it more ordinary.' **4**

6.3.10.2 Service improvement

When discussing how services for women with PFD might be improved in an ideal world, women articulated the need to raise the profile of PFD by advertising the condition and the

services available. This would have the double effect of making it easier to seek help because women were better informed and therefore empowered. Once women have sought help they felt that support throughout their treatment pathway would be beneficial. The importance of Pelvic Floor Exercises and their role in women's long-term health should be more widely known and publicised. To aid women suffering from PFD, public toilet facilities should be improved and a cure for the problem found.

'*There is a question of how you support women once they come in, and I think it was really good that the GP knew what I was talking about and her attitude.'* **3**

'We need to know much more about what they mean about pelvic floor. We need to talk about it in a positive way in ante natal classes, not necessarily in a negative way. You've got to talk about having a good birth and protecting yourself to avoid these bowel problems.' **3**

'I think a lot of women need to go to physio to understand their bodies, understanding how pelvic floor exercises work and how our bodies can regenerate, to get our bodies back to work.' **10**

'A poster, in patient language. A leaflet of the things that could go wrong, then you might be a bit more informed so that you would be able to seek help a bit better.' **7**

'If it was advertised a bit more, so that people are aware of the problem. You've got loads of posters telling you "look after your heart" and there's nothing about bladders.' **7**

6.3.11 Summary of thematic analysis

Following the third stage of thematic analysis (selective coding and data abstraction) data were organised around a core category. Opprobrium appropriation was selected as the core category on account of its critical importance in the coping and help seeking pathway of women with PFD. Opprobrium is essentially a state of disgrace resulting from society's reaction to a problem. From this Phase of the research it is evident that women perceive the sense of disgrace, ignominy and reproach associated with PFD problems. The degree to which women appropriate opprobrium is dependent on their feelings of self worth as women in society and also their personality. Thematic analysis has demonstrated a strong link between the dimensions Kinship and Social Factors and Cultural Beliefs and Lifeways. These dimensions, as illuminated by the informants with PFD, all reflect the key impact of society on women's coping and help seeking behaviour. Opprobrium appropriation (the perceived stigma and social taboo and the role of women in society) significantly influenced help seeking and coping strategies as women feared the stigma that might follow public knowledge of their PFD problem.

There are domains of the Sunrise Enabler in which opprobrium has no apparent impact or link. The Sunrise Enabler identifies potential influences that might explain care related to the stated domains. Depending upon the constructs being explored not all domains of the Enabler will be involved. This is not a failing of either the Enabler or the research process but rather a clear delineation of the domains in which opprobrium impacts on the help seeking and coping behaviour of women with PFD. Using the Sunrise Enabler to explore help seeking beliefs and practices was appropriate as the Sunrise Enabler was developed to facilitate the exploration of any construct that may impact on care practices. Using the Sunrise Enabler in this study has enabled the delineation of the dimensions which impact on help seeking behaviour and has facilitated the observation that three overlapping factors (Kinship and Social Factors, Cultural Values, Beliefs and Lifeways and Political and Legal Factors) all relate to society and women's role within their society or culture. As a result of this data synthesis the overarching impact of opprobrium appropriation has been illustrated. Opprobrium appropriation (a sense of shame or disgrace) is influenced significantly by the role of women in society and the women's sense of self worth. The less status and self worth a woman feels she has, the more PFD is likely to impact on the degree of opprobrium appropriation for that woman.

Educational Factors and Technological Factors appear to overlap with knowledge and understanding key issues in both factors. Knowledge is seen as a key factor that prevented help seeking as this influenced a women's perception of their problem and also their health beliefs. Knowledge of potential treatments and a fear of surgery as the only option impacted on women's desires to seek help.

Religious and Philosophical Factors were identified as positive coping mechanisms which supported and enabled women throughout their help seeking journey. Personality has been shown to both positively and negatively impact on coping mechanisms and on help seeking behaviour. It is speculated that different personality traits influence how a women senses or perceives opprobrium and as a consequence how she reacts to that appropriated threat.

Care Influencers demonstrate the range of barriers, triggers and facilitators of help seeking and these findings have been replicated and amplified in the informants' ideal world comments on what would aid help seeking and service provision. Worsening symptoms on quality of life and fear that there might be a serious cause for their problem was a recurring trigger to help seeking. The majority of informants identified the impact society played with respect to the stigma and embarrassment associated with the problem and the role obligations of women in modern society. Lack of knowledge and a poor relationship with their GP and fears about surgery were also seen as major barriers to seeking help. Knowledge and having a trusting relationship with a GP were the key themes in facilitating help seeking behaviour. Knowledge,

empowering women and altering society's perception of PFD to remove the stigma and taboo were re-affirmed as key to facilitating help seeking behaviour by women in an ideal world scenario. Such recurrent patterning of the themes throughout the dimensions of the Sunrise Enabler demonstrates the different yet consistent ways in which the phenomenon of coping and help seeking occurs in women with PFD and the impact of opprobrium appropriation. A summary of the Phase 2 thematic analysis is presented in Table 6.4. In the column 'Link to Opprobrium' the text in italics are potential and speculated links with opprobrium posed as questions. These potential links will be discussed in more detail in Chapter 8, in the presentation of a conceptual framework.

Categories	Themes	Link to Opprobrium
Kinship and social factors	Kinship Low priority in society Knowledge learnt from friends and family Social support Social Societal pressure Feminist Pressure Societal pressure	Women articulated a fear of the shame and disgrace they perceived society would place on them with respect to their PFD symptoms. Limited social support and limited knowledge within society placed women with PFD in a situation they perceived to be stigmatizing and shameful.
Political and legal	Perception of PFD associated only with the elderly	PFD was perceived to be a condition associated with ageing, in those younger women this caused feelings of shame and embarrassment that it had happened to them as a younger person. Even in the older informants despite the societal perception that it was a problem of ageing it was considered embarrassing and if known about would bring them disgrace.
Cultural Values, beliefs and lifeways	Gender Issues Role obligations	The role obligations of women in society and the perceived intimate nature of PFD symptoms caused feelings of shame and embarrassment.
Religious and Philosophical Factors	Formal religious faith Personal philosophy	*Does religious or philosophical belief protect or minimize opprobrium appropriation?*
Personality (New knowledge)	Personality Traits Emotions Permission	Women developed a stoical ability to mask and contain their symptoms and avoided aspects of social interaction to prevent their PFD symptoms becoming known – thus avoiding the perceived disgrace that would follow if their problem was discovered
Educational Factors	Knowledge from antenatal classes General knowledge from society/family/friends Communication and Language Education	*Is lack of knowledge and public awareness a direct result of the patriarchal design of NHS Health Services? As a consequence of lack of knowledge and awareness of the problem do women feel isolation and therefore a heighten perception of opprobrium?*
Technological Factors	Health care beliefs Knowledge of and access to services/GP Perception of problem and its severity Service expectations	*Would empowerment of women with knowledge surrounding PFD and available services and treatments reduce opprobrium appropriation?*
Socioeconomic Factors	Financial Employment Practical issues	*Does the financial dependence of women whose role is in the home impact on opprobrium?*

Table 6.4 Summary of Phase 2 Thematic Analysis

The following chapter presents the results from Phase 3, which are the Turkish, African and Orthodox Jewish focus groups. These focus groups were used to validate/refute the themes discerned in from Phases 1 and 2, identify universality and diversity amongst differing cultural groups of women with PFD, and identify the cultural values, beliefs and practices that impact on women with PFD.

CHAPTER 7: PHASE THREE RESULTS

7.0 Introduction

In Phase 3, focus groups were used to validate/refute those themes discerned in Phases 1 and 2 and identify universality and diversity amongst differing cultural groups of women with PFD. Phase 3 comprised three sub-group specific focus groups, Turkish women, African women and Orthodox Jewish women with PFD. These groups represent the ethnic mix of the local population served by the East London Hospital. The focus groups aimed to explore the emic perspective of women with PFD from diverse cultures and to identify the cultural values, beliefs and practices that impact on women with PFD from these cultural groups. In addition, the focus groups were intended to facilitate an understanding of why women with PFD from different cultures do not seek help earlier in their symptomatology and understanding the coping mechanisms that these women develop to compensate for their symptoms.

Phase 3 focus groups followed a semi-structured format, using questions that had been derived from the thematic analysis of Phases 1 and 2, as a guide (Appendix 4). This allowed me freedom to raise other questions in the focus groups to enable elaboration. The closing part of the focus groups placed informants in an 'ideal world' situation, giving them permission to speak freely about what they would have liked to have known about their condition; the things that might have made it easier for them to cope, and the services they would have liked to receive.

The Turkish focus group was aided by a Hospital employed Health Advocate (HA). All questions were translated into Turkish and the responses translated into English. This entire process was recorded and the audio tape and transcription were reviewed by another Hospital employed HA to confirm accuracy of the translation. All Phase 3 focus groups were fully transcribed for analysis. The analysis was structured using Leininger's modified Sunrise Model, with the themes being organised under the eight categories of the model (Figure 5.1, Figures 7.1, 7.2, 7.3); technological factors, religious and philosophical factors, personality, kinship and social factors, cultural values, beliefs and lifeways, political and legal factors, educational factors and socio-economic factors. The emphasis of the focus groups was on exploring the cultural values and lifeways of each group and the impact of these cultural lifeways on help seeking and coping behaviours.

This chapter describes the thematic data arising from the Turkish, African and finally Orthodox Jewish focus groups. For each group the demographic data will be presented followed by the narrative of the thematic analysis and detailed data from the interview transcripts. Care influencers are not delineated as per the previous chapter. Rather a summary of the universality and diversity of the group findings is presented in section 7.4; Table 7.4, with respect to help seeking and coping constructs in women from different cultural backgrounds.

7.1 Turkish Focus Group

This focus group highlighted issues associated with the role of women in the Turkish culture, the negative impact that PFD had on their perception of their status and treatment within the Turkish community and their associated opprobrium appropriation.

7.1.1 Ethnohistory

Over 12000 Turkish refugees have arrived in the UK since 1988. Ninety five per cent of these are Turkish Kurds (Rutter 1994). Most Kurds live in the mountainous areas of eastern Turkey, northern Iraq, north-west Iran and Armenia. There are estimated to be 25 million Kurds forming what they claim to be the largest community in the world without a country (Born 1996). Most Kurdish people speak some Kurdish as it is central to their ethnic identity, as well as Turkish. In Kurdistan the literacy rate is 48% (Rutter 1994). The majority of Turkish Kurds are Sunni Muslims (Towle & Arslanoglu 2003).

From 1915 to 1918, Kurds struggled to end Ottoman rule over their region. The Treaty of Sevres stipulated creation of an autonomous Kurdish state in 1920, but the subsequent Treaty of Lausanne in 1923 failed to mention Kurds. In 1925 and 1930, Kurdish revolts were forcibly suppressed. Following these events, the existence of distinct ethnic groups like Kurds in Turkey were officially denied and any expression by the Kurds of their ethnic identity was harshly repressed. Until 1991, the use of the Kurdish language in Turkey, although widespread, was illegal. The Partiya Karkerên Kurdistan (PKK) is an ethnic secessionist organization using diplomacy towards the Turkish state, but also force against military targets for the purpose of achieving its political goal. Between 1984 and 1999, the PKK and the Turkish military engaged in open war, and much of the countryside in the southeast of Turkey was depopulated (Office of the Prime Minister 1993).

The 2001 Census (ONS, 2001) does not provide specific information on the number of Turkish Kurds in the East End of London. There is a category ‘other white’, which totalled 25,000. The figure, although not precisely known, comprises a significant proportion of service users at the hospital.

7.1.2 Demographics

This focus group was attended by five women, all of whom had sought help for their PFD problems. Informants are identified using the letters A to E. One of the informants worked as a Turkish Advocate in another hospital and as such was considered a key informant as she had knowledge of other Turkish women and their perception and behaviour with respect to PFD (informant B). The group was also attended by a hospital employed Turkish Health Advocate (informant HA), who translated throughout the focus group. The advocate also had cultural understanding and lengthy experience of supporting women with PFD and added to the depth of discussion. As such she is considered to be a key informant. The demographics of the informants are shown in Table 7.1

Informant identification	Age (years)	Marital status	Number of children	Working or retired	PFD Symptom Spectrum
A	57	Widowed	1	Disability allowance	Urinary incontinence Cystocele
B	40	Married	2	Employed	Rectal Evacuatory Dysfunction Stress Urinary Incontinence
C	41	Married	2	Unemployed -house wife	Sexual Dysfunction Urinary Incontinence
D	43	Divorced	1	Unemployed - housewife	Urinary Incontinence Prolapse/ sexual dysfunction
E	35	Married	1	Employed	Vaginal prolapse Urge incontinence
HA (health advocate)	Unknown	Married	Unknown	Employed	N/A

Table 7.1 Demographics Turkish Focus Group Informants

7.1.3 Kinship and Social Factors

7.1.3.1 Kinship – Knowledge

This group did not discuss issues regarding PFD with their family or friends and as a result the women were unable to give any examples of knowledge or health behaviours which they had learnt from their kins. This factor identified no new data but reinforced the fear of opprobrium the women perceived if their PFD was known about in their community.

7.1.3.2 Kinship – Social Support

The extended family is considered home, and is the social support structure for women. Some immigration or asylum seekers have less family in this country and therefore describe feelings of social isolation.

'I have a cousin who comes to me when I'm really bad and does a little bit of housework. That's the only help I have.' E

'I don't have many members of my family in this country, an auntie and a couple of other family members try to give me advice. They try to give as much help as they can.' A

'*Most of them they are here. That's why I have a full support from them.'* D

7.1.3.3 Social - Societal Pressure

The over arching theme which arose under this conceptual heading was that of societal pressure. All Informants clearly articulated the perceived stigma; disgrace and embarrassment associated with PFD. Women considered that PFD problems were to be hidden; never to be talked about. There was a perception that they would be outcasts if the matter was known by their family/friends (the clan). Therefore PFD was kept a secret; particularly to be hidden from the husband. There was a huge worry for women that if the husband found out about the problem, he would think poorly of them. They may be reproached and feared the husband might take another wife. These fears resulted in the women not wishing to discuss PFD. This generated feelings of shame and isolation because of their hidden problem.

'You don't say it. It is something you hide, you don't say, you don't talk about it openly.' HA summary of the women's feelings.

'I would be an outcast, disgraced.' A

These issues are further discussed in section 7.1.5, where the immigrant Turkish society in England is described; particularly with regard to the patriarchy of the clan structure and the low position and vulnerability of women in this society.

7.1.4 Political and Legal Factors

Interestingly, political asylum was not mentioned in the focus group and government policies or the rights of citizens in this country were not seen as factors impacting on women with PFD. Women talked about the organisation of their local communities and the role and status of women in their 'clan' male dominated society. This is discussed in the following section.

7.1.5 Cultural Values, Beliefs and Lifeways

A patriarchal society was described in which women experienced many cultural pressures as their lives were governed by clan decision making. The women discussed their role in Turkish society, the pressures of marriage and the importance of bearing a male child. All of these issues impacted on women's coping and help seeking behavior and significantly impacted on the women's perception of their own self worth.

7.1.5.1 Women In Society

In Turkey there is a division between rural and city areas. The rural areas are perceived as being more rooted in traditional culture. Turkish society is organised in a clan system, with the richest male of the clan ruling. Although there are examples of acculturation occurring in those

living in the UK there remains a pressure for the 'old' cultural behaviours to continue in this country. Women are perceived as being of a lower status than men, although this belief is stronger in rural areas than city areas. Men have the power within the society and the family, and women have no input into decisions that are made. However in the cities there are some examples of women and men working together and women having some say in life/family decisions.

'If someone is coming from a rural area, the man has the power and the woman is always in the back. But when you go the city, it's similar to London, the man and the women they work together. The women also have a say in what their plan for the future is.' B

'It is not just villages where the woman is second. It can happen in the cities as well, it depends on the individual.' C

A clan is a large extended family and is described earlier in this section, the richest male is the head of the clan. In a clan there is no sexual equality. The male child has more power than a female. Clans condone and support domestic violence and bullying. Therefore imputation for what is perceived as shameful is not uncommon. The clan culture continues in England. Clan's influence and control women's behaviour. For example, women may not be able to remarry, if widowed, if the clan leader does not approve. This may leave the woman alone to cope with everyday life with no practical assistance provided by the clan. Therefore although women are controlled by the clan they may not be supported by the clan. The clan or father may arrange a woman's marriage. This arranged marriage is dissimilar from Asian arranged marriages in that the couple will meet before the wedding. In this country the custom still exists but is not actually enforced and children may choose their own partner from someone they have met.

Clans are perceived by Turkish women in this country as a 'bad thing'. Women are opposed to the clan structure. In rural areas clans ensure the continuation of the treatment of women as second class citizens as that is all the young people see. They have no positive role models of equality and subsequently perpetuate the behaviour. This is changing in the cities where young people see some examples of equality. Although apparently powerful in the decision making role for women, the clan system does not appear to offer support to women. In the UK the family unit is smaller (as relatives are residing in Turkey). Family support is given to women.

'I lost my partner about twenty five years ago. I had a son; if I got married again the people in my community will look at me. Why are you getting married? It would be like I would be a bad

person if I wanted a second marriage. This gives me a burden with my life because I have to cope with everything.' A

'I am against clans because usually the men marry three or four times. Most of them don't go and study, they don't read and write. I am against totally what they are practicing.' D

7.1.5.2 Role and status of women

Many women, particularly from rural areas have no education. They are expected to marry between 14 - 17 years of age. Marriages are arranged by the clan. In marriage women are expected to produce male children and ensure the sexual satisfaction of their husband. Women are encouraged to have many children. If women cannot produce a male child the husband may take a second wife. A male child ensures the continuation of the family (clan) name. A husband always wants a son first; daughters are not as important. Multiple wives do happen in the UK, not officially but in secret. Often the second wife will be younger. The first wife has no choice in this, and she cannot stop the husband taking a second wife. The HA described issues of ultrasound in pregnancy being used by Turkish men to determine the sex of the child. If female, it is aborted. Women in the group explained they were trying not to let this happen in the UK, by using support from social services and advocates. However, to their knowledge and experience it is still occurring in the UK.

'In the clan women have no equality; the male child has more power than the female.' E

'The pressure on women in the community is great. I had issues where domestic violence was concerned, and I had to remove one of the patients and put her into a women's refuge, but that was looked bad upon.' B

'The clan men marry three or four times, they have a lot of children. Maybe twenty children.' D

'I've come across multiple wives. It does happen here unofficially. They do it openly. They get a second wife and I witnessed this.' B

'Arranged marriages, it's not the same as the Asian community. The Asian community they don't see each other, they don't have any communication, they don't talk, but in Turkey it's different.' B

'They bring pictures from Turkey, show it to the girl and if she likes him, they go to Turkey and they get married. This is still happening.' E

'I fell in love with someone, I went out and I had the opportunity to do that, but everyone doesn't, and the arranged marriages are different. Like, for instance, my brother he was told to get married to my cousin because the family wanted them. There was a period where there was an engagement where they got used to each other and then both of them agreed and they did get married.' B

'From the beginning they want a son. The girls are not important at all.' A

'If the wife cannot have kids or they cannot produce a male child, then the partner goes and remarries.' A

For Turkish men sex is very important but women have no knowledge of what is expected of them in a marriage or the fact that for men it is perceived that sex is the most important thing in marriage. If a husband judges that a women's vagina is too lax following childbirth he may take another wife. Women may be pressured into seeking surgery to tighten the vagina. If a husband is not sexually satisfied he will be unfaithful. Many families break up because of this.

'The men in our community say that after women have babies they are so loose that they cannot satisfy them. That's why they start to be unfaithful to their partners.' D

'When you get married you are a virgin, you're tight. When you have a child, you're wide, that's what the husband notice first.' C

7.1.6 Religious and Philosophical Factors

7.1.6.1 Religious beliefs and health

The Koran states no intercourse during menstruation; equally women cannot pray when menstruating or fast (during Ramadan). Post delivery there should be no sexual intercourse for 40 days, during this time women should rest and care for the baby but men do not respect this.

'Religion does affect us, if we are with our periods, we don't pray, we don't have sexual intercourse, we can't fast.' C

'After you've given birth there's a 40 day period where you don't have intercourse, and if you're still bleeding after the 40 days, you shouldn't be having intercourse. That's the special time when the woman should rest and care for her baby.' B

'But the men they don't really care that much about you. They don't even hold on for three days.' D

7.1.7 Personality Factors

7.1.7.1 Personality traits

Women did not explicitly describe aspects of their personality with regard to their help seeking behaviour. Rather they discussed their feelings of low self worth, fearing rejection by their husbands and disgrace within the clan. This negative perception of themselves seemed to impact on their coping behaviours and amplified the embarrassment and shame associated with PFD.

7.1.7.2 Emotions

The emotions described by women were the shame and embarrassment they felt about having PFD problems and the fear of how their husband or family might react to them.

'I am hiding it. I feel too ashamed and embarrassed to talk about it with my partner. Is he going to think differently about me? ' B

'I kept it secret that I was incontinent but when I was sitting with another ten people in the room, my friend had a material chair, and actually my incontinence passed the material. The disgrace it caused me, so much embarrassment, to the extent that it made me ill.' A

7.1.7.3 Permission

Women did not feel that being asked directly by a GP or health care provider would have aided their help seeking behaviour. They consciously decided not to seek help and to hide the problem for fear of reproach and rejection from their local clan and family. Once they had made the decision to seek help they had no concerns raising the issue with the doctor.

7.1.7.4 Coping strategies

Women described the coping strategies that they had developed to enable them to live with their PFD. These coping mechanisms were predominantly negative in nature and involved containment, avoidance and masking. The coping strategies were developed by women to shield them from the perceived opprobrium they would experience were their PFD problem known. There was no disagreement amongst the group regarding their coping strategies.

'I am using nappies; I hide it from the community and other people around me.' A

'Of course I hide it from my family.' C

'Definitely I hide it too, and from my husband.' D

'It is not a subject I talk openly about.' E

'Hiding is the first stage.' B

7.1.8 Educational Factors

Often women from the villages can't read or write. There is a written form of both Kurdish and Turkish but due to the political situation, written Kurdish material has been removed. In the rural Kurdish communities Turkish may not be spoken. Clans control these villages and what language is spoken. Men will often be educated to speak Turkish but the women only Kurdish. However if the clan does not allow it women have no education and cannot read or write.

'Kurdish, but bear in mind most of the people especially from the villages, they don't know how to read and write.' A

'Yes we do have written material in Kurdish and they can speak it but because of the political issues in Turkey, all those materials have been removed.' C

7.1.8.1 Knowledge

Personal and health issues are not discussed. Issues such as menstruation were not discussed even with their mother and sexual issues were never discussed by mother and daughter. The

women did not learn from their mothers that problems could occur post pregnancy and they had not heard of PFD or incontinence. There was no knowledge of pelvic floor exercises as being important post delivery. In Turkey there is a practice of wrapping the abdomen tightly in a sheet of material for 40 days post delivery to keep 'everything tight'. When some of the women tried to do this in the UK they were stopped by the midwife. When asked if any of their female relatives had ever shared post delivery stories or problems all informants unanimously said *'No'.*

'It's a cultural thing after you have the baby you get something and you rub your stomach to keep it tight in. She tried to do it here and the nurse removed it and said to her 'you cannot do that because it stops the blood coming out.' HA

'It's a sheet, it's a big and you wrap it tight.' C and D (merged narrative)

'The only thing that my mother said to me was don't walk bear feet because you're gonna end up having gynae problems.' C

When asked if they had any information from ante natal classes all women replied *'no'.* They either received no information on possible PFD problems or they did not attend ante natal classes.

'I had one child in Turkey, one here and both times nobody gave me any information.' D

'I have two children. The first one I had in Turkey with the midwife. The second one I had here, but neither of them told me about pelvic floor exercise.' C

7.1.8.2 Communication and language

In this country the Turkish advocates translate into Turkish for women, then a male member of the family may have to translate for the women from Turkish to Kurdish. This means women may need male family members with them and this may impact on the openness of discussions. As a consequence education has a substantial impact on women's ability to communicate.

'Kurdish Communities they don't know Turkish. There are some villages they only speak Kurdish and they don't know Turkish. Some of my patients I used to speak to them in Turkish. The husband used to translate to Kurdish and I used to translate to English.' B

'It's nothing to do with language, because here we have interpreters' .E

7.1.8.3 Perception of the problem

There was a belief amongst the women that pregnancy and childbirth had caused their PFD problem.

'We have lack of education because there are not enough schools there and most things are coming from lack of education.' C

'*That's the reason that we have all these issues because they didn't see or know any other way.'* HA (Summary of the women's discussion)

'The thing that comes to my mind is having the baby, because I didn't have it before.' C

'Started with pregnancy, but bear in mind I used to go for regular exercise and I stopped it after I got pregnant and afterwards, then it started happening, but it is lack of exercise because I stopped exercising.' B

7.1.9 Technological Factors

7.1.9.1 Health beliefs

In Turkey herbal remedies are popular. The UK NHS is perceived to be not as good as the Turkish health system. There is a form of NHS in Turkey and people pay a small extra amount to see a specialist (the specialist they want to see). In this country the system is perceived as much slower as the GP has to be seen and they may or may not refer you to a specialist. There is a perception that those who are unemployed may not be offered the full range of treatment options by a GP. When discussing the first help they might seek for an illness they stated:

'Herbal, definitely like herbal teas and herbal remedies.' C and D (merged narrative)

When asked about health care in Turkey and the UK the women acknowledged *'there is a difference between the countries'* but all reported they were *'not happy'* with UK medical services.

'It's better than nothing. But the system the Turkish people are used to in Turkey and here are different.' B

'There is an NHS system there as well (in Turkey), *which has improved at the moment.'* B

'The service here is so slow, like for example by the time you reach to see someone specialist, it takes such a long time. In Turkey, even though you have the NHS with a little amount of money you can see a specialist in whatever subject, whenever you want.' B and D (merged narrative)

'Even though for twelve years I've worked in the NHS as an interpreter, when it came to my personal needs, I was really vulnerable in hospital. The point is, when I've had this bladder problem, because of the time, it was over when I came to the doctor. Now I've got the problem again, and when I go to the doctor, by the time I'm gonna get the appointment, it's gonna be over. It's because when I'm ill with a cough, like an asthmatic attack I've been getting for months, I lose urine.' B

7.1.9.2 Knowledge of services

The women had a clear understanding that the route of access to hospital services was via their GP. In the previous section examples are shown of their concerns with regard to the service initially available to them. The women indicated that delay in referral impacted on their help seeking behaviour.

7.1.10 Socio-Economic Factors

Some of the women articulated social issues relating to their lack of social support and the need for convalescence to be provided by social services. For many of the women their socio-economic circumstances were directly related to the clan society and as a consequence clan pressures impacted on help seeking behaviour. There was a perception that moving to the UK would make an improvement in their social circumstances and that the state would automatically provide services such as convalescence.

'*I suffered enough in Turkey. I want some sort of help that will ease my life, make it easier to live, to bear.'* A

'I have a lot of health issues. I need a break but the DSS says to me I don't have the right to go on holiday and they are pressuring me to bring them my passport to prove to them that I didn't go abroad that's a pressure. I am on my own. I need a break, it's a pressure and it's very difficult for me to cope.' D

7.1.11 Ideal world comments

7.1.11.1 Aids to help seeking

Women stated that if they had knowledge they would have sought help earlier. Some women didn't even know what incontinence was. When asked if anything would have made it easier for them to come and seek help, they again attributed knowledge to be key in help seeking.

'*If it was different circumstances, and we had the knowledge about this*.' A

'*If I had the knowledge, as soon as I see like the first signs of incontinence I would go and seek for help. That's what I would have done*.' B

'*If I had the knowledge, I would have sought help more quickly. If I knew beforehand the knowledge that I know now, then it would have been quicker for me to seek help.*' C

7.1.11.2 Service improvement

The women identified that they would have liked the opportunity to attend classes for Pelvic Floor Exercises, with a crèche, and identified the need to translate written information and hold classes in a community health centre to ensure dissemination of information and knowledge. The women felt it was important to educate Turkish men as well as women; possibly a reflection of the patriarchal clan society under which these women were subjugated. Without changing the position of women in the Turkish culture, presumably women will continue to fear disgrace and shame from their community and the risk of being an outcast should their PFD problems become known.

'Pelvic floor exercises are very important. But I think it would be helpful if they have some sort of classes but with a crèche available with this, because we all have kids and if you don't have someone to babysit, you cannot attend.' C

'Do some promotion about pelvic floor exercise, teaching the community about what they can do and what the difficulties are for women when they have a pelvic problem.' E

'*Translations, is one thing that we need, but the second thing, is to do health promotion in certain centres, to arrange a woman's group in GP surgeries*.' HA

'*We should address female and male as well, because women have a problem because of them*.' B

7.1.11.3 Summary of Turkish Focus Group Thematic Analysis

It is apparent that the Turkish women's position in their society is seen as lower than that of males. They constantly fear the reproach of their patriarchal and clan dominated society and are offered little in the way of community support. Women fear that if their PFD becomes known they will risk becoming a social outcast. Equally PFD problems may be cited by the husband as a reason for taking a second wife. Although the extended family usually plays a significant role in the social support structure of Turkish women, the participants described a reduced social support structure because of their asylum status (with family members being either deceased or in Turkey). As a consequence these women described how they endeavour to mask and contain their PFD for fear of opprobrium. Figure 7.1 summarises the key findings from this Turkish Focus Group depicted within the Sunrise Enabler. Similar Figures for both the African and Orthodox Jewish Focus Groups can be found in sections 7.2.11.3 and 7.3.11.3.

Figure 7.1

7.2 African Focus Group

This group was attended by only two women. Issues around possible reasons for non-attendance or non-participation were discussed at the group session and will be alluded to in section 8.4. The discussion highlighted issues surrounding the role of women in the African culture, the shame and embarrassment of incontinence and, as a consequence, the impact that culture and PFD has on women's self esteem and their feelings of disgrace.

7.2.1 Ethnohistory

Modern African migration to the UK can for the most part be related to the legacy of the British Empire. The continent of Africa provided some of the earliest and many of the latest colonies of The British Empire. The earliest colonies, on the West Coast of Africa, were a legacy of the Slave Trade in that area; the later colonies developed as trading centres. The British Empire comprised the dominions, colonies, protectorates and mandates ruled or administered by the United Kingdom (UK). From 1922 the British Empire was disbanded and most of the territories became independent states. After independence, many British colonies joined the Commonwealth of Nations, a free association of independent sovereign states, of which both Nigeria and Ghana are members. Immigration to the UK from former colonies such as Nigeria was not uncommon. It is estimated that about a quarter of a million Afro-Caribbean people arrived to settle permanently in the UK between 1955 and 1962. The British government then moved to pass the '1962 Commonwealth Immigration Act' restricting the entry of immigrants.

7.2.2 Demographics

One woman was born in Nigeria, (informant A), *'I was born in Nigeria, in Lagos, I've been here the past twenty two years',* the other (informant B) was born in this country of Nigerian and Ghanaian parents and works as a midwife.

Informant	Age (years)	Marital status	Number of children	Working or retired	PFD Symptom Spectrum
A	51	Separated	3	Working	Urge and stress urinary incontinence
B	39	Married	2	Working	Faecal incontinence

Table 7.2 Demographics of African Group Informants

7.2.3 Kinship and Social Factors

7.2.3.1 Kinship - Knowledge

The women articulated little knowledge of potential problems following childbirth, as this was not something that was discussed with their mothers. They knew that incontinence existed but it

was never talked about. It was associated with being a child and a lack of control. Informant B, working as a Midwife was more aware of the acute problems related to third and fourth degree tears at delivery but was unfamiliar with the term PFD and the potential impact of PFD years post delivery.

'My best friend, she had heard of it. One of the women she works with. Hers is worse than mine. They walk to work together and before she reaches work in the morning she has already wet herself. She is running to toilet all day, always taking spare knickers, worse than mine. Anyway this is what my friend told me; at least I know other people are like me. My friends said it's not only you.' A

7.2.3.2 Kinship - Social Support

Both informants had family and friends in the UK but did not consider social support to be instrumental in impacting negatively on their help seeking behaviour, rather social pressure and the fear of disgrace , as described below, played a negative role in help seeking.

7.2.3.3 Societal Pressure

The women expressed fear of gossip and the shame which would arise if their PFD problems were known within their community. PFD problems were to be hidden; never to be discussed as it is something for which they feel ashamed. In addition it would be a reason for the husband to take another wife or mistress. Societal pressure and the resultant opprobrium appropriation impacted significantly on the informant's help seeking behaviour.

'They can't send anybody away. But they will think of you badly. Where I come from if something like this happens to you, never say about it. Keep it to yourself. But if you can tell someone, your GP or anybody who can help you, you must. It helps to talk. Go and see the GP but don't let people gossip about you.' A

''I did the pelvic exercise and everything I was told. But I was so worried, why me? I feel so disgraced.' A

'Young children when they sleep they wet the bed. I never heard of it in adults, and I was so ashamed; I can't say anything in front of anybody. ' A

'Whenever some of my friends are going for an outing I don't go. I can't trust my bladder, I can't trust myself. I would be ashamed of myself.' A

'Even amongst work colleagues it is something I would rather keep to myself.' B

7.2.4 Political and Legal Factors

Government policies or the rights of citizens in this country were not seen as factors impacting on women with PFD. Women discussed their local communities and the role and status of women. It was society itself which was considered to have an impact on women with PFD.

7.2.5 Cultural Values, Beliefs and Lifeways

Generally it was felt that there was a cultural pressure, with issues surrounding patriarchy, the position of women in society and the stability of marriage. All of these significantly impacted on women's coping and help seeking behaviour ; particularly with regard to self esteem and their perception of themselves.

7.2.5.1 Women in Society

In the African continent there is division between rural and city areas but also between countries. The rural areas are perceived as being more rooted in the culture, more traditional. Villages have their Village Chief who is a rich male. There are examples of acculturalisation occurring in those living in the UK but some 'old' cultural behaviours do continue in this country but are not spoken about as freely as they would be in Africa (for example, multiple wives and mistresses).

The man is perceived as the head of the house; the bread winner. The women's role focuses on caring/supporting the children. This is strongest in rural areas and in the cities. In the UK it is more common for women to have jobs and have more say in the running of the house and decision making. There is still the view that the husband must be obeyed and respected and his views accepted. In the UK it is more difficult for women (due to financial pressures). Women *'have to be everything*'; a woman working outside of the home is more common in this country.

'In my country Nigeria, the men are the head of the house and they are supposed to look after the women to fight for them. So the women are not lazy and can do something to support the children. The bread winner is the old man who is supposed to look after the children; care for the woman; to sort out everything.' A

'It's different because here we have to be everything. So we have to behave. We have to work more in this country. It's quite, quite different.' A

‘*Yes, here women do tend to work, but maybe only part time so they can still care for the children and the home.’* B

‘For me it’s slightly different. My family are a bit more westernised in the sense that we were brought up here. I think there has been a lot of changes and in the sense that there has been a lot of separation like divorces, etc. So that has an impact, so the woman then becomes the head of the household. You know, the partner or husband has left the home. I think that African culture, Nigerian or Ghanaian, I think they really are adapting more to the Western world, so, you’ll find more women actually having more of a say in what’s done in the household.’ B

In rural areas there is a village chief who is the richest male. Rich males may have up to 8 wives. This reflects status, position and riches. They will all live together under one roof. Sometimes young women will be made to marry an older rich man. This continues in Nigeria but can happen in the UK, although it is not spoken about as openly as it used to be. Now it is more likely for men to take a girlfriend and support her in another home. But it is not just chiefs that have multiple wives. ‘Normal’ men can have two wives if they have the money and position. There is not a formal system of arranged marriages. Usually people meet at school or university but occasionally the father will arrange a marriage to his friend’s children.

‘People you meet at school or the university or just go out and meet somebody you like.’ A

‘Rural parts of the country they used to do that, give you my daughter to marry. Just married; very young, made to marry and to an elderly man. In some parts of Nigeria the man has ten wives or seven wives.’ A

‘Knowing that the person you are to marry is from a decent home. I think that’s like most cultures. I know in my family, it doesn’t matter where you’re from as long as they come from similar backgrounds to ourselves; i.e. good upbringing, well educated and have the means, then that’s fine.’ B

There is a dowry system, the father of the bride draws up the list of what is wanted and gives this to the groom’s father. No dowry no marriage. This persists even in this country.

'You can't marry without a dowry in Nigeria. A dowry, the list of what they want, it depends on the family. You have to complete the list before you can marry.' A

'Nigerian people who are here, they are still practicing the same thing now. It is the same now. One of my friends is getting married here and it is the same procedure.' A

7.2.5.2 Role and status of women

The normal age for marriage is 21, after being educated. Having children is very important. Up to 4 children is the norm. There appears to be no pressure to produce male heirs. There is a stigma attached to early marriage (perhaps due to the focus on education) and early marriage can 'bring a curse' on the family. There is a stigma, even in the UK, to children born outside of marriage. The role and status of African women in the UK is changing. Now there is divorce and so women have become heads of households and work outside of the home. There was a feeling that men born in Africa had little insight into feelings of women; a lack of intelligence or concern.

'It's more about education. Parents would say, "Go out; educate yourself, and then its marriage". Education is such a big thing for us first and foremost, and once you're educated, got a good education, got a good job, then they would expect you to obviously then look at marriage and then children.' B

'Children are the big thing, before you have children, you get married. The impact of the Western world distorts that, but that strong cultural thing remains. There can be quite a stigma attached if you're not married and have children.' B

'About marriage, the families, the parents are as specific on education as she said. So, education first and whenever they are ready marriage. So everybody who wants to be married has to be at least 21; is the common age in Nigeria. If you marry or get pregnant before then it is a shame on the family. They will curse your family; you won't be able to go out.' A

'Men take many wives because they are rich. They say look at me, my position.' A

'It is considered a status having more than one wife.' A and B (merged narrative)

'My grandfather had eight wives. He was the chief of his village. My father has many siblings of which I don't even know three quarters of them. I know that is more the thing in the rural areas,

and especially those who are quite wealthy. But then again, you know, a lot of what goes on in the Western world is having an impact, you know, in modern Nigeria, Ghana, where it seems that, one wife, one husband is more the norm. Multiple wives' still happen, but I don't think it's as common as it used to be or if it is it's not spoken of as boldly as it used to be.' B

It is speculated that the fear of being usurped; of the husband taking a second wife, would impact on women and their perception of the opprobrium that would be linked to PFD. This fear of opprobrium would amplify women's feelings of personal insecurity and low self worth.

7.2.6 Religious and Philosophical Factors

7.2.6.1 Religious beliefs and health

Religion does not appear to impact greatly on health care practices or beliefs. Regardless of religious beliefs, whether Christian or Muslim, it was considered important to accept health care advice. The informants did not consider that religious beliefs impacted at all on their coping or help seeking behaviour and as such added no new knowledge.

7.2.7 Personality Factors

7.2.7.1 Personality traits

Personality was not identified as playing a part in help seeking or coping behaviour, and the informants did not explicitly describe or identify aspects of their personality. Rather they discussed shame and fear of reproach as being key triggers to their coping behaviour.

7.2.7.2 Emotions

For the most part the women described a fear of their problem being discovered and the resultant gossip which may occur. It is speculated that this fear may originate from the women's perceived sense of opprobrium and the damage to their self repute that would occur if their PFD problems were known.

'I thought to myself, is this what I'm reduced to? I was so embarrassed and ashamed, in front of my children. I just thought I don't know what's happening to my body.' B

'I just can't cope. People look at me and it's the last thing they expect to see. You know what you're going through inside. I just get so fed up, I find it very upsetting.' B

'I am afraid so I keep it secret so there is no gossip.' A

7.2.7.3 Permission

The women did not feel that being asked directly by a GP or health care provider would have aided their help seeking behaviour and discussion about permission did not yield any new data with respect to coping or help seeking behaviour.

7.2.7.4 Coping strategies

Coping mechanisms included hiding, containment, stopping drinking, avoidance of social situations, and regularly waking in the night to pass urine. Women appeared to choose carefully who they would tell, as fear of gossip was great. Masking, through use of fashionable clothes, makeup and hair, and a great emphasis on body image was used to conceal that there could be a problem.

'For me it is better not to tell them, I don't tell anybody. Only just my friend.' A

'If I have to come into hospital for a procedure, I would have to say that I am in hospital to my family especially, but I know how I would word it. So, it wouldn't sound so awful.' B

'For me, hiding it is best. I don't want gossip; people talking about you.' A

'I just make sure I look my best, best clothes, fashionable hairstyle.' B

7.2.8 Educational Factors

As was previously discussed, both women had had the opportunity of a good education and could read, write and speak their own African language and English. They did not feel disadvantaged by a lack of educational opportunities as education is highly prized within their culture and they felt it *'gives you independence.'* With education women would not be reliant on others; they could work if they wanted to.

7.2.8.1 Knowledge

There is a practice of wrapping the abdomen tightly in a sheet of material for a month post delivery to keep 'everything tight.' This is believed to help the abdomen go down and also help with the discharge of blood. The lochia is bathed away in a bucket of hot water with herbs. The woman sits in it and cleans herself. It is a 'duty' to do this for a month following delivery.

'When I had my first child, my Mum tied this cloth around my tummy and I had to sit. I can't remember for how long now, you tied it for so many hours a day, you build the hours up. Your tummy goes down. I was a lot younger, so that would have happened anyway possibly. But, women still do it. They say after you've had the baby, the lochia, I can't remember what my Mum did, put something in really hot water and a bucket. Then you sit on it, and it's supposed to flush away, but I can't remember what it was for.' B

'When I had the baby, I press. You have to press your tummy. The tight sheet. Because you will see the lump and blood coming out black, then you sit on the bucket; the hot water herbs clean everything. When you had the baby you do it for at least a month, it is your duty to do it.' A

7.2.8.2 Communication and language

The informants acknowledged that this was probably a problem that happened to many women. Embarrassment and concerns about being disgraced meant it was never spoken about.

'I think it happens to a lot of women, but embarrassment is exactly what it is, and therefore women will not vocalize it, and they will try and be as discrete or hide it as much as they can because they do find it embarrassing. I find it embarrassing even though I'm in the medical profession.' B

'I think it happens to a lot in the Ghanaian and Nigerian society of women, it's just that it's seen as a disgrace on the woman.' B

'*One of my friends from back home came to stay with me, sleeps in my bed with me. She woke me up. 'Oh, look its wet in here, something's wet.' I'm too ashamed. I was wet, my knickers, and the bed. I have to tell her, I can't leave it I can't hide it anymore.'* A

7.2.8.3 Perception of the problem

There was a belief that pregnancy and childbirth had caused their PFD problem. However a lack of knowledge of the cause of the problem was a barrier to seeking help. It could be associated with stress or tiredness. The trigger to help seeking was being no longer able to hide or mask the problem. Being unable to hide or protect oneself from opprobrium was a significant trigger.

'*I didn't go, I thought maybe it was tiredness or stress so it took me about 6 months.'* A

'*I realized there was a problem pretty much straight away so just sought help immediately. Working in a hospital that helped. Having a good relationship with the staff as well as the doctors. That really did help me, and I was therefore able to get quick efficient help straight away.'* B

'My bladder, I think maybe it's the weakening of the bladder following my babies.' A

'I know my problem is caused by a third degree tear.' B

7.2.9 Technological factors

7.2.9.1 Health beliefs

In Nigeria/Ghana herbal remedies are popular. The UK NHS is perceived as being very good, with educated doctors. The rapport/interaction with clients is valued and as a consequence there is great trust in English medicine.

'We really appreciate it. It's the best, in terms of medical world this country, I can't compare it at all to my country. They are really perfect; very intelligent and their ways of dealing with you are super. We trust.' A

'It's different. For example, if someone had a similar illness back home, and it was treated locally with no sort of medical intervention, then there would be distrust, thinking it's not necessary. You don't have to go through all of that. You can have it done like this. Some of the hospitals are very good and affiliate to some of the top hospitals in this country. So, I would disagree with you a little bit. Yes they do believe that the healthcare system here is great, but

also you can almost receive and achieve great healthcare back home. It's just that you have to have the money in order to do so, and that's the biggest flaw.' B

Herbal treatments are the first port of call in both Nigeria and Ghana and are very commonly used. Some families have a book of herbal remedies which is passed on through the generations. Consequently many families are able to make their own medicines from herbs that grow in their gardens. The local herbalists also make medicines for people for a small charge. Examples were given of ointments to rub on the face for headaches, soaps for eczema and treatment for PFD problems (although it was not specifically known what these were).

'There is herbal medicine, if you have a headache there are some ointments that are locally made in Nigeria. You rub on your face. It works. Herbs will relieve you; you go in the garden and boil some leaves. Just natural herbs from the garden. We have got a book from my family. My forefathers got the book, every treatment is inside that book, you just have to follow.' A

'There are some remedies that my mother told me about. They are good. There is something like black soap and I remember because we've all got sensitive skin in my family. When you have a rash, or eczema, it really does help if you use the soap.' B

7.2.9.2 Knowledge of services

There is a national health service in both Nigeria and Ghana but it is very much a two class system. If an individual can afford to pay for treatment it will be very similar to that of the UK NHS.

'*The Government provides some health service. They give advice about how to look after yourself. They give injections and vaccinations.'* A

'My family are very much from this part of the world. So my parents have adopted the healthy lifestyles from this part of the world. Even back home, back in Ghana and Nigeria, there is a healthy aspect, especially when it comes to diet, although the food, how it's prepared can be high cholesterol, very oily , but it's always fresh.' B

'I think I can speak for Ghana and Nigeria having been there two years ago doing a bit of research of my own in relation to pregnancy, pregnant women and in relation to women's health

in the gynaecology perspective. It was interesting to see that they are actually having health promotion. It's just actually getting it into gear and there's various institutions, especially the non Government organizations, that are actually implementing various health schemes in order to get women involved with health promotion, like contraception, and safe sex.' B

Both women felt confident in their ability to access services via their GP and did not feel that lack of knowledge about services impacted on their coping or help seeking behaviour.

7.2.10 Socio-Economic factors

The women did not raise any issues with regard to the impact that PFD might have had on their financial or employment status. They did not perceive that this had any impact on help seeking behaviour.

7.2.11 Ideal word comments

7.2.11.1 Aids to help seeking

In an ideal world, PFD would have no stigma or disgrace associated with the problem. As a consequence women would feel able to go to their GP to discuss PFD as freely as if they were going to see him about a cold or 'bug'. Therefore women would speak more freely about the problem without the fear of gossip or the perceived risk of opprobrium.

'It would be easier for me not to feel ashamed. Easier to talk about, like you go to the doctor for a bug. For it to be the same. When I can say I'm going to the hospital for this, and not to have this stigma attached to it. Because there is a stigma, the stigma being your bowels and everything else. Then I could talk about it because it helps to talk about it, but I can't.' B.

'But the only problem is that people will not speak out, you don't know what is happening to them. They will not speak up because they are ashamed.' A

7.2.11.2 Service improvement

The informants did not raise any issues with regard to ideal world service improvements. Instead the discussion centred on shame and embarrassment and its impact on women and their perception of themselves within society. At the end of the discussion I asked the women why they thought some women had declined to participate. They indicated it could be that a clash of cultures, embarrassment and pride might be the main reasons for lack of participation in the focus group. They indicated that it was unfortunate as it would have been beneficial for them to learn from other women's cultural perspectives.

'I know that the majority of women that I know, are from South Africa, South West, the Caribbean and they all understand. They'd never, ever, ever speak of it with anybody else. If it were my Mum in my position, I know that's exactly what they will do (her girlfriends), on the phone, have a good old gossip. I would break that down a bit more to age, background and rigid mindset. Those born in Nigeria will have that sort of mindset and way of thinking.' B

'I think that there is a possibility that it's not just personal shame. Embarrassment is one thing in itself, let alone to have someone from, for example let's say Ghana and Nigeria, because they are two people that clash. I would imagine that the Nigerian woman would be sitting there thinking OK, I'm not going to say anything, and the Ghana woman would be thinking Oh, God, I am not saying anything in front of her.' A

'The Nigerians tend to be more outward, more extrovert and those from Ghana are more introvert, Nigerians have this thing about them. I'm half Nigerian so don't take this personally. They feel very proud, they're very proud people, and Ghanaians, I'm not saying they're not proud people also, but more in a quieter fashion as opposed to Nigerians.' B

'I can't see a Nigerian woman who's probably dressed to the nines, seeking help and sitting there saying well I've got a bowel problem and talking about it very freely. I might be Nigerian and this woman here might be Ghanaian, but it may happen, that we have a mutual friends somewhere.' B

'There's this huge embarrassment thing, not wanting to talk about it amongst African women, there's that part of it. Clashing and pride, that's secondary but that could possibly be it.' B

'I can't hide it, I can't anymore. If another African can speak maybe so can I. I can't speak for them, but I want to know for me, I want to know more about it from them, I want to know more about it.' A

7.2.11.3 Summary of African Focus Group Thematic Analysis

It is apparent that the African women's position in their patriarchal society is perceived to be associated with fear and uncertainty. Multiple wives are not uncommon even in the UK. This practice reflects the status and wealth of the male but leaves women insecure in their marital position. There was fear that if their PFD problem became known within their community they

would be gossiped about and reproached. This social pressure played a negative impact role in help seeking and as a consequence these women described how they endeavour to mask and contain their PFD for fear of opprobrium. Figure 7.2 summarises the key findings from this African Focus Group depicted within the Sunrise Enabler.

Figure 7.2

7.3 Orthodox Jewish Focus Group

This group was attended by three Orthodox Jewish women. A lack of hospital crèche facilities prohibited other women who wished to attend from participating. The discussion highlighted the important role that women hold in Orthodox Jewish society and the associated position and status of women within the society. Issues surrounding self esteem and empowerment with respect to help seeking behaviour were articulated. This group had a much higher feeling of self worth and did not describe the issue of embarrassment or shame as impacting negatively on help seeking behaviour. They articulated very strongly their feelings of support and status within their community.

7.3.1 Ethnohistory

Orthodox Judaism is the formulation of Judaism that adheres to a strict interpretation and application of the laws in the Talmudic texts ("Oral Torah"). Orthodox Judaism is characterized by the belief that the Torah and its laws are Divine and eternal. The Talmud interprets the divine laws and is the basis of everyday life. Hasidic Judaism is a Haredi Jewish religious movement. The movement originated in Eastern Europe in the 18th century (Grodin 1995, Feldman 1986).

Stamford Hill is at the centre of an Orthodox Jewish, predominantly Hasidic community estimated by Hackney Council to be some 20,000 strong (ONS 2001). It is the largest Hasidic community in Europe (Economist 2006). From the 1880s, an influx of Jews arrived in Stamford Hill escaping from the poverty of the East End of London. In 1926, the Union of Orthodox Hebrew Congregations was established in Stamford Hill, and this became a magnet for other strictly observant sects, fleeing Stalinist and Nazi persecution in the years before and after World War II (Baker 1995). The Orthodox Jewish community relies mostly on private education for schooling, with all Jewish children attending Jewish private schools. An emergency response first-aid service called Hatzola is run by volunteers. Haredi families have on average 5.9 children, almost 2.5 times the average for England and Wales (ONS 2001).

7.3.2 Demographics

There were three orthodox Jewish informants; A, B, C (informant B attended with her 11 month old child as no child care facilities were available). The demographics are presented in Table 7.3. All the informants were from the Hasidic community in Stamford Hill.

Informant	Age (years)	Marital status	Number of children	Working or retired	PFD Symptom Spectrum
A	71	Married	8	Retired school teacher	Cystocele Vaginal prolapse Urinary Incontinence
B	32	Married	3	Housewife	Stress urinary incontinence Rectal Evacuatory Dysfunction
C	23	Married	1	Housewife	Faecal Incontinence

Table 7.3 Demographics of Orthodox Jewish Focus Group Informants

During analysis and thematic exposition it became evident that in the Orthodox Jewish Culture it is impossible to consider Kinship and Social Factors, Cultural Values, Beliefs and Lifeways and Religion and Philosophical Factors separately, as the overarching themes encompass all these constructs**.**

7.3.3 Kinship and Social Factors

7.3.3.1 Kinship – Knowledge

Despite the strong sense of community support expressed by the informants, they considered PFD problems a private matter which they would not discuss with their women friends but would discuss with their Doctor. As a consequence there was no knowledge from their kins with regard to PFD. Despite the reluctance to discuss such matters the informants were adamant that were the problem to be public within the community they would not be ostracised in any way. The subject was simply not discussed because it was deemed a personal issue.

'*Nobody would shun anyone for having a problem.'* A, B and C (merged narrative)

"Continence would not be discussed like a headache or a sore throat. Simply because it's a more private, personal kind of problem.' B

7.3.3.2 Kinship - Social Support

It is evident from general reading and interview data that kinship and social support are at the heart of the orthodox Jewish community. The Jewish worldview is frequently viewed as one of suffering and persecution and the strength of their cultural identity is in part a result of ethnocentrism about their valued lifeways. Haredi Judaism advocates segregation from non-Jewish culture, although not from non-Jewish society entirely. In pre-War Europe, all towns or

cities with a Jewish population had one communal organisation. As a result of the dispersal caused by the War, larger populations may have more than one community, each centred around one synagogue, with the various communities together providing services such as a *mikvah* (immersion pool), *gemach* (free-loan fund), and *kashrut* (kosher food) supervision (Berkowitz et al 2008). Tzedakah is a Hebrew word commonly translated as charity. Tzedakah refers to the religious obligation to perform charity, and philanthropic acts, which Judaism emphasises, are important parts of living a spiritual life. Tzedakah is seen as a religious obligation, which must be performed regardless of financial standing, and must even be performed by poor people.

'We believe in looking after each other. It starts with the Synagogue. We look after each other and we have our own organizations, but we do use the general organizations as well.' A

'That's our policy to help each other.' C

'Helping others is our priority. We feel the world exists for good deeds; just to try and help each other. God is good and we emulate God. God raised us to do goodness. At the end of the day we're left with our good deeds and not with our possessions. ' B

'We have much bigger families. If we didn't help each other, there just would be no way. People have just stepped in to fill the need. It's not that we're spoilt more than other people, but because we can't manage.' A

Women described feeling well supported within their communities, not only by the Rabbis but also the community as a whole. They felt very strongly that they were part of and valued in the community.

'There's lots of Rabbis serving the community that people can turn to for help or advice, and that's who people turn to.' C

'It's very often the young people who have the get up and go and work and support the community. We all did it. We were young once, we led them, now let them do the hard work.' A

7.3.3.3 Social – Societal Pressure

The women did not describe any pressures from their community. They articulated feeling supported as women and as a consequence raised no issues with regard to societal pressure that impacted on coping or help seeking behaviour.

7.3.4 Political and Legal Factors

The political and legal system in England has no impact on the lives of Orthodox Jewish women, as the daily laws and practices of their religion, as described in the Talmud, are fundamental to their daily lives. Observance of holy law is the responsibility of each individual but as women, they had the responsibility to ensure that their homes and children were also observant. These cultural lifeways are described in the following section.

7.3.5 Cultural Values, Beliefs and Lifeways

7.3.5.1 Women in society

The informants proudly articulated their important role in continuing the Jewish faith (Jewish teaching says that the religion is passed on by the mother) and as a consequence the importance of the role women play in the community and family. Equally they described the importance of their role in the home, ensuring the home and children were observant. This was seen as a daily immersion of women in holy work. As a result of this daily holy work they were exempted from the rigour of prayer at the synagogue required of all men.

'We are proud to be women, to have a women's role. Some people think we are downtrodden as we don't have the same privileges as men when it comes to praying. Certain commands they have to keep, we don't. But we don't mind, we like it.' A

'The woman is basically the one that runs the house and does everything for it.' B

'The men are not occupied all the time with this kind of holy work; in raising the next generation and being so involved with the families and children, they need an external prompt of more prayer. We are in it all the time; we can't for a second forget where we come from, where we're heading to, what our roles are. So it's not that we're under privileged. On the contrary. We've got it going all the time from what we're doing.' C

Traditionally women do not work after marriage but focus on their role within the family. This was mainly felt to be because of the logistics of childcare when they have large families rather than women not being educated or able to undertake employment.

'They've got a full time job running their home and their kids.' A

*'If you've got one, it's easier. You don't have such a demand to be at home if you've only got one, but when it comes to us, we've got much more than that. We can't work.'.*C

Preparation of the home prior to Sabbath and before specific religious festivals such as Passover take up a large amount of the women's time. It is considered an important and fulfilling occupation.

'We do this as a privilege. It comes to the festival and wow, everything is gleaming and bustling. Everybody's excited. It's beautiful.' A and B (merged narrative)

7.3.5.2 Role and status of women

The normal age for marriage is 18, with a husband found by either the family or a community matchmaker. Once a match is made the woman will have the opportunity to meet her intended husband many times to ensure they wish to marry. Previously a dowry was an important part of the marriage matchmaking process but now it is much less so.

'M*arriage is normally from 18. You get engaged at 17½.'* A, B and C (merged narrative)

'*There are people in the community who have the role of trying to match up people. A matchmaker.'* A and B (merged narrative)

'*They will meet many times, and then if they decide to get engaged, they're engaged. It used to be some period of waiting before they got married just to get their act together and everything. Some people it would be three months; some people six months and it can even be twelve months.' B*

'*Once upon a time a dowry was much more important.'* A.

The importance of having children cannot be overestimated for the Orthodox Jewish woman. All the informants described it as '*our raison detre.'* The bearing and bringing up of children is key to the role of women in this community and large families of up to 12 children would be considered the norm. The raising of such large families is supported by the community but also with advice from the Rabbi. Women did not consider they were forced to have large families. They did not feel pressured to have more children if they felt unable to cope, stating that the Rabbi would support and advise them with regard to this. They described community support for those women unable to have children, with private fertility treatment paid for by the community. They considered that no women would be excluded from the community if they were unable to have children.

'It is such an important role in the Jewish culture, to make the next generation. You are the link to the future. So women will do everything they can to have children.' A

'People will not stop having children because they don't have money. There's so much help within the community. If somebody has got too many children who he can't feed, there will be charities that will help feed them.' B and A (merged narrative)

'*They're very careful* (The Rabbi)*. They would never tell somebody, 'no time off you have to go on producing children yearly.' There's not such a thing.'* B

'*We feel sorry for women who cannot have children. We admire them for how they go on. We admire them for their bravery, because it's hard and it's painful*' .B

7.3.6 Religious and Philosophical Factors

7.3.61 Religious beliefs and health

The women articulated clearly that their lives revolve around the teachings of the Orthodox Jewish religion. Women do not have the same obligations as men with regard to prayer and synagogue attendance. Women are responsible for ensuring that their family lives within the teachings of the Torah and Talmud on a day to day basis, specifically with regard to the dietary requirements of Jewish Orthodoxy.

'We don't mix meat and dairy, not to mix is absolute law. Apart from that people can decide to go on special diets not mixing proteins and carbohydrates.' C

Prior to any type of surgery or medical treatment it is the norm to consult with the Rabbi for a blessing. Equally they may ask someone they know to pray for them in Jerusalem, at the Western Wall. Prayer was considered extremely important when undergoing medical treatment.

'Before major surgery, a lot of people would like to consult a Rabbi not so much to be told what to do, but to have his blessing and good wishes. You want a saintly man to know what you're having and to pray for you. A lot a lot of people in the community would call an elder Rabbi for their blessing.' C and A (merged narrative)

'In Israel there's one wall remaining in the Holy Temple. We would ask somebody to go and pray there for us, or pray at other holy places. We have a great belief in prayer. ' C

In the teachings of the great Rabbis and the Talmud, there is medical and health advice to be found, but it was acknowledged that interpreting or finding this advice was difficult. Hence the importance of the advice of Health Advisors provided by the community and the Rabbi. The role of Health Advisors is discussed in section 8.3.9.

'We believe that the Rambam, a previous saint, was the biggest doctor of all time. Everything is based in the Talmud, but me I wouldn't know how to find some medical advice there.' B

'The Rambam does have remedies. The Rambam has compiled Books of remedies and treatments. It can be difficult to interpret.' A

7.3.7 Personality Factors

Personality and coping mechanisms were briefly discussed by the informants, whose coping mechanisms were more positive in nature and involved help seeking, supported by the Health Advisors and the Rabbis. There was no perceived stigma associated with PFD and it had no impact on their important role within the community. The subject was viewed with embarrassment, but this was because it was perceived as a private matter for which they would seek medical help. The women did not articulate feelings of low self worth nor did they articulate feelings of shame or disgrace. The women did not describe personality traits, emotions or permission seeking as impacting on their coping or help seeking behaviour. They described active help seeking by consulting with Health Advisors, the Rabbi and their GP. As a consequence their coping mechanisms did not involve masking or containment. In fact coping was perceived to be help seeking and following medical advice.

‘*We speak with the Health Advisor and consult with our Doctor.’* A

‘*For everything we have advice. We then see the doctor as normal.’* B

It is speculated that despite having a challenging role within the home and community, the support and high level of perception of their own self worth negated feelings of opprobrium and the negative impact this has on coping and help seeking behaviour.

7.3.8 Educational Factors

The Orthodox Jewish Communities have their own schools. Boys and girls are educated in separate schools. The school curriculum follows a standard curriculum for approximately half of the school day; teaching subjects such as history, geography and mathematics with the teaching in English. The rest of the time focuses specifically on a Jewish curriculum, history and religion. These classes are taught in Yiddish.

‘S*eparate Boy’s schools and girls schools with female teachers for the girl’s schools and male teachers for the Boys schools.’* C

‘They spend half a day on normal school subjects, the other learning about Jewish subjects.’ A

Girls finish their education at 18, when they marry, and do not go on to mainstream University education. Men can continue their studies, either at University or in business. A number of men choose to continue their religious studies and study at synagogue schools under the tutorship of learned Rabbis.

7.3.8.1 Knowledge

There is a degree of embarrassment associated with PFD and women’s health issues in general. In school there are no human biology or health education sessions. It is left up to parents to discuss these issues with their children if they consider it appropriate.

‘Our girls are not educated at all with regard to this kind of thing. They don’t discuss any of this, and the Synagogue is definitely not a place for education, it’s a place of prayer.’ B

'I teach in school, in primary school. A girl had got her period and she knew nothing about it. On the other end of the scale, I had a child, a five year old boy came to school with a shiny new book and he took it into the playground. A boy comes running to me 'have you seen this book that so and so has.' It was the most explicit book on childbirth I'd ever seen. Made for children. I took it to the headmistress and left the ball in her court. We have two extremes; one mother educates her child to the nth degree; some mothers don't at all.' A

7.3.8.2 Communication and language

All the women spoke English fluently but considered Yiddish the universal language of the Orthodox Jewish community. Yiddish is taught in schools and enables effective communication between all Jews, regardless of the country where they have been brought up. The ability to speak Yiddish enables a sense of belonging, no matter where in the world they might be.

'Yiddish, it's the universal language of the Jewish people. Spoken all over the world.' A

'Hebrew is the original language of the Jewish people, but now it's become localized to the Israeli language in a more modernized way than the original Hebrew. Generally speaking Jews around the world speak Yiddish which is an accumulation of many different languages put together.' C

'You can speak to any Jew all over the world. It's spoken all over the world. If you can speak Yiddish you have got contacts.' C and A (merged narrative)

7.3.8.3 Perception of the problem

PFD symptoms were perceived as a medical problem which could occur following childbirth. Women described it as being like any other medical condition.

'This is a normal problem. It can happen to anybody. It's a normal thing.' C

'It's like having a runny nose.' B

7.3.9 Technological Factors

7.3.9.1 Health beliefs

There is a tradition of using homeopathic medicine and there are homeopathic practitioners within the Orthodox Jewish community who advise and provide homeopathic medicines.

'Homeopathic is quite popular.' B

'Homeopathy is widespread in the community. There are a lot of people who prefer it as a first choice. What we can eat and what I can be doused with.' C

7.3.9.2 Knowledge of services

The Orthodox Jewish community in East London relies on the advice of two full time Health Advisors. These gentlemen are knowledgeable about health services and the expertise of specific medical consultants. Prior to either seeking medical help or embarking on treatment it is considered the norm for these Health Advisors to be consulted prior to the women possibly seeking the view of their Rabbi. These Health Advisors work on a voluntary basis and are not paid by the community. This is another example of the formal role 'charity' takes within the community.

'We have these two gentlemen (Health Advisors); *afterwards I would phone up and say I've been offered this, that and the other. Do you think it's a good idea? And he will advise me. I will listen to him.'* A

'They delve into the medical side of everything. They know all the Consultants. They really work very hard on their subject. They know it inside out, and they can tell you which the best hospital is for this; who is the best Surgeon for that. They will arrange private consultations if necessary.' B

The women described the support structures available in the community to help them prior to and after delivery of their children. The community runs its own ante natal classes. These classes, run by religious women, focus on the process of labour and cover the need for Pelvic Floor Exercises to be practiced after delivery. Other than attending the hospital during labour for the delivery, all their other support services are provided by the community. Following delivery there is a nursing home for women to stay in for up to ten days following delivery. These

services have been developed to meet the needs of Orthodox Jewish women having large families. They were developed in response to the current trend in the NHS for mothers to be discharged from hospital 12 hours post delivery. The mother and baby nursing home is not free, but for those unable to pay there are no charges. Therefore no woman is excluded. The women considered that around fifty per cent of the community used this facility, whilst others went home and were helped by their mothers.

'We have child welfare classes run by religious women.' A, B and C (merged narrative)

'We have childbirth classes before the baby's born, in the community. The Talmud class teachers do educate you about pelvic floor exercise and they taught us to do exercises. A lot of us go to the mother and baby home after we have babies. A physiotherapist comes and educates on pelvic floor exercises.' B

'Nowadays we're chucked out of hospital after six hours and with half a dozen children at home, you need to be looked after. The community had to galvanise into action to do something to help these women cope. So we have a beautiful state of the art mother and baby home, where you have a big nursery with nurses looking after the babies at night; where you're pampered with three glorious meals a day with only very little hours for visiting. A place for mothers to recuperate.' B

7.3.10 Socio-Economic Factors

The women did not articulate any financial barriers to help seeking. Money is not seen as a barrier to help seeking and certainly not a barrier to having a large family. There is a strong support network within the community. The tradition of charity ensures that all within the community are supported**.**

7.3.11 Ideal world comments

7.3.11.1 Aids to help seeking

The informants considered that a regular check-up appointment for women by their GP, where they were asked directly if they had any continence problems would be useful**.** This would raise awareness of the problem but equally would ensure that women were given permission to discuss the subject if they did feel any embarrassment about raising the subject themselves.

If you are advised to have smear tests every few years, maybe there could be advice for women who are having babies. A reminder once every few years. Is everything OK with your pelvic floor? Do you have any incontinence? Are there any problems? Maybe some women accept this as part and parcel of getting older.' C

'Our GPs should take more interest in us and ask.' A

'These issues should be addressed at the post natal visit with the doctors and the nurses.' A, B and C (merged narrative)

7.3.11.2 Service improvement

Women discussed ways in which current services might be made more accessible to women with large families (when child care can be problematic). Their views highlighted that services currently based in hospital might be provided in the community. For example, equipment might be loaned to avoid repeated trips to hospital.

'Let's say physiotherapy. There is one biofeedback machine that we have in the hospital. Loan it. Give the woman a slot of three weeks with it at home so you don't have to come travelling all the way.' A

'If there could be facilities more locally. Your local GP clinic would be more accessible.' B

'If there was a crèche facility that young women can come to the hospital and leave their babies to seek help. It's such a hassle getting out, and trying to place the little ones.' C

'Even Ikea have a crèche. It would help people.' A

Despite previously acknowledging that raising awareness of PFD would be beneficial the informants did not consider that educational or support groups would be useful for women with PFD issues as the subject remained a private one. Instead women considered the education and support for women with PFD problems would be best dealt with by their GP. One of the informants had attended a group education session at the hospital. These groups are provided

as part of the PFD Service. Three specific sessions are held addressing the pelvic floor, the healthy bladder and bowel function.

'*We all had the same problem.'* A

'People don't want to discuss in public. People would feel more comfortable discussing it with the doctor.' C

'I did attend a group run by a physio here. We all got on very well together. There was no problem. We all said our little bit and we all asked questions and joined in, and we were one happy family, like a nation.' A

7.3.11.3 Summary of Orthodox Jewish Focus Group Thematic Analysis

Orthodox Jewish women perceive that they have a high level of support within their community. The matriarchal society valued the role of women and attached status to their role in continuing the Jewish faith. The women did not perceive any stigma associated with PFD and did not fear reproach or ostracism from their community if their problem was known. Orthodox Jewish women cited many examples of the support mechanisms they had within their community, as a consequence these women described positive help seeking behaviours such as discussing PFD problems with the Rabbi, Health Advisor and GP in order to seek help for the problem. Figure 7.3 summarises the key findings from this Orthodox Jewish Focus Group depicted within the Sunrise Enabler.

Figure 7.3

7.4 Summary

The three focus groups have explored the coping and help seeking behaviour of the Turkish, African and Orthodox Jewish women with PFD. It is apparent that both the Turkish and African women's position in their society is seen as lower than that of males. They fear the reproach of their patriarchal society and are offered little in the way of community support. As a consequence they endeavour to mask and contain their PFD for fear of opprobrium. Conversely women in the Orthodox Jewish community articulated their important role in society, their pride in their role and status within the community. They received a high level of community support and as such did not have the same fear of opprobrium as women in the Turkish and African groups. However the similarity remains that PFD is a private matter and not openly discussed.

When considering the key aspects of universality and diversity amongst women with PFD with respect to their coping and help seeking behaviour, it is apparent that there is far more universality than diversity. All the categories evidenced in the Conceptual Framework of Opprobrium Appropriation have key areas of universality. These are synthesised and presented in Table 7.4. The categories with the most universal themes were Kinship and Social Factors, Cultural Values, Beliefs and Lifeways and Personality. These factors also have the strongest links to opprobrium.

Categories	Themes	Link to Opprobrium
Kinship and social factors	Kinship- knowledge Kinship- social support Social – societal pressure	Women, to varying degrees, articulated a fear of the shame and disgrace they perceived society would place on them with respect to their PFD symptoms. Limited social support and limited knowledge within society placed women with PFD in a situation they perceived to be stigmatizing and shameful.
Political and legal	Perception of PFD associated only with the elderly	In younger women this caused feelings of shame and embarrassment that it had happened to them as a younger person. In older informants it was considered embarrassing and would bring them disgrace.
Cultural Values, Beliefs and Lifeways	Gender Issues Role obligations	Role obligations of women in society and the perceived intimate nature of PFD symptoms caused feelings of shame and embarrassment.
Religious and Philosophical Factors	Formal religious faith Personal philosophy	
Personality (New knowledge)	Personality Traits Emotions Permission Positive coping strategies Negative coping strategies	Varying degrees of masking and containment and avoidance of social discussion and interaction to prevent their PFD symptoms becoming known.
Educational Factors	Knowledge Lack of knowledge Communication and Language	
Technological Factors	Health care beliefs Use of herbal/traditional remedies Knowledge of and access to services/GP Perception of problem and its severity	
Socioeconomic Factors	Practical issues/time off work and childcare	

Table 7.4 Synthesis of Constructs Identifying Universality

This phase of the research has generated knowledge with regard to the impact of opprobrium appropriation and the importance of the status and role of women within their society. It would appear that fear of failing in their role obligations is heightened by the need to cope with their PFD and that this is generally linked directly with opprobrium appropriation. It is evident that women can perceive a sense of disgrace, ignominy and reproach associated with PFD problems. The degree to which women appropriate opprobrium is dependent on their personality, culture and their feelings of self worth as a woman within their society.

In the following chapter the key areas that have arisen during the research process are discussed and the new findings relating to the apparent impact that opprobrium plays in women's coping and help seeking behaviour is posited.

CHAPTER 8: DISCUSSION

Chapters 5, 6, and 7 presented the findings establishing the impact that opprobrium has on the help seeing behaviour of women with PFD. The core category opprobrium emerged throughout the data identified by frequency of occurrence and close affiliation to the main dimensions of Kinship and Social Factors, Cultural Values, Beliefs and Lifeways and Personality Factors. The study results will be reviewed and the importance of opprobrium appropriation in relation to help seeking in women with PFD posited. This chapter aims to demonstrate how the conceptual framework of Opprobrium Appropriation was generated and how this research contributes to the body of existing knowledge. The core category of Opprobrium is now discussed.

8.1 Defining Opprobrium

Using a thesaurus, the repeating constructs of shame, stigma, embarrassment, reproach were explored. The word opprobrium was found which encompasses all of these constructs. The noun opprobrium is defined as the disgrace, shame or the reproach incurred by conduct considered outrageously shameful, resulting in loss or damage to ones reputation.

Loss of, or damage to, one's reputation can occur because of a perceived disgrace from a condition such as PFD. For women with PFD, opprobrium is essentially a state of disgrace resulting from society's reaction to their medical problem. It is evident in the data from each phase of the research, that women who participated in this study, perceive a sense of disgrace and reproach associated with PFD. It is probable that women's coping and help seeking behaviour reflects the degree of opprobrium women perceive. This study suggests that perception of opprobrium or the degree of opprobrium appropriation will vary depending on the woman's culture, education and personality.

8.1.1 The impact of opprobrium on help seeking behaviour

Culture and the position of women in their society have a significant impact on coping and help seeking behaviour. In the Turkish and African focus groups, women articulated that their position in society was lower than that of males. They feared the reproach of the patriarchal society in which they lived and received little community support. As a consequence negative coping mechanisms were developed to mask and contain the problem for as long as possible; therefore preventing disgrace. However, women from the Orthodox Jewish culture articulated the importance of their role in society and the pride and status they held within their community. They received a high level of community support and sought help quickly for their problems as they did not perceive the same level of disgrace or fear of reproach. It is evident that women can perceive a sense of disgrace, ignominy and reproach associated with PFD. The degree to which women appropriate opprobrium is dependent on their personality and their cultural feelings of self-worth as women in their own communities.

Thematic analysis has demonstrated a strong link between the dimensions Kinship and Social Factors, Cultural Values, Beliefs and Lifeways and Educational Factors. These dimensions reflect the key impact of society on women's coping and help seeking behaviour. Knowledge, stigma, social taboo and the role of women in society significantly influenced help seeking behaviour and the subsequent coping mechanisms utilised by women. Women developed a stoical ability to mask and contain their symptoms and avoided aspects of social interaction to ensure their PFD problems remained secret. This is evident, for example, in informant B who indicates 'hiding is the first stage' in her coping strategy. Informant A also indicated that she 'kept it secret that I was incontinent'. These negative coping mechanisms enabled women to avoid the perceived disgrace that would follow if their problem was discovered.

The categories shame, reproach, disgrace, stigma and embarrassment were seen repeatedly throughout the interview data. Table 8.1 summarises the context and verbal expression of these categories.

Table 8.1

Table 8.1

8.1.2 Conceptual Framework – Opprobrium Appropriation

Leininger describes the development of Culture Care Theory as a creative process of concept explication, reformulation and resynthesis (Leininger 1988). The development of the conceptual framework explicating opprobrium appropriation has followed Leininger's description of concept explication, reformulation and resynthesis. The societal pressure perceived by women with PFD has been clearly delineated in the informant narratives presented in Chapters 5, 6, and 7. Equally the variation in individual and cultural opprobrium appropriation has been described and the relationship to personality and cultural role requirements outlined.

It is speculated that opprobrium appropriation in knowledgeable, educated women equates to positive help seeking behaviour. However in cultures in which women have little education, knowledge or status, fear of opprobrium leads to negative help seeking behaviours such as masking. Although generalisability was not the goal of this study, given the wide range of contexts in which the help seeking behaviour and coping mechanisms of women with PFD are identified, triangulated and validated, a conceptual framework of coping and help seeking behaviour in women with PFD has been developed. From the research data it has been possible to identify the significant impact of opprobrium appropriation on help seeking behaviour. The abstraction and synthesis of this data has been used in the development of a conceptual framework to describe opprobrium appropriation and its impact on help seeking behaviour in women with PFD. The conceptual framework is graphically presented in Figure 8.1

The Conceptual Framework utilises the modification of the Sunrise Enabler (Figure 5.1) to depict the range of factors which impact on help seeking behaviours. The key constructs from Shaw's Framework (event, situation, condition, cue) are also used but in a continuous rather than a linear fashion, to depict help seeking pathways. In the Conceptual Framework, the factors associated with Opprobrium Appropriation are depicted in a circular fashion to demonstrate the continuous and over arching impact of opprobrium. However, the data supports strong links between Kinship, Cultural values, Beliefs and Lifeways, Personality Factors and Educational Factors in respect to coping and help seeking in PFD.

Figure 8.1 Conceptual Framework

8.2 Critique of findings

8.2.1 Knowledge

Lack of knowledge was clearly identified as a significant barrier to help seeking. This was identified consistently in all phases of the study. Mason et al (2001) identified lack of knowledge as a barrier to seeking help with many informants identifying the need for information, feeling that written information and advertising of problems in clinics would give them permission to ask and seek help. The asking of a direct question by a healthcare professional was perceived by women as giving them permission to talk about the problem and this theme was validated in all phases of the research (Porrett & Cox 2008, Mason 2001). Women described how in an 'ideal world', they would like their GP to routinely ask them about any PFD symptoms, this they felt would give them permission to discuss the matter. Results from this study replicate these findings and highlight clear information needs and clarify the importance of the role of the health care professional in facilitating help seeking. Recommendations for practice are discussed in Chapter 9.

8.2.2 Embarrassment and shameful conditions

The literature provides evidence to support the embarrassment that women with symptoms such as urinary incontinence feel, and the depression, frustration and distress this causes (Shaw et al 2006, Horrocks et al 2004, Hunskaar et al 2004, Norton 2004, Oh & Park 2004, Mason et al 2001, Shaw et al 2001, Johanson et al 1999, Roe et al 1999, Lafferty 1996, Goldstein et al 1992). These findings are replicated in women with PFD. These study findings confirmed that a proportion of women felt they could not or did not want to talk about their condition with a health professional, mainly due to the embarrassment they felt about having the problem. It is reasonable to extrapolate from this that such feelings have a negative effect on help seeking behaviour. It can be speculated that fear of reproach or disgrace might prevent a women from raising the subject with a health professional, if a women perceives that her PFD symptoms might be a cause for shame or disgrace it is probable that she will choose to mask these symptoms rather than risk disgrace. Embarrassment alone accounts for between 11 and 47% of women with urinary incontinence not seeking help (Goldstein et al 1992, Norton et al 1998). Embarrassment often stems from women finding it difficult to know what the correct terminology or language is to use to describe their symptoms (Brittain et al 2001). Language was raised as a concern for some participants in this study, who were unsure how to describe or explain their symptoms to the GP.

Faecal or urinary incontinence, the lack of control over bodily functions taught as a child, is seen as a taboo subject and a socially unacceptable topic of conversation (Ashworth & Hagan 1993). The subject of PFD is avoided not only with health care professionals but family and friends as well. Women described telling very few friends for fear of their reaction and the potential for gossip. Possibly because of the fear of disgrace or shame that might follow from such a

disclosure. It is probable that it is the fear of shame or disgrace (opprobrium appropriation), rather than an actual negative response from family or friends which is a negative trigger or barrier to help seeking for many women. There has been much written by Douglas (1966) on the cultural perception of what is shameful. In her seminal work 'Purity and Danger' she describes 'dirt' as anything which a given culture classifies as filthy or taboo. The classification of something as taboo or shameful (such as incontinence) is a tool that culture uses to bring order or establish boundaries for a culture. For example, a culture may consider that evacuation of faeces, other than in a controlled manner in an area designated suitable for defaecation, is taboo. The culture may be attempting to establish hygiene order and to establish boundaries for adult behaviour. Therefore in the eyes of that culture someone with faecal incontinence will be breaking the taboo on a number of counts. In this study, it has been clearly shown how women from patriarchal cultures (and who consider their position in their society to be low) perceive very acutely the shame associated with their PFD condition.

The literature suggests that elderly people consider incontinence as a normal and inevitable part of the ageing process (Mitteness 1995, 1990). A number of participants in this study considered that incontinence was something that happened as a natural part of the ageing process. It could be argued that linkage of incontinence and normal ageing is possibly an attempt by the woman to protect her self-esteem, to mitigate herself from the perceived opprobrium that culture places on incontinence.

8.2.3 Coping mechanisms

Focusing specifically on illness, coping is defined as the cognitive and motor activities a sick person uses to preserve bodily function, with coping strategies being the specific techniques that an ill person selects to deal with an illness and its consequences (Lipowski 1970). Findings from this study have identified the impact that personality, emotion and permission seeking had on women's coping mechanisms. Women described numerous coping strategies they had developed to enable them to live with their PFD. For the most part these coping mechanisms involved containment, avoidance, alteration of lifestyle and meticulous planning. Women described coping mechanisms such as containment and the use of self help strategies, but following a subsequent change in their role obligations (such as the terminal illness of their spouse) denial and masking became the predominant coping strategy. Denial and masking continued until their social situation changed to allow them to undertake a further secondary appraisal of their situation. At secondary appraisal women invariably altered their coping mechanisms and either continued with their previous active coping strategies or sought help. These findings demonstrate the circular nature of help seeking and coping pathways and confirm that the modification of Shaw's framework has produced a framework which more accurately reflects women's experience of employing different coping strategies at different times.

Health beliefs together with personality attributes (Porrett & Cox 2008, Oh & Park 2004, Shaw 2001) and social support have been identified as impacting on the recognition of a health threat. Personality attributes comprise decision-making style (Facione et al 2000). A view of fatalism, as opposed to optimism (Facione et al 2000), and philosophies about altruism/opportunism and a cultural heritage (Brittain et al 2001) will impact on the individual's recognition of the health threat and their ability to manage the problem, with women either expecting that health outcomes are the result of their own actions (internal locus of control) or the actions of others (external locus of control) (Holm et al 1999).

Stressors can be classified as dimensions such as controllable versus uncontrollable, expected versus unexpected, chronic versus acute and positive versus negative. Within this theoretical paradigm it has been possible to identify and confirm that for some women PFD is an expected stressor, perceived as a chronic stress that is controllable for others it is an unexpected stressor that occurs acutely and is uncontrollable.

8.2.4 Coping and help seeking pathway

It is suggested that stress and health-related responses are triggered by certain events that are termed event, situation, condition and cue (Shaw 1999, Lazarus & Folkman 1984). It was evident from the interview data that all informants underwent these stages of primary and secondary appraisal. For the majority of women the event that was most universally significant was the deterioration and worsening of their symptoms. Equally for the majority the cue to help seeking was the increasing impact on quality of life of their worsening symptoms. The degree of impact on quality of life depends on whether the individual woman perceives PFD as a problem and the coping mechanisms she employs to deal with the problem. It can be postulated that PFD only causes stress in a woman if she appraises it as relevant to her well-being and that in order for a woman to view PFD as a stressor it must be personally relevant. There must be a perceived mismatch between the woman's ability to cope with PFD and continuing with her life situation. If a woman perceives that she has a high quality of life and is happy with the way things are, the woman is less likely to recognise that she has a health problem since it is not perceived to affect everyday life.

Shaw's framework presents coping constructs in a linear fashion (Figure 3.2), suggesting that women progress through these stages in sequence. Data from this study has identified that women may enter this coping cycle at any stage and may progress or regress through the process, dependant on other factors occurring in their life at that given time. Consequently the Shaw framework was adapted to demonstrate the fluid nature of these concepts (Figure 6.2). The Coping Framework was used in this study to aid data collection and organise themes arising from the data. For each woman experiencing PFD symptoms the coping mechanism at

each of these coping stages will differ as a number of variables will impact and interact with her coping mechanisms. It is essential that the four concepts: event, situation, condition and cue are seen as fluid states. A woman may progress through these four stages in a linear fashion, but equally may start her coping and help seeking pathway mid way through these concepts with, for example, condition. Participants in the study did not use the terms event, situation, condition and cue. These are the etic terms used by Shaw to describe a help seeking pathway. The Phase 2 semi-structured interview guide (Appendix 2) was developed specifically to identify the individual women's perception of what the event, situation, condition and cue were for her. It is apparent from this study that etic terms used within Shaw's model are useful for the researcher to facilitate data organisation but they are not terms used or recognised by the study informants. This is another example of the difference between the emic and etic perspective with respect to help seeking behaviour.

8.2.5 Personality

The Sunrise Enabler is a conceptual picture and holistic depiction of the diverse components of Culture Care Theory. The Enabler facilitates the discovery of potential and actual influencers on care and health phenomena. Leininger does not identify that personality might have an impact on an individual's lay care beliefs and practices. Personality was identified in the literature pertaining to coping and help seeking behaviour as an important variable in health care behaviour (Oh & Park 2004, Brittain et al 2001, Shaw 2001, Facione et al 2000, Rotter 1966). The Life Health Care History participant identified that her pragmatic personality impacted significantly on the management of her PFD symptoms and consequently coping and help seeking behaviour. As a result of these findings, the Sunrise Enabler was modified to include personality as a significant influence on lay care beliefs and practices. The modified enabler aided data collection in Phase 2 and has facilitated the generation of evidence relating to the relevance of personality in coping and help seeking behaviour. This study suggests that personality influences lay care beliefs and it is apparent that decision making style and personality traits impact on help seeking behaviour. This knowledge delineates a new perspective on coping and help seeking which will inform further large scale studies.

8.2.6 Care Influencers

Previous studies provide little evidence to support positive opportunities in help seeking (Table 4.2), but it is thought that good contacts and previous experience with Primary Care services may promote help seeking behaviour. Equally there is evidence that increasing exposure in advertising and magazines influences attitudes and knowledge about incontinence (Horrocks et al 2004, Brittain et al 2001). By using the modified Sunrise Enabler it has been possible to discern the Care Influencers that impacted on coping and help seeking behaviour. The Care Influencers organised under the headings help seeking barriers, help seeking triggers and

facilitators have been summarised in Table 7.3. Each informant identified her own personal help seeking trigger. These all centred on worsening symptoms, decreasing quality of life and the fear of a serious underlying cause of their symptoms. With respect to the barriers to help seeking the majority of informants identified the impact society played with respect to the perceived shame associated with the problem alongside the role obligations of women. Lack of knowledge was seen to be a significant barrier to help seeking. Obviously each informant had an individual perception of the things which facilitated them in their help seeking process. What was evident was the significance of having both knowledge and a trusting relationship with the GP in facilitating help seeking. The 'ideal world' scenario gave informants permission to speak freely about the things that might have made it easier for them to cope, seek help and the services they would like to receive. Women described the things which would have facilitated help seeking and also discussed how services could be improved to facilitate help seeking. Knowledge, empowering women and altering society's perception of PFD to ameliorate the opprobrium associated with the problem were re-affirmed as key to facilitating help seeking behaviour. It can be reasonably assumed that the new knowledge generated from analysis of the 'ideal world' data adds another dimension to our understanding of the Care Influencers and identifies the Professional and Generic Care Beliefs that can be directly applied to recommendations for service development. The contribution to knowledge from this study include the lay care practices that women with PFD employ in order to cope with the problem, and an appreciation of the laycare practices utilised by women. Understanding of care influencers has facilitated recommendations for service and practice development.

8.2.7 Race and help seeking

Ethnic and racial groups in the UK have traditionally been less successful in gaining access to health care than the indigenous population; further, some of their needs have been neglected (Lanceley & Cox 2007, Hopkins & Bahl 1993). Findings from this research did not identify that ethnicity itself impacted on help seeking. Rather it was the beliefs of individual cultures which impacted on help seeking, and not barriers imposed externally to accessing health services.

Leininger maintains that there is a major cultural gap between generic and professional care values and practices, and reducing the knowledge gap between nurses and diverse cultures remains a problem in nursing. This professional nursing knowledge gap perpetuates cultural imposition, which can lead to destructive care practices (such as non attendance for hospital appointments and non compliance with treatment regimes). Having insights into the cultural care beliefs surrounding PFD, in particular the use of herbal medicines, will allow practitioners to include herbal/natural treatment recommendations alongside traditional medical therapies. For example the use of a tight sheet wrapped around the abdomen post delivery and the use of warm sitz baths (as described by the African women) could easily be incorporated within post natal advice. It is clear from the comments raised by the Turkish Focus group informants that

English healthcare is not perceived by all to be first class when compared to the healthcare system they are accustomed to. As a consequence there is the probability that Turkish women using PFD services may be dissatisfied with the services they are offered unless their perceptions of a 'good' service are understood and elements of these beliefs included in care packages. For example Turkish women described the health care service as laden with delays, arising from presentation to their GP and onward referral. It is possible that community based drop in centres providing a community outreach service from the hospital based PFD service might more fully meet the needs of this cultural group. Further and more detailed recommendations for practice are described in Chapter 9.

8.3 Pelvic Floor Dysfunction

This study has provided data relating to PFD incorporating the range of potential symptoms that women might experience. PFD is a syndrome in which women may experience a number of symptoms simultaneously and until now little data could be extrapolated from the literature with regard to coping behaviours and help seeking in PFD. Hence the importance and value of this research. Help seeking is a complex process. It is apparent that a combination of personal attitudes and practical barriers prevent women with PFD seeking help.

Until now, PFD and the multiple symptoms arising from the condition have mainly been reviewed in isolation, and most commonly only help seeking in urinary incontinence is addressed in any detail. Similarly, the cultural and personality factors which impact on women's attitudes towards seeking help for their symptoms have until now been poorly understood. There was an absence of data with regard to these constructs and variables in relation to women with PFD. However data from this study has identified universality and diversity in coping and help seeing behavior in women with PFD as opposed to urinary incontinence alone. It can be argued that the apparent lack of data with regard to PFD, as opposed to individual symptoms, reflects the way in which services for women with PFD remain fragmented and symptom driven, with relatively few integrated PFD clinics provided in this country. Data from this study have identified that both personality and culture have a significant impact on coping and help seeking behaviour.

PFD is a term which embraces a multitude of symptoms or symptom complexes relating to an individual's perception and personal satisfaction with bodily functions which relate to the pelvic floor. It is essentially an etic term which is not used by women with PFD symptoms. Women present complaining of a symptom. If multiple symptoms are discovered on history and examination, an explanation of how these symptoms link can be made. The focus on symptoms is entirely reasonable but the raising of public awareness with respect to PFD is considered necessary if women are to have more knowledge about their bodies and available treatments (should they wish to seek help). The fact that currently women are unfamiliar with the term PFD

or are unaware of the term PFD emphasises the emic and etic perspective in PFD. Until services are better advertised and knowledge is raised amongst women of the potential variety of pelvic floor symptoms they might experience, this will continue to be an issue.

8.4 Limitations of the study

When considering the limitations of the study it is acknowledged that the informants participating in the study reflect the views of a small number of women and cultures only. Despite the small sample size, the constructs relating to coping and help seeking were identified, triangulated and validated in a variety of contexts. Consequently it has been possible to develop a Conceptual Framework of Opprobrium Appropriation. The Conceptual Framework can be used in further large scale studies to explore coping and help seeking in wider study populations. The methodology of using Life Health Care Histories and semi-structured interviews to gain a longitudinal perspective from informants is limited by memory. To facilitate informant recall the semi-structured interview guides were constructed ensuring that salience (how important the issue is) and the number of events (cue and triggers) were considered by the informants (Foddy 2001). It is argued that as informants considered both salience and the number of trigger events, this counteracted the effects of elapsed time. In this way the importance of events or feelings in an informant's life (with regard to PFD) will be remembered because the informant will perceive the factors or events that have influenced them to be salient.

Crèche facilities were not made available to informants who wished to participate in the study. This precluded many from participating. Given the target sample group of this study, crèche facilities are necessary if women are not to be excluded from participation due to lack of social support or child care facilities.

Recruitment to the African focus group proved extremely difficult, with only two participants agreeing to take part. Following discussion at the focus group it appeared that a 'clash of cultures' and pride was responsible for non-participation as women from different African countries would not risk 'loosing face' in front of African women from different countries. Given this cultural knowledge, it would have been more appropriate to explore the views of African women either by individual interview, or in group discussions with group members of similar African subculture.

This study involved those women who had sought help and had been referred to a PFD service for treatment. It is acknowledged that this is a selected group. Epidemiological data relating to the incidence of PFD in the UK, for reasons including attitudes towards reporting of symptoms and advice seeking, is limited. Nevertheless, PFD affects up to 1 in 3 women, with Maher et al (2004) suggesting in a Cochrane review, that pelvic floor prolapse may occur in up to 50% of parous women. Swanson et al (2005) report on a Canadian study in which women over the age of 45 years from two family practice clinics were mailed a questionnaire assessing general health and continence status. The 61% response rate found more than half of the responders reporting urinary incontinence. The study does not identify the percentage of those who reported urinary incontinence that had sought help for the problem however it is reported that embarrassment alone accounts for between 11 and 47% of women with urinary incontinence not seeking help (Goldstein et al 1992, Norton et al 1998).

It is acknowledged that the number of participants involved in the study was small; the data gained from the study population was rich and will inform further large scale populations studies. The study has provided valuable insights into women's lives that suggest the need for further research (section 9.2).

This study aimed to explore (from a sample of help seekers) the coping and help seeking behaviours which facilitated help seeking for PFD. The understanding that has been derived from this study of a complex phenomenon has resulted in specific recommendations being made for clinical practice to facilitate help seeking (Chapter 9).

8.5 Summary

In the Sunrise Enabler there are four levels of abstraction and analysis. In Level One the focus is on explicating the structure of the culture of a group. In Level Two the aim is to delineate the specific meanings of health to individuals or groups. In this study Level One and Two abstraction and analysis was undertaken during Phases 2 and 3 of the research process, with both individual and cultural insights being discerned with regard to the coping and help seeking behaviour of women with PFD. Level Three is designed to understand the folk and professional systems of care. The literature review pertaining to coping and help seeking behaviour, the background review of Pelvic Floor Dysfunction alongside personal experience of designing and delivering PFD secondary care services have all informed understanding of the folk and professional systems of care. Level Four guides the development of care that is culturally acceptable. Elements associated with Level 4 can be found in Chapter 9.

This study aimed to learn from women with PFD, to understand the coping mechanisms they develop to live with PFD and the triggers that prompt help seeking, whilst gaining knowledge of cultural diversity and universality in women with PFD from different cultural backgrounds. These study aims have been achieved. The research process has generated new knowledge. Synthesis and abstraction of the Sunrise Enabler (Leininger 1988) and Shaw's Framework (1999) has developed specific tools for use in exploring coping and help seeking in women with PFD. Thematic data analysis has identified the role that personality and the cultural position of women within their society play in the help seeking behaviour of women with PFD. The construct of opprobrium has been clearly described as impacting on the phenomenon of coping and help seeking behaviour. A Conceptual Framework of Opprobrium Appropriation has been developed. Through this research, a deeper understanding of issues surrounding women seeking or not seeking medical treatment for PFD has been gained. With this greater insight, recommendations for service development, provision and availability of services and health education programmes can be made to specifically meet the needs of women with PFD. These recommendations for practice are described in the following chapter alongside areas for further research.

CHAPTER 9: CONCLUSION

This thesis depicts women's experiences of PFD and articulates unique knowledge which has been discerned through the research of their emic perspective. Tacit knowledge within this group in relation to coping and help seeking behaviour has been revealed. This chapter will propose means by which recommendations for practice and service development can be made ensuring cultural congruence. Dissemination of research findings will be suggested. Areas for further research will be identified arising from the areas of new knowledge discerned by this research.

9.1 Recommendations for practice and service development

The lower aspect of Leininger's Sunrise Enabler (Figure 3.1) can be used to develop culturally competent care for women with PFD. Leininger identifies that three modalities: Cultural Care Preservation, Cultural Care Accommodation and Negotiation and Culture Care Repatterning and Restructuring guide nursing judgements decisions and actions. Using the emic knowledge discerned from this study, alongside the etic knowledge described with regard to PFD services, it is possible to make recommendations regarding service provision in order that culturally congruent care for women with PFD is provided. These centre around the need to raise knowledge and awareness of PFD and to educate Primary Care practitioners (both medical and nursing) on the importance of giving women permission to discuss their PFD symptoms. The service recommendations also include the need to integrate secondary and primary care PFD services in order to ensure that PFD symptoms are not treated in isolation, but rather a comprehensive treatment and advice service is offered to women.

In the literature, PFD and the multiple symptoms arising from the condition have traditionally been reviewed in isolation. As a consequence there has been an absence of data with regard to coping and help seeking behavior in women with PFD. Data from this study has identified universality in coping and help seeing behaviour in women with PFD as opposed to urinary incontinence alone. It is argued that the apparent lack of data with regard to PFD, as opposed to individual symptoms, reflects the way in which services for women with PFD remain fragmented and symptom driven, with relatively few integrated PFD clinics provided in this country. The co-existence or sequential development of symptoms residing in PFD, and the universality of the 'ideal world' service needs of women, has led to efforts to integrate the evaluation and treatment of pelvic floor disorders, rather than segregate them along traditional specialty boundaries (MacLennan et al 2000, Wall & DeLancey 1991). Currently the institution, in which I work, is negotiating with the commissioning PCT to develop and provide an integrated primary and secondary care PFD service. I have had the opportunity to be instrumental in the proposal and planning of this service development. Data from this study is integral to the service specification proposed to the PCT and includes community outreach clinics, drop-in community

services, and publicity and promotion of the service. Importantly the integrated PFD service will be responsible for providing education to primary care health care providers on all aspects of PFD. This integrated service, including both primary and secondary care, is seen as the ideal service model for ensuring seamless patient focused care for women with PFD. Knowledge learnt from this study has allowed me to lead these service developments, and as such my role in practice development has been enhanced by the study process and findings. The service will provide an ideal environment in which to undertake further studies. Areas for further research are discussed in more detail in section 9.2.

Davis and Kumar (2003) suggested that collaborative approaches are needed in PFD services. Findings from this study support the premise that interdisciplinary and multi professional strategies are needed if this area of health care is to be improved. Currently services for women with PFD remain fragmented, with many specialties working in isolation. Continence Advisors provide continence advice and an extensive continence treatment and containment service in the UK, but they are considered only one aspect of a PFD Service. PFD Services are multidisciplinary services providing a range of services which are not currently able to be provided by a Continence Nurse working in isolation. Primary and Secondary Care Integrated Services are now a reality and Continence Advisors play an integral role in these services but alone do not constitute a PFD Service. Women's Health Physiotherapists, Colorectal Nurses and Continence Nurses combine to offer a range of treatments such as Bladder retaining, Biofeedback, Pelvic Floor retraining, Rectal Irrigation and Percutaneous Tibial Nerve Stimulation, alongside medical drug therapies and surgery. Back in 1996 it was identified that '*incontinence* (just one symptom of PFD) *is often a complex and multifaceted problem which may need input from a wide variety of disciplines*' (Norton 1996 p 44), and multidisciplinary clinics, such as pelvic floor clinics are described as a way of ensuring a coherent service without gaps or overlaps. The findings from this study support the need for the development of integrated seamless services for women with PFD.

Lack of knowledge was clearly identified as a significant barrier to help seeking. This was identified consistently in all phases of the study. The asking of a direct question by a healthcare professional was perceived by women as giving them permission to talk about the problem and this theme was validated in all phases of the research (Porrett & Cox 2008). Results from this study highlight information needs and clarify the importance of the role of the health care professional in facilitating help seeking. It is recommended that GP PFD education sessions reinforce the need to direct questioning of women with regard to PFD, rather than the current assumption amongst GPs that women will volunteer this information. Equally older women have been shown to be more likely to consider PFD as an expected stressor. As a consequence many develop coping mechanisms to contain the problem. It would be feasible to recommend that on the occasions that a GP sees an elderly woman for a routine six month prescription

review, they ask specifically about experiencing any PFD symptoms. Davis & Kumar (2003) suggested that there were major deficits in service provision for women with PFD; particularly with respect to the education of health care professionals. Six years on, it is apparent there has been little improvement. Integrated services with the focus on education and raising the profile of services would significantly impact on help seeking behaviour. Integrated services for women with PFD in the UK should be the norm, not the exception.

Addressing the issue of increasing women's knowledge of PFD, two recommendations have already been made and these are currently being developed. The first service development involves continuing the relationship that has been developed during the course of this study with the Hospital Advocacy service. The working relationship with the Turkish Advocates has become much closer since the advocates' involvement in Phase 3 of the study. The advocates are keen to continue the 'advocacy' component to their role and I am therefore planning a series of health education events at Turkish women's community centres. The events will encompass general advice and education regarding PFD. Funding is being sought to pay for the production of posters and leaflets, which will be in Turkish and Kurdish, identifying services that are available for women with PFD. If these sessions are evaluated as useful it will be proposed to roll out the education sessions, using the template devised for the Turkish Women's group, to other cultures residing within the location. The second recommendation is to ensure that posters, written in Turkish and Kurdish, are available in the waiting areas of key GP practices. I am working with the advocacy service and the Primary Care Trust to ascertain which GP practices are used by the Turkish population; once accomplished, these will be targeted.

When planning PFD services, community outreach services should be considered as an integral and essential component of the service. If possible PFD services should provide crèche facilities. This will enable women to seek help and will reduce the pressure of role obligations which is a major barrier to help seeking.

It is known that fear of not having the correct language to describe the PFD symptoms women are experiencing, is a barrier for some women. Equally a poor relationship with their GP is a barrier to help seeking. Commissioners of PFD services should consider the possibility of community drop in centres. Women could present to the PFD service without a GP referral. These services could be offered, possibly once a month, and organised in the same manner as drop in sexual health clinics, where self referral is the norm. Local chemists could provide information of the date and venue of these self referral clinics and the information could also be displayed in GP practice waiting areas. In discussing paternalism in the NHS, Christensen and Hewitt-Taylor (2006), suggest that a realignment of the traditional power base in medical services is needed. Nowhere could this more appropriately be channelled but at women's

services (traditionally developed by male doctors and provided in a set format through GP referral). By developing drop in facilities, or services to which women could self refer, it would significantly alter this power base. For true empowerment of women, issues such as power and control must be addressed.

Health Care professionals working within the area of PFD should seek to engage with the Pharmaceutical and Medical Devices Industries. Funding from commercial companies can be used to help promote and publicise PFD services. Many companies have research and development funds which can be applied for to pay for projects such as community outreach education programmes, leaflet translation and poster printing. Often nurses in particular, are wary of working with commercial companies; however it is recommended that nurses become more commercially aware. All employing NHS Trusts will have guidance on working with the commercial sector and will support individuals in developing commercial links. Given the current financial climate, it is probable that the further development of integrated PFD services will not be a front line DoH target. PFD service providers will need to look at all potential areas of income generation if PFD services are to be publicised and promoted.

There was significant consensus amongst the informants about what service improvements they would like to see in an 'ideal world' scenario. Data from this study clearly identified the 'ideal world' suggestions regarding public advertisement of PFD problems and an increase in media coverage. Women considered that this would lessen the stigma that was perceived to be associated with PFD. PFD services should be well advertised. Dissemination of PFD Services will enable women to seek help as they will know what services are available. Local PCT's should include listings of PFD services within their area, alongside the information they currently list such as all night pharmacies and chiropody services. Collaborative working between PFD Secondary Care providers and Primary Care Public Health Departments has the potential to increase public awareness of PFD problems. All Public Health Departments have a strategic programme of Health Promotion activities and full time health promotion specialists. It is recommended that PFD Service Managers and nurses working within PFD services develop collaborative links with their local Public Health Department. By working with Public Health, Secondary Care providers can ensure that PFD is on the annual Public Health Promotion agenda and can assist in raising the profile of PFD.

9.2 Areas for future research

Findings from this study have raised several areas for future research. The Conceptual Framework of Opprobrium Appropriation requires further testing and validation in a larger scale study. The impact of opprobrium on coping and help seeking behaviour needs to be more fully

understood in different cultural groups for example; white women, women under 60 years of age, those women over the age of 65 years. Equally further studies are needed to investigate the potentially different impact of opprobrium in women from matriarchal versus patriarchal societies.

This study has identified the key importance that women's role obligations and position in their society plays on coping and help seeking behaviour. This area requires further exploration as well as whether feminist theory may be a suitable methodology to explore issues such as empowerment and emancipation of women with respect to coping and help seeking behavior, role obligations, societal position and status of women. Essentially Feminist research has an agreed agenda to change situations where women experience discrimination and to challenge conventional patriarchal constructs of the world. With the knowledge discerned from this study clearly identifying the impact opprobrium appropriation, role obligations and societal status has on help seeking behavior, it is considered that Feminist Theory could be an effective tool with which to further explore this construct.

In order to seek help women have to progress through four distinct processes: event, situation, condition, and cue (Shaw 2001). This help seeking pathway is necessary in order for women to reach the decision that their PFD symptom is a problem which has the potential to cause harm, and for them to actually seek help. For some women the pathway will stop after the trigger event when costs or barriers prevent further progress. For others, progression will continue further down the pathway. The potential for maladaptive coping mechanisms and barriers to prevent further progress exist at each stage. Maladaptive coping strategies and barriers to help seeking will vary for each individual. Clarification of barriers which are specific to women with PFD is essential, if services are to be developed to meet the needs of service users. Further exploration of these specific topics, coping mechanisms and help seeking behaviour in women with PFD is warranted so that specific information needs, health promotion, health professional training and education and service promotion can take place to offset barriers to help seeking.

This research has confirmed the important role that personality plays in help seeking behavior. Personality influences lay care beliefs and it is apparent that decision making style and personality traits impact on help seeking behavior. Understanding how a woman perceives herself is important in planning the care for an individual woman. It is speculated that there are benefits in assessing a woman's Locus of Control and Coping mechanisms prior to developing a care plan. It is postulated that this assessment will allow a culturally congruent care plan to be developed. This issue requires further exploration.

There is little focus on the emotional coping mechanisms involved in coping and help seeking behaviour. Further knowledge of these coping mechanisms may be useful in helping women who have adopted maladjusted coping mechanisms.

Stigma is identified in the literature as one of many factors which impact on help seeking behaviour. Findings from this study have delineated the negative impact that stigma, shame and taboo play on the help seeking behaviour of women with PFD. Recent work by Taft et al (2009) explored the impact of stigma in Inflammatory Bowel Disease, concluding that in those patients who perceived stigma, they had poorer outcomes when controlling for illness and demographic variables. They concluded that perceived stigma is a potentially important psychosocial factor in IBD patient care and warrants further investigation. Exploring the impact of stigma (opprobrium) on the treatment outcomes of women with PFD is an area that requires further investigation.

9.3 Publication Strategy

The phase 1 and 2 study findings have already been published along with background papers on the subject of PFD; these are identified in Table 9.1.

Publications related to research	
Year	**Publication details**
2008	Porrett T, Cox C Coping mechanisms in women living with Pelvic Floor Dysfunction. *Gastrointestinal Nursing Journal* 6 (3) 30-39
2007	Porrett T, Cox C Coping and help seeking behaviour in women with Pelvic Floor Dysfunction. *Journal of the Association of Chartered Physiotherapists in Women's Health.* Autumn 101, 4-15
2006	Porrett T Understanding pelvic floor dysfunction and its relevance to colorectal nursing. *Gastrointestinal Nursing Journal* 4 (3) 20-26
2006	McGrath T, Porrett T Evaluation of factors which contribute to faecal incontinence Part .1 *Gastrointestinal Nursing Journal* 4 (3) 34-40
2006	McGrath T, Porrett T Assessment and management of faecal incontinence Part 2. *Gastrointestinal Nursing Journal* 4 (4) 34-40
2005	Hall A, Porrett T Colorectal nurse specialist management of rectocele. *Gastrointestinal Nursing Journal* 3 (6) 24-28

Table 9.1 Publications related to research

Alongside these publications a number of conference papers have been presented and a number of invited papers presented. The paper presentations are summarised in Table 9.2

Papers presented		
Year	**Conference and paper title**	**Invited or submitted**
Oct 2009	*'Nurse led management of patients with RED and faecal incontinence'.* Managing a Pelvic Floor Service- Pitfalls and Pointers. National Conference, Southampton	Invited speaker
Sept 2006	*'The emic perspective of women with Pelvic Floor Dysfunction (PFD)'*.Transcultural Nursing Conference – Annapolis, USA	Submitted abstract and accepted for Presentation
Sept 2006	*'The relevance of culture care theory and ethnonursing in the study of subcultures not specifically governed by ethnicity'.* Transcultural Nursing Conference – Annapolis, USA	Submitted abstract and accepted for Presentation
March 2006	*'Pelvic Floor Dysfunction'.* City and Hackney GP Education Forum Meeting	Invited speaker
Jan 2006	*'Pelvic Floor Dysfunction and the rationale for service redesign'.* City and Hackney District Nursing Conference	Invited speaker
Nov 2005	*'The use of ethnography as a research tool'.* RCN Gastrointestinal Nursing Conference	Submitted abstract and accepted for presentation

Table 9.2 Presentations related to research

The findings from this study will be written up for publication to ensure that health care providers are aware of the impact on their practice. Papers will specifically target the GP population. Other papers are planned specifically for Practice and District nurses, midwifes and colorectal nurses, all of whom can impact on the help seeking behavior of women with PFD. A paper is currently being prepared for submission to the Journal of Advanced Nursing; this paper explores opprobrium and the development of the conceptual framework Opprobrium Appropriation. It is also proposed to submit abstracts to The Transcultural Nursing Conference, The National Midwifery Conference, the National Conference of Health Visitors and the International Urogynaecology Association Conference.

9.4 Summary

Grounded within the naturalist paradigm, this research has employed an exploratory descriptive design using ethnographic methods. As a micro-ethnographic study, it has focused on the emic perspective of a defined group: that being women with PFD who present to an East London Hospital for treatment. The research study has encouraged the development of knowledge through clarification of the women's experiences of living with PFD and the coping mechanisms developed prior to seeking help. It has delineated the impact of opprobrium on both coping and help seeking behaviour. The study aimed to understand coping and help seeking behaviour and to elicit factors which impact on these behaviours. This has added to the ethnographic perspective of the study and has enabled a broader understanding of the concept of coping and help seeking in women with PFD. The unique contribution of this study has been identification of the lay care practices that women with PFD employ in order to cope with the problem and has generated an appreciation of the laycare practices utilized by women.

The study aims have been achieved and new knowledge has been discerned associated with opprobrium appropriation. Recommendations for service development and practice have been made alongside areas for further research. The increasing prevalence of PFD is well known, with studies suggesting that over the next 30 years the number of women seeking help for PFD symptoms will increase at twice the population growth rate (Sze et al 2002, Luber et al 2001, Kuh et al 1999). Knowledge and understanding of women's coping and help seeking behaviour is essential if services are to be developed to meet this growing need.

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APPENDIX 1

Life Health Care History Interview Guides

Ann is a pseudonym used to protect the informant's anonymity

INTERVIEW GUIDE/QUESTIONS

Ann thanks for agreeing to be involved in this research project, I really value your participation in the study. You received an information sheet regarding the study, inviting you to participate, and a consent sheet, which you signed. Do you have any questions which have arisen from this information which you would like to ask?

This discussion is an opportunity for you to tell your personal story with regards to your health, care and illness experiences. I would like to learn about you and how you have known and experienced health.

- *I would like to start by talking about where you were born and what you remember about your early days of growing up, keeping well or being ill.*
- *Describe any special events or experiences in your childhood or adolescence, regarding health, that were important to you* (maybe like childhood illnesses, first visit to the opticians, visit to the school nurse)
- *Please describe any memories you might have of your health or illness experiences that were pleasant* (childhood, adolescence, mid-life years)
- *Please describe any memories you might have of your health or illness experiences that were unpleasant* (childhood, adolescence, mid-life years)
- *Would you outline for me examples of health care activities or advice shown or given to you by your family, friends or partner*
- *Ann I'd like to hear about your general philosophy about health and keeping well*
- *Ann have your religious, political or cultural values helped or hindered your life health goals or health behaviour?*
- *Please describe any special family or friend care or professional care that has impacted on how you have dealt with health or illness*
- *Who have been the key people who have taken care of you or influenced your own health care?* (mother, partner, GP, friends)
- *Throughout your life what factors have seemed to keep you going, living or establishing healthy patterns of living?(* alcohol, job, friends, partner)
- *Ann describe any other aspects of your life which you think were or are important in relation to health or illness*

I'd now like to ask some questions which relate to your recent but ongoing hospital treatment

- *Describe the specific factors that prompted you to seek medical help*
- *Before seeking medical help how did you cope with or compensate for your symptoms?*

- *Since seeking medical help how have you coped with or compensated for your symptoms?*
- *Since you first began to experience these problems describe the factors that have seemed to help keep you going or able to cope (* alcohol, job, friends, partner)
- *Describe any factors which you think may have negatively impacted on your ability to cope or get on with your life*
- *In considering the various treatments that you have received , tell me how they have , if at all, influenced your ability to cope with the problem*
- *When first seen at the Homerton you had symptoms (problems) that were the main reason for you seeking help. Describe these for me*
- *Ann, it later transpired in the course of your treatment, that you had other symptoms that could be treated but you did not initially discuss these. I'd really like to understand how you prioritized seeking help for your problems*
- *Which of your symptoms did you consider to be a problem and therefore wanted treatment for and which did you consider as 'normal' after having a baby?*
- *Describe the specific reasons that you did not seek help for certain symptoms?*
- *How would you assess the impact that these health problems have had on you physically?*
- *How would you assess the impact that these health problems have had on you psychologically?*
- *Describe the social impact these health problems have had on you*
- *Describe the economic impact these health problems have had on you*

Ann, in the past we have discussed that the range of medical problems which you are experiencing can be associated with childbirth and is in fact described as Pelvic Floor Dysfunction.

- *How would describe your knowledge or understanding of Pelvic Floor Dysfunction before coming to the Homerton?*
- *Please outline any conversations you have had with anyone (such as your mother, girlfriends, partner or GP) in which you discussed the potential problems which can be experienced following having children?*
- *Prior to seeking medical help what did you consider to be the cause of the problems you were experiencing?*
- *The anal fissure appeared to be the major problem that brought you to hospital but you also had other issues with regard to urinary problems and sexual function. Describe how you perceived the relationship of these problems to each other*

- *In considering the various treatments and interactions you have had at the Homerton , tell me how they have, if at all, altered your perception of the relationship of these problems to each other*
- *Please outline for me what you consider to be normal and acceptable health problems that women experience*
- *If you think back to your level of knowledge and the information you received about Pelvic Floor Dysfunction before you sought help for your problem , tell me how , if at all, more information or knowledge might have influenced how you managed your problems or influenced your seeking medical help?*

Closing of interview, making arrangements for future meetings/transcription of the interview and sending of transcription to Ann.

- *Ann to conclude this discussion is there anything else you would like to add to help me understand more fully how you have coped with Pelvic Floor Dysfunction and the impact this problem has had on you and your family*

Ann I'd like to thank you very much for participating in this study. A transcript of this conversation will be typed up and a copy sent to you, with a stamped addressed envelope, for your comments and confirmation of its accuracy. Once you have had the opportunity to make any additional comments and confirmed the accuracy of the transcript, I will send you a copy to keep for your records.

Clarification questions and interview outline

Ann, thank you for agreeing to see me again and answer questions which aim to clarify my understanding of your personal story with regards to your health and illness experiences. You have previously signed a consent form which also covers this interview. Before we start do you have any questions or comments which you would like to make?

- *Ann, you describe your mother having a complicated delivery when she had you. Can you recall how you know this?*
- *Would you please describe any other discussions or conversations that you can recall with your mother with regard to pregnancy or labour?*
- *Ann, as you stated, your mother obviously needed a period of recovery following your birth, which may have been similar to your recovery period following the birth of your second child. Did you ever identify this similarity or discuss it with your mother?*
- *Ann you were breast fed for a number of months following your delivery. Do you think this influenced your behaviour following the birth of your children?*
- *After your second delivery you continued to breast feed even though you identified that you were not coping particularly well and the baby was not thriving, what were the influences or pressures that led you to do this?*
- *Ann, your brother was born when you were 7. Do you know whether this was a difficult delivery for your mother or if she had any complications? Do you remember your brother having any childhood illnesses or accidents?*
- *Having lived and coped with a severe allergy since childhood you identified that you have developed a pragmatic approach to managing the problem. Do you think this pragmatic approach has effected how you manage other aspects of your life health needs – such as drinking water, eating fibre, doing pelvic floor exercises?*
- *Ann, you describe on a number of occasions how as a family you coped with your allergy by joking about it. Joking and humour are powerful tools to help us cope with a situation. Can you describe for me how joking /humour help you cope with your bottom and bladder problems?*
- *Ann, at one point you talk about wanting to be a nurse, please tell me more about this early career idea and what influenced your change of career path?*
- *You describe going on your own to the GP (a family friend) because you had bad abdominal pain. Did you make the appointment to see the GP and go on your own?*

Once the GP had diagnosed 'constipation' did you get any advice or information from him or anybody else about managing constipation?

- *Ann you describe very clearly that you learnt a lot from your mother with regard to managing your allergy. Could you describe for me practices you have learnt from other people that help you keep healthy? Best friend, partner, work colleagues?*
- *We spoke about your philosophy regarding your health and well being and this appears to relate primarily to your responsibility for caring and looking after others, but who is responsible for your health and wellness needs?*
- *Ann you describe time or rather lack of it, as a key factor that prevents you looking after yourself, could you explain this in more detail for me?*
- *In our previous conversation you talked about juggling balls in the air, 3 you could do (job, children, partner) but add another, health, and it becomes impossible. I am interested to learn more about how you manage to juggle the 3 balls without feeling or being healthy?*
- *Have you ever considered that you might do the juggling better and quicker if you had some 'you' time in which to relax, exercise and look after yourself?*
- *Ann, you talk about not knowing if your children have a nut allergy and therefore you ensure that they don't have nuts at all. What is your long term plan for managing this issue in your children?*
- *Ann, you describe very clearly the problems you had following the delivery of your first baby - that sex was very painful and you thought you might not have been sewn up correctly. Can you help me to understand why you did not choose to seek medical help for this?*
- *Following the delivery of your second child you describe the treadmill of your existence, having a baby who was ill and being in severe pain and difficulty yourself. You had a routine follow-up appointment at the Hospital (given to all women who have bad tears) and it was at that consultation that your problems became evident. If this routine appointment had not been made for you and come along when it did, what do you think you would have done? How would you have continued to cope? And for how long? What might have helped you to stop and focus on yourself? (friends, family, GP)*
- *Ann, you describe that you learnt to live with the chronic pain you had and that it takes a long time before it becomes unacceptable to you. Could you please help me to understand more fully what you mean by that?*

- *In our previous conversation we talked about the first hospital consultation when we met and you remember me describing the situation you were in as 'unacceptable'. You describe then feeling able to tell people about this problem (you had not previously as you thought they would not be interested or sympathetic). Who did you choose to tell and what was their reaction? Why had you thought they might be disinterested or not sympathetic with regard to your problems?*

- *You described keeping a lot to yourself, being really stoic, but that it was a relief to let go. After our consultation, in which plans for your treatment were made, what changed to allow you to feel able to share this problem with people?*

- *Ann you describe being angry with yourself because you were pre-occupied and hadn't sought help earlier. What strategies did you employ to mask/cover the problem? In retrospect do you think someone else might have realized how serious the problem was and taken over?*

- *Ann did you at any time consider that your illness might be impacting on the well being of your second baby and your ability to look after him?*

- *You mentioned that you had an aunt who had a prolapse – can you tell me more about your aunt and what you know of her problem?*

- *Ann you mentioned 'old wives tales' about problems women experience after childbirth. Where did you learn these old wives tales from?*

- *You describe your experience of urinary incontinence as 'mortifying', and 'really embarrassing'. How do you cope with this problem in your day to day working life? Is there anything you avoid doing involving work or your social life because of a fear of urinary incontinence happening?*

- *Ann you described urinary incontinence as 'an irritation that you could live with' because it didn't hurt. Am I correct in believing that you might only seek help for a medical problem or this continence problem if it was painful?*

- *When we discussed what you considered to be normal or acceptable health problems that women experience following childbirth you identified that you are not really the same person again because you are a mother but everyone expects you to be the same. Could you help me to understand this more? Was the fact that you were a different person a good or bad thing in your eyes? Do you think your partner or family viewed this change in the same way? How might you have been supported so that you could have dealt with the exhaustion and urinary problems?*

APPENDIX 2

Phase Two Semi-structured Interview Guide

Phase Two Semi-structured interview guide

Thank you for agreeing to be involved in this research project, I really value your participation in the study. You received an information sheet regarding the study, inviting you to participate, and a consent sheet, which you have signed. Do you have any questions that have arisen from this information that you would like to ask?

This discussion is an opportunity for you to tell your personal story in regard to your health, care and illness experiences of living with Pelvic Floor Dysfunction. I would like to learn from you about how you coped with this issue and the experiences which led you to seek help.

- *When or how did you realize you had a condition/problem that was affecting you or causing you difficulty?* (Knowledge, insight, event, trigger)
- *Did you think that this condition/problem was a normal occurrence which was to be expected or was it an abnormal occurrence/problem which you had not expected to happen?* (Coping and perception of problem, cue, condition, threat, knowledge, stress theory)
- *For you was this condition/problem a potential threat to your well being?* (Stress theory)
- *Have you had other health care problems in your life*? (Health care beliefs, how coped with other problem might impact on current coping).

If yes *How have you coped with or managed these?*

- *Please describe for me your understanding of the problems that could occur immediately or sometime after having children?* (Knowledge) *How did you come to know this?*
- If they respond from antenatal classes I will continue to ask the following 2 questions:-
- *Were issues such as urinary incontinence and prolapse discussed at these classes?* (Knowledge)
- *Did you have any written information given to you explaining these potential conditions and what symptoms they could cause?* (Knowledge)
- *Were you able to discuss your condition/problem with friends or family?* (Social support, knowledge, embarrassment, culture)

- *In what ways would you have liked family members and friends to support and care for you in regard to this problem?*

- *Did you perceive your condition/problem as being a medical condition?* (Inevitability, incontinence perceived as a social problem not medical, health belief)

- *Did anything prevent you from going to seek help for this problem*l? (Such as not knowing who to see, embarrassment, time pressure, social role obligations, work obligations, finance, transport, embarrassment, culture, religious beliefs)

- *Please describe for me what made you seek help when you did.* (Trigger events). *I would like to understand if the severity of your symptoms had an impact on when you sought help?*

- *After you first realised you had a problem (PFD condition) how long was it before you sought help?* (Delay, coping) *At this stage did you feel that this condition/problem might be affecting your quality of life in any way?*

If respondents answer that there was an impact on their QoL I would proceed to:-

- *Describe for me the ways in which this condition impacted on your quality of life.*

- *I am interested to know if anything prevented you from seeking help immediately or made it difficult for you to seek help?* (If there was a delay)(Knowledge, embarrassment, insight, social and role obligations, transport, finance)

- *Describe for me the ways you found to cope with and manage your condition prior to seeking help.*

- *Describe for me any measures you might have taken to try and treat or cure this yourself.* (Lay care beliefs)

- *What did you know about any medical treatments that were available for your condition/problem?* (Knowledge, health beliefs)

- *Once you had realised you had a condition/problem* (Trigger event) *describe for me the stages you went through in deciding how to manage the situation and what would be best for you to do.* (Event, situation, condition, cue)

- *Describe for me any things you think made it easier or helped you to seek help.* (Knowledge of health service, good relationship with GP, knowledge of who the best person was to seek help from)

- *Once you had discussed your PFD condition with your GP (or nurse, midwife) what help or advice did you receive?*

- *When people become ill or anticipate problems, they often pray or rely on their religion or spiritual beliefs. Have your beliefs and practices helped you to cope with your PFD condition?* (This is a direct question from the Sunrise Enabler)
- *Why do you think women who have similar problems to yours might find it difficult to ask for or receive help?*

To conclude the interview I want to give the woman the opportunity to describe for me the 'in an ideal world' scenario so that opportunities to facilitate help seeking behaviour can be extrapolated.

- *In an ideal world what might have made it easier for you to seek help?*
- *Describe for me any things that might have made it easier for you to cope with your PFD problem in an ideal world.*
- *In an ideal world how might the services that were offered to you be improved?*

To conclude this discussion is there anything else you would like to add to help me understand more fully how you have coped with Pelvic Floor Dysfunction and the impact it has had on you and your family?

I'd like to thank you very much for participating in this study. A transcript of this conversation will be typed up and a copy sent to you, with a stamped addressed envelope, for your comments and confirmation of its accuracy. Once you have had the opportunity to make any additional comments and confirmed the accuracy of the transcript, I will send you a copy to keep for your records.

APPENDIX 3

Phase Three Semi Structured Interview Guide

FOCUS GROUP GUIDE

1. **I would like to thank you all for agreeing to be involved in this research project; I really value your participation. This part of the study aims to understand the cultural beliefs that you have regarding your health and how this might have impacted on your coping and help seeking behavior. The knowledge from this study will allow us to make recommendations for how services can be targeted and developed to more adequately meet the needs of women with PFD from diverse cultural backgrounds. You received an information sheet regarding the study, inviting you to participate, and a consent sheet, which you signed. Do you have any questions which have arisen from this information which you would like to ask?**

2. **This group discussion is an opportunity for you to tell me about your cultural beliefs with regards to your health, care and illness experiences. I would like to learn from you about your culture and specifically your beliefs about health care. These opening questions are to enable me to gain an overview of your culture.**

Opening questions relate to the culture in general

- Can you tell me about your reasons for coming to live in England? (Reasons for migration, salient historical events, discrimination of women, asylum).
- Can you describe for me the perception and role of women in your culture?
- Are you able to read/write your own language?
- Can you read or write English?
- In your culture who is the head of household?
- What is the preferred age of marriage in your culture?
- In your culture what is the belief about children, number of children, and the role and status of childbearing women?
- In your culture what is the role of extended family?

These questions relate to general health care beliefs

- I'd like to hear about your general philosophy about health and keeping well
- Are there any religious influences on your health care practices?
- Can you give me any examples of folk medicine that you know of or have used? (Herbal medicines, other therapies, family remedies passed down from previous generations)
- Can you describe for me predominant beliefs that influence your health care practices?
- Would you outline for me examples of health care activities or advice shown or passed down to you by your family, friends or partner
- Who have been the key people who have taken care of you or influenced your own health care? (mother, partner, GP, friends)
- Who decides when to seek health care for family members and who assumes responsibility for health care in your culture?
- In your culture how do you respond to illness? (For example with regard to pain - ?verbalisation of pain, outward signs of illness, be stoical or vocal about the problem?)
- What are your beliefs about English medicine/treatment? What are your perceptions of health care practitioners and their status within your culture?
- Is health a gift from god over which you have no control? Or do you have control over your own health ?whose responsibility is your health (Help seeking beliefs and behaviours)
- In your culture do you have local healers?
- Have you used local cures and medicines for your health problems?

3. **I'd now like to ask some questions which relate to your recent Pelvic Floor Dysfunction**

- What specific cultural values or beliefs have impacted on you with regards to your PFD problem?
- Were there any barriers to you seeking help for your medical problem? (Accessibility, affordability, awareness of service, attitudes of pt or caregivers, language).
- If there was a delay between you realising you had a problem and seeking help what coping mechanisms did you employ to help you manage?
- What was the 'trigger' that prompted your help seeking?
- If you sought help immediately – why?
- How does your culture perceive incontinence and problems such as yours?
- Do you know of any local healers, local cures or medicines to treat this problem?
- What do you believe causes this problem?
- Did you tell your family about the problem or have you kept it to yourself?
- Did you consider your problem as 'normal' or expected after having a baby?
- Describe the social and family impact these health problems have had on you
- Did you know anything about Pelvic Floor Dysfunction before coming to the Homerton?
- Please outline for me what you consider to be normal and acceptable health problems that women can experience

4. **Ideal world scenarios**

- In an ideal world what might have made it easier for you to seek help?
- Describe for me any things that might have made it easier for you to cope with your PFD problem in an ideal world.
- In an ideal world how might the services that were offered to you be improved?
- In an ideal world would anything have made the help seeking process easier?

5. **Closing of focus group**

To conclude this discussion is there anything else you would like to add to help me understand more fully your beliefs about health and how you have coped with Pelvic Floor Dysfunction? I'd like to thank you very much for participating in this study.

APPENDIX 4

Consent and Patient Information