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Social Support for Women with Chronic Pelvic Pain

by

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Dedication

In memory of my friend Stephanie Glover. Stephanie's absence was sorely felt throughout the writing of this thesis but the memory of her warmth, intelligence, wit and daring, remains an inspiration.

Acknowledgments

I would like to thank my academic supervisor, Stephen Joseph, for believing in the research idea and in my ability to carry out the project; for reading endless drafts and providing prompt and constructive feedback; and finally for kindness at times when I felt overwhelmed by the conflicting demands of my work and personal life. I am also grateful to my clinical supervisors, Polly Ashworth and Christine Cordle, for their help with gaining ethical approval for the project; providing access to participants; and for giving valuable feedback about report drafts. A number of other professionals also went out of their way to find potential participants for the project, David Nunns, Nicky Burns and Karen Easton deserve particular acknowledgement for this. I am indebted to the National Endometriosis Society for allowing me to place a notice on their website, and to the women who so swiftly responded to my appeal for participants. This project would not have been possible without the women who agreed to take part in it. The honesty and openness with which they described their experiences, made the project seem worthwhile. Finally, some forms of social support are beyond measure. My husband, Michael, has remained unceasingly supportive and enthusiastic about my endeavours despite the extra burden of family responsibility that has fallen to him as a consequence.

Declaration

This thesis was carried out under the academic supervision of Stephen Joseph, Chartered Health Psychologist, who helped to design the study; acted as independent auditor for the qualitative analysis in chapter two; assisted in the statistical analysis in chapter three; and lent his editing skills to the written reports. Clinical supervision was provided by Christine Cordle and Polly Ashworth, Chartered Clinical Psychologists. Apart from this input the thesis is entirely my own work and has not been submitted for a degree to any other university. Authorship of any papers from this work will be shared with the above.

The literature review (chapter one) has been submitted for consideration for publication (Appendix 1) in the British Journal of Psychosomatic Research (Warwick, Joseph & Cordle). The main paper (chapter two) is being prepared for submission to Psychology and Health (Warwick, Joseph, Cordle & Ashworth, in preparation), and the brief paper (chapter three) is being prepared for submission to the British Journal of Health Psychology (Warwick, Joseph, Cordle & Ashworth, in preparation).

Summary

Social support has been shown to reduce the effects of stress and help individuals to cope. However, research suggests that the effects of social support depend on whether there is a match between the type of support offered and the needs of a particular situation, and from whom the support is offered. The aim of this study as a whole was to examine the social support experiences particular to women who are faced with the distressing problem of chronic pelvic pain (CPP).

The literature review (chapter one) revealed that although pain is defined as a subjective experience, research in this field has rarely been concerned with the experience of CPP from the perspective of the women who suffer it. The first study (chapter two) therefore aimed to gain a detailed description of social support transactions as experienced by women with CPP. Eight women with CPP were interviewed about what has been helpful and unhelpful in terms of social support from their partners, families, friends, acquaintances, doctors, nurses and other women with CPP. Interpretative phenomenological analysis (IPA) of interview transcripts revealed both helpful and unhelpful efforts at support from the various support providers. Findings are discussed in relation to extant literature and in terms of their clinical implications. The second study (chapter three) was concerned specifically with social support from partners. Standardised measures of pain experience, social support and psychological well being were administered to 29 women with CPP. Correlational analysis revealed significant associations between particular perceptions of partner support behaviours and depression and pain severity. Finally, the research review (chapter four) reflects on the extent to which this research project fulfils evolving criteria for the assessment of qualitative research.

CHAPTER ONE

METHODOLOGICAL AND CONTENT CRITIQUE OF QUALITATIVE STUDIES ON WOMEN'S VIEWS OF CHRONIC PELVIC PAIN

ABSTRACT

Chronic Pelvic Pain (CPP) is a common and distressing problem for women, which has proved difficult to diagnose and treat. A greater diversity of theoretical and empirical perspectives is necessary to improve understanding of the social, psychological and physical dimensions of CPP. Pain is defined as a subjective experience and yet few studies have been concerned with the experience of CPP from the perspective of the women who suffer it. By means of a systematic literature search six studies were identified which focused on the 'insider' perspective of CPP. The selected studies were assessed according to evolving criteria for evaluating qualitative research. Common findings are discussed, for example 'disruption to women's lives', 'search for cause', 'effects of support', 'ways of coping', and 'difficulties with the medical encounter'.

1.1 INTRODUCTION

Chronic pelvic pain (CPP) is a distressing and often disabling pain problem, which some women endure for years. It can be defined as non-malignant pain of at least 6 months duration, suffered by women in the lower abdomen or pelvis. This pain can be continuous or intermittent and is not exclusively associated with the menstrual cycle or sexual intercourse [1]. It is a common problem, a three-month prevalence rate of 24% has been found among women aged between 18-50 years in the UK population [2]. In primary care an annual prevalence of 38/1000 has been found [3].

CPP has proved difficult to diagnose and treat [4]. Difficulties in diagnosis and treatment stem from the fact that underlying physical pathology is not easily detectable [1]. Furthermore, even when there is visible evidence of pathology, the relationship between pathology and pain is complex [5, 6]. Generally, researchers now acknowledge that there is a complex interrelationship of social, psychological, and physical factors that accounts for the experience of chronic pain [7,8]. Nevertheless, recent reviews [9,10] reveal that much CPP research remains based on the more traditional biomedical model. There is a growing consensus that attributing CPP to either physical pathology in those women where it is detected, or to psychological factors in those women where it is not has been both scientifically questionable and clinically unhelpful [11,12]. Grace argues that a radical deconstruction of the organic-psychogenic dichotomy is necessary for progress to be made in CPP research and calls for a greater diversity of theoretical and empirical perspectives on CPP [13].

Most studies have examined CPP from what Conrad [14] describes as the 'outsiders' perspective. Outsider perspectives tend to see the patient, disease or illness as an object or something to be affected, their orientation is deductive and medical questions are their central concern, the subjective reality of the sufferer is minimised or ignored. In contrast, there are relatively few studies that have been concerned with exploring the experience of CPP from the perspective of the 'insider'. In their review of the literature, Savidge and Slade [9] propose that more idiographic exploration of women's experiences of CPP would expand information regarding women's appraisals, beliefs and processes of adjustment. The purpose of this review was to assess to what extent the shift of attention to an 'insider' perspective was now able to contribute to our understanding of CPP.

Computer-based literature searches were conducted on PsychINFO and MEDLINE databases using various combinations of the keywords 'chronic pelvic pain', 'qualitative', 'phenomenological', 'idiographic', and 'interpersonal'. Two hundred and eight titles and abstracts were examined in order to locate empirical peer-reviewed studies that investigated women's own accounts of their experiences of CPP. Eight articles were found. On further examination two of these were rejected [15, 16] because although they employed qualitative methodology to elicit the views of women with CPP their main aim was to evaluate a treatment intervention. The six selected studies are summarised in Table 1.1 These studies signify a relatively recent and novel research interest because all the studies were conducted in the last decade with no evidence of CPP being investigated in this way before 1990.

Table 1.1 Identified studies concerned with subjective experiences of CPP

Authors	Focus	Participants		Data collection	Analysis	Results/comments
		N	Source			
1. Zadinsky and Boyle, 1996 [20]	Self-care practices in the context of culturally prescribed roles	14 women seeking care for CPP	Fee paying CPP clinic (USA)	Semi-structured interview, audio taped and transcribed	Constant comparative method. Ethnograph software	Descriptions were organised in terms of assessing the need for self-care, developing and sustaining self-care practices
2. Fry, Crisp & Beard, 1991 [22]	Patients' models of CPP	64 women with CPP	Specialist outpatient CPP clinic (UK)	Structured interview	Content analysis.	Few participants had clear ideas about cause of CPP. A significant proportion knew what they did not want in terms of treatment. Worries focused on interminability and effects on sex and work.
3. Savidge, Slade, Stewart & Li, 1998 [24]	How women experience and perceive CPP and the care they receive for it	21 women who had undergone diagnostic laparoscopy with negative result, 12-18 months previously	Via operating lists for diagnostic laparoscopy from 2 UK teaching hospitals	Semi-structured interview, written notes and audiotape	Qualitative thematic analysis	Most women described pain yet few were in receipt of continuing medical care. Their pain affected many areas of their lives. Issues included uncertainty, anxiety and a sense of not being believed. Interactions with medical professionals were considered important and had an impact in terms of whether their pain was validated. Dissatisfaction with the quality and quantity of information given by doctors was common.
4. Grace, 1995a [25]	To identify the nature of the problems women experience in their use of health services with respect to the diagnosis and treatment of CPP.	6 focus groups each with 5-7 women with CPP	3 focus groups via local Endometriosis Support Group. 2 focus groups via local women's health group, 1 focus group via a pelvic pain clinic.	Focus group sessions audio taped and transcribed	Discourse analysis.	Themes of particular concern: (a) doctors negated women's experience of the pain and its meaning to her and this affected her ability to take responsibility for her condition; (b) the medical extraction of symptoms overshadows women's discursive interpretation of them; and (c) the concept of 'pelvic pain without organic pathology implies an absence that becomes filled with the spectre of neurosis or psychological problems.
5. Grace, 1995b [26]	To investigate whether and to what extent specific groups of women with CPP experience particular problems with the medical encounter	336 women who had used the health services in NZ for CPP	178 from Endometriosis Support Group. 44 from women's health centre's and personal networks, 144 from NZ health services.	A questionnaire based on Grace's qualitative study above	Frequency, cross tabulation and cluster analysis	Problems surrounding communication with the doctor, diagnosis, medication and surgery were common. Women who had one type of problem tended to have others. Women of lower socio-economic status were found to be more likely to experience these problems.

Authors	Focus	Participants N	Source	Data collection	Analysis	Results/comments
6. Selfe, Van Vugt and Stones. 1998 [27]	To explore gynaecologists' attitudes about pelvic pain in women and to test for possible relationships between gender, ethnicity, age and years since training.	1 of the 3 focus groups conducted comprised 3-8 women with CPP	Gynaecology outpatient clinic (UK).	Focus group session audio taped and transcribed.	Qualitative analysis of focus group data using Ethnograph software.	Women reported having the expectation that diagnosis would lead to curative treatment. Having no pathological cause left feelings of disappointment and being fobbed off. Time was an issue, doctors not giving enough time in consultation or women's time being wasted in referral process. Participants attributed distinct incidents to origin of pain.

1.2 ASSESSMENT OF METHODOLOGICAL PROCESS

Criteria for the evaluation of qualitative research continue to evolve [17,18,19]. Characteristics of good qualitative research include: 'sensitivity to context', 'commitment and rigour', and 'transparency and coherence' [19].

Sensitivity to Context

Study 1 (Zadinsky & Boyle, 1996): Study 1 [20] is concerned with self-care practices in the context of the culturally prescribed roles of women with CPP. It is based on theories of self-care and socio-cultural theories about health [21] that consider illness behaviour, role changes and the influence of social networks in illness experience. Individuals are regarded as active agents of their care within everyday social contexts. Hence by means of semi-structured interview participants were asked about the things they commonly did when they experienced pain, what special practices helped them most with this pain and how they learned to live with it.

Study 2 (Fry, Crisp & Beard, 1991): Study 2 [22] is based on the approach of Kleinman [23] and is concerned with understanding patients' socio-cultural models of their illness. The authors suggest that the mismatch between doctors' and patients' models of illness undermines doctors efforts to help. Their rationale is that greater knowledge of the patient's model will improve the consultation process and consequently patient care. Their questions were therefore designed to elicit the illness models of patients with CPP.

Study 3 (Savidge, Slade, Stewart & Li, 1998): The other studies (3-6 of Table 1) focus on women's beliefs and experiences of CPP in relation to the medical encounter. In the introduction to study 3 [24] references are cited which highlight the way in which dichotomous approaches to the study of CPP have led to women being blamed for their pain, and the reality of their experience being challenged. As a consequence, the authors claim that there has been little in the way of systematic approaches to care or interventions for pain relief, and that women's needs remain unexplored. Therefore, by means of semi-structured interview their study aimed to generate descriptive data regarding women's involvement with professionals, their perceptions of the pain, and to gain insight into factors perceived as helpful or unhelpful to their care.

Study 4 & 5 (Grace, 1995a, b): Study 4 [25] was initiated in response to concern from a voluntary body (The New Zealand Endometriosis Support Group) that a large number of women were encountering problems when seeking help from the medical profession. Therefore by means of focus groups, women with CPP were invited to describe the nature of these problems. Study 5 [26] is a quantitative survey and has been included in this review because it represents the second phase of study 4. It was conducted to discover the extent of the problems with the medical encounter that were identified in the focus group phase.

Study 6 (Selfe, Van Vugt & Stones, 1998): Study 6 [27] is also concerned with experiences of medical care. Although the main aim of this study is to investigate the attitudes of doctors towards women with CPP, it has been included in this review because one of the 3 focus groups conducted in the study was designed to elicit the views of women with CPP about their medical care. The authors of this study are explicit about the influence of feminist, sociological and cultural literature on the study design.

Commitment, Rigour, Transparency and Coherence

Study 1 (Zadinsky & Boyle, 1996): Commitment, rigour, transparency and coherence are to a large extent achieved by study 1 [20]. A good level of detail about the study setting and participants is provided. This enables us to question whether interviewing participants at home might have been more appropriate than at the clinic indicated, since the focus of the study is on self-care practices in every day life. Randomisation would not have been appropriate for this sample of only 14 women. However a sample size sufficiently large to be statistically representative could not be analysed in the depth appropriate to the research question. Therefore the study's use of purposive sampling was a useful way of ensuring that the sample included a range of different types of women who suffer with this pain.

The study procedures were reported in detail. The collection of data was thorough with all women being interviewed for 1 to 2 hours, 6 women were interviewed more than once, and some were telephoned to clarify what had been said in the interview. All interviews were audio taped and transcribed. Additional field notes were taken in order to contextualise data, analyse interview techniques and record personal reflections. This reflexivity contributed to transparency in that it provided understanding of the assumptions and values that the researchers brought to influence the research.

The method of analysis was clearly stated and the study gained 'member validity'. In other words, a study participant and a woman with CPP who did not take part in the study were both given manuscript drafts and each confirmed that the study findings were similar to their experiences of CPP. This suggests that the report had resonance for readers which is not surprising given that it appeared to be well organised under headings pertinent to theories of self-care, it was easy to read and was well grounded in textual examples. One is left wondering however, about what steps would have been taken if 'member validity' had not been achieved would participants' interpretations have been given precedence over researchers' interpretations?

Study 2 (Fry, Crisp & Beard, 1991): Commitment, rigour, transparency and coherence were less well realised by study 2 [22]. Little detail was provided about the study setting or sample, other than that participants were the first 64 of a larger series being studied in another investigation, not referenced. The large sample seems disproportionate to the nature of the research task of eliciting patients' personal models of illness. It is likely that such an investigation would produce data at a level of detail that would be prohibitive to collect and analyse. However, the questions posed were relatively closed and thus perhaps limited the scope of participants' responses. Although this may have rendered the data more manageable it probably reduced its contribution to our understanding of the phenomena. No indication was given as to how questions were posed or how responses were recorded. Very little was offered in terms of describing the analysis procedure other than that categories of response were grouped together in results. The boundaries between data and interpretation were blurred in this report and methods and procedures were obscure.

Study 3 (Savidge, Slade, Stewart & Li, 1998): In contrast, study 3 [24] provided a detailed description of setting, sample, procedure and analysis. Twenty-one women were given semi-structured interviews, a larger sample than that of study 1. This was perhaps possible because written notes were taken with audiotape back up so that content could be checked, in place of time consuming verbatim transcriptions. Although this is a less reliable method the result was nonetheless richly descriptive. Abundant examples of data were used to illustrate this coherent report.

The study claimed to have gained inter-rater reliability for its analysis. A person independent from the study was reliably able to allocate participants responses to the particular category headings that had been imposed by the author. For researchers who believe that knowledge cannot be objective, but rather is always shaped by the purposes, perspectives and activities of those who create it, the use of 'inter-rater reliability' as a check on the objectivity of a coding scheme is meaningless [19]. An 'independent audit' [17] may have been more appropriate. Initial notes on research questions, interview schedule, audio tapes, annotated transcripts, codings, initial categorisations, draft reports and the final report, can all be scrutinised by an independent auditor, not in an attempt to suppress alternative readings or necessarily to reach a consensus but rather to validate one particular interpretation.

Study 4 and 5 (Grace 1995): The depth and breadth of studies 4 [25] and 5 [26] combined suggest a high level of commitment and rigour. Six focus groups were conducted in study 4 and their procedure was meticulously reported. Participants were sourced from different community groups hence bringing a range of different experiences. It is the only study to have participants from other than medical settings. This improves its representativeness because a recent epidemiological study has revealed that 41% of women with CPP do not consult with medical services [2]. A good description of the analysis procedure was given, although a reference for 'lexicology' would have been helpful. This study was unique in its use of discourse analysis and in its presentation of a metadiscourse. This is a singular discourse which goes beyond the individual and idiosyncratic patterns contained in the text but which reflects most of the instances. This provided a condensed and powerfully resonant narrative of women's experiences. However, a number of common themes were also offered and these would have benefited from examples of data to illustrate them. This would have enabled the reader to interrogate the interpretations made by the author.

The two phases of this research accomplish both general and specific tasks. A specific, comprehensive and complex understanding is gained from study 4 and then this information is used to inform an investigation (Study 5) of how generalised the phenomena are. The use of qualitative and quantitative methods complement each other and provide an example of triangulation, this is where a number of different methods or sources of information are used to tackle a question with the rationale that this might result in greater accuracy.

More detail about the development of the questionnaire for study 5 in relation to the findings of study 4 would have improved the transparency of this work. This aside, the procedure for the large-scale survey with 336 respondents was thoroughly reported. There was a very detailed presentation of results that at face value appear to have important practical utility.

Study 6 (Selfe, Van Vugt & Stones, 1998): It is harder to comprehensively assess the research process of study 6 [27] because the focus group for women formed only part of the study as a whole. However, there was adequate description provided in the report about the procedure of the focus group and the analysis of the data. There was also a coherent discussion of the themes that emerged from the transcribed data and this was illustrated with textual examples.

1.3 DISCUSSION OF RESEARCH FINDINGS

Having established the characteristics of these studies, we were interested in what they were able to tell us about the 'insider' perspective on CPP. Some themes were common to several studies.

Disruption to Women's Lives: There are descriptions of how CPP has a distressing impact in terms of disturbing sleep, affecting mood (study 1, 2 &3) and causing weight gains or losses (study 1). A particular issue was the negative impact on sexual relationships, also the disruption of work, family and social activities (study 1,2 &3). These accounts of disruption to so many aspects of women's lives provide clues to the factors which may lie behind the high levels of depression and anxiety in women with CPP that have been found by numerous quantitative studies [see for example 28, 29]. Furthermore, these descriptive accounts offer ideas for new areas of investigation. Do some of the disruptions have greater impact than others? Are there ways to alleviate the negative impact of some of these factors, the disruption to sexual relationships, for example? Considerable research has focused on investigating the incidence of childhood sexual abuse in CPP populations [see for example 30, 31]. Some studies have suggested that women with CPP have problems with their current sexual relationships [32, 33]. Fry [34] comments that it is not surprising given the nature of CPP that sexual problems are common in women who suffer it. Further qualitative investigations might offer a better understanding of how CPP impacts on current sexual relationships and how this disruption might be managed.

Search for Cause: The desire to find a cause for the pain, a clear diagnosis which, would serve to validate women's experiences of pain and help others to understand that they are suffering, was commonly reported (study 1, 3, 4, 5, & 6).

Pain was attributed to various specific incidents, for example reproductive stressors, bereavement, family member's illnesses and specific medical problems (study 2, 3 & 6). Interestingly this desire to find an explanation and meaning to the pain has also been found in a phenomenological study of the experience of chronic benign lower back pain [35]. This would suggest that this difficulty may be common to people experiencing intractable forms of pain which have little medical endorsement in terms of a diagnosis of physical pathology. It may be that this lack of endorsement is in itself an exacerbation of the pain experience.

One problem associated with not having a diagnosis is that the door is left open for fearful speculation about cause. Women expressed fear that cancer might be at the root of the pain (study 1, 2, & 3) and were grateful if they could be reassured otherwise. These findings are consistent with the results of a nomothetic study [36] of fears and beliefs in patients with pelvic pain syndrome. One fifth of participants in this study were afraid they had a serious disease; it was argued that such beliefs had clear implications for management in terms of providing repeated reassurance to patients.

Effects of Support: Women with CPP described finding support in religious beliefs, and from family members rather than friends (study 1), and from other women with CPP (study 3 & 6). Social support has received very little attention in CPP research and yet psychological research has found evidence to suggest that social support may mute the effects of stress and help individuals to cope [37].

Ways of Coping: Participants in study 1 reported using a wide range of self-care practices to help them cope and stressed that an enduring sense of self worth helped them to maintain such practices. However, some women reported only having a limited range of self-care practices (study 1). Furthermore, others described feeling helpless, out of control and stuck (study 3 & 4). Clearly further studies are necessary to disentangle these apparently conflicting findings. The literature on coping in relation to chronic pain [38] might provide a good theoretical basis for an exploration of which strategies women find most useful for coping with this distressing pain problem. Coping as a central focus has as yet received little research attention in CPP.

Not Taken Seriously by Doctors: There are also common findings in women's descriptions of their experiences of the medical encounter. Participants expressed the feeling that doctor's patronised them and did not take them seriously (study 3, 4, 5, & 6). They said they were made to feel 'silly' (study 6) or 'neurotic' (study 4). Grace (study 4 & 5) notes that, although women reported that doctors implied that their problems were psychological rather than physical, hardly any were referred for psychological therapy. The 'neurotic' label served simply as a way of discrediting the problem. There is evidence to suggest that women are more likely than men to be diagnosed as suffering from a number of painful 'syndromes' which by default rather than good evidence are considered to be psychogenic [39]. Lennane and Lennane [40] developed a critique of the application of the concept of psychogenic aetiology to a number of disorders including CPP. They are critical of the shaky scientific basis of assigning a partial or total psychogenic cause to these disorders and discuss the damage done to women in the process.

Feelings of not being taken seriously were reinforced by the lack of time allocated to the consultation. Women were more satisfied by doctors who gave them time, were honest about the limitations of medical treatment and who made themselves available for future consultation if necessary (study 3).

Although CPP has been described as frustrating to both patients and clinicians, the focus of research has been on the physical and psychological pathologies of the patient only recently has attention been paid to the attitudes of doctors. Gynaecologists' variable attitudes towards hysterectomy decisions for problems such as CPP have been shown to be associated with their opinions about roles of doctors and patients in decision making, gender, practice type and place of training [41]. Another study [27] identified 5 attitudinal dimensions in gynaecologists about their patients with CPP which were defined as 'efficiency' 'complexity, 'sociocultural liberalism', 'pathology' and 'communication'. The strength of some of these attitudes varied in relation to the age and gender of the gynaecologists. There is no straightforward link between attitude and behaviour. However, health care studies have shown that communication between doctor and patient is influenced by the characteristics of the doctor and of the patient, the type and stage of illness and cultural variables within specific historical and geographical contexts [42].

'Insider' experiences of both patients and doctors inform our understanding of the consultation process for CPP. The doctor patient relationship deserves research attention because it has been shown to influence patients' behaviour and well being in terms of satisfaction with care, adherence to treatment, recall and understanding of medical information, coping with disease, quality of life and even state of health [42].

Lack of information: More than one of the selected studies reported considerable dissatisfaction with the amount of information given by medical professionals. Study 5 revealed that 80% of women who had surgery stated that they had not been informed of therapeutic alternatives. Fifty-five per cent of the sample said they were not informed about drug side effects. This has particular significance because 45% felt they couldn't live with the side effects and 44% thought the side effects were worse than the benefits. When asked what advice they would give to someone who was just beginning to experience CPP, the need to be persistent in trying to get information from the GP without being 'fobbed off', was stressed (study 3).

Better Information about Diagnosis and Laparoscopy: However, there was some satisfaction with regard to explanations relating to diagnosis. A proportion of women felt that their GP (52%) or their gynaecologist (62%) had explained their diagnosis adequately or very adequately (study 5). Of course this would not apply to those women for whom no diagnosis had been found. Particular satisfaction was reported with regard to explanations about the process of laparoscopy (study 3).

Dissatisfaction with Referral Process: There was also some dissatisfaction with the referral process with women complaining that GPs either did not refer them to the gynaecologist or were slow to do so (study 4 & 6). This finding is echoed in an innovative study designed to explore GP's perceptions about the diagnosis, treatment and management of women with CPP [43]. GP's responses suggested that their perceptions about the underlying psychosocial characteristics of patients with CPP affected their referral and management strategies. Management strategies appeared to vary particularly for cases without an identified organic basis.

Expectations of Treatment: The selected studies reported apparently conflicting findings about expectations of treatment. Fry et al [22] (study 2) reported that most participants had no clear idea of what they wanted from treatment other than anything to take away the pain, whereas Savidge and Slade [24] (study 3) reported that women wanted explanations and/or treatment, including counselling, hormone replacement therapy and hysterectomy. It is possible that these different findings were due in part to the setting in which women were asked what kind of treatment they thought they should receive. However, as the report of study 2 gave no information regarding where women were asked this question and by whom, it is difficult to judge whether the discrepancy between the 2 studies was due to the differing social demands of the interview setting.

Satisfaction with Treatment: There was variation in how satisfied women were with the treatment they had received. Study 5 revealed that 60% of the sample were satisfied with the results of surgery. However, 36% reported side effects from surgery and 24% felt that this outweighed the benefits. Furthermore, women of low socio-economic status tended to have most problems with the medical encounter. Study 3 found that the majority of their participants had continuing pain 12-18 months after a negative laparoscopy. Any decreases in pain were variously attributed to hysterectomy, hormone replacement therapy or reduced stress and anxiety.

These varying perceptions of treatment are interesting in the context of inadequate research evidence about treatment effectiveness. Laparoscopy does not appear to improve long term outcome for CPP; little benefit has been shown for endoscopic adhesiolysis except in a small subset of women with dense adhesions involving the bowel; it has not been determined what the therapeutic effect of ablation of endometriosis may be; and furthermore despite its high utilisation there are no randomised trials assessing the effectiveness of hysterectomy for CPP [44].

1.4 CONCLUSION

The reviewed studies reveal that many aspects of women's lives are disrupted by CPP. The idiographic focus of these studies begins to provide insight into how women manage CPP in the context of their lives.

It has long been acknowledged that CPP has psychosocial dimensions but they have rarely been described in any detail. The reviewed studies reveal that the doctor patient relationship is one psychosocial dimension that women describe as having considerable influence over their experience of CPP. Women report that they feel patronised and misunderstood. This may be because their pain is approached in terms of a dichotomy; if the pain is seen as organic it is valid, whereas if the pain is seen as psychogenic it is invalid. The reported experiences of the medical encounter have clear implications for practice and for further research. Ways need to be found of improving communication between doctors and patients so that women with CPP feel better informed, less fearful, and better understood.

On the whole the reviewed studies stood up relatively well to evaluation according to evolving criteria for the assessment of qualitative research [17,18,19]. However, they are pioneering studies. There remains considerable scope for further investigations of the 'insiders' experience of CPP that employ diverse theoretical and methodological perspectives. This should greatly improve our understanding of the social, psychological and indeed physical dimensions of this pain experience so that more can be done to alleviate the suffering of so many women.

1.5 REFERENCES

1. Moore J, Kennedy SH. Causes of chronic pelvic pain. *Bailliere's Clin Obstet Gynaecol* 2000; **14:** 389-402.

2. Zondervan KT, Yudkin PL, Vessey MP, et al. The community prevalence of chronic pelvic pain in women and associated illness behaviour. *Br J Gen Pract* 2001; **51:** 541-547.

3. Zondervan KT, Yudkin PL, Vessey MP, et al. Prevalence and incidence in primary care of chronic pelvic pain in women: evidence from a national general practice database. *Br J Obstet Gynaecol* 1999; **106:** 1149-1155.

4. Beard RW. Chronic Pelvic Pain. *Br J Obstet Gynaecol* 1998; **108:** 8-10.

5. Balasch J, Creus M, Fabregues F, et al. Visible and non-visible endometriosis at laparoscopy in fertile and infertile women and in patients with chronic pelvic pain: a prospective study. *Hum Reprod* 1996; **11:** 387-391.

6. Gamsa A. The role of psychological factors in chronic pain. II. A critical appraisal. *Pain* 1994; **57:** 17-29.

7. Melzack R, Wall PD. Pain mechanisms - a new theory. *Science* 1965: **150:** 971-979.

8. Melzack R. Pain and stress: a new perspective. In Gatchel RJ & Turk DC (eds) *Psychosocial Factors in Pain. Critical Perspectives*, pp 89-106. New York: Guilford Press, 1999.

9. Savidge CJ, Slade P. Psychological Aspects of Chronic Pelvic Pain. *J Psychosom Res* 1997; **42:** 433-444.

10. Fry RW, Crisp AH, Beard RW. Sociopsychological factors in chronic pelvic pain: a review. *J Psychosom Res* 1997; **42:** 1-15.

11. McGowan LP, Clark-Carter DD, Pitts MK. Chronic pelvic pain: a meta-analytic review. *Psychology and Health* 1998; **13:** 937-951.

12. Grace VM. Mind/body dualism in medicine: The case of chronic pelvic pain without organic pathology: a critical review of the literature. *Int J Health Serv* 1998; **28:** 127-51.

13. Grace VM. Pitfalls of the medical paradigm in chronic pelvic pain. *Baillieres Best Pract Res Clin Obstet Gynaecol* 2000; **14:**451-431.

14. Conrad P. Qualitative research on chronic illness: a commentary on method and conceptual development. *Soc Sci Med* 1990; **11:** 1257-1263.

15. Albert H. Psychosomatic group treatment helps women with chronic pelvic pain. *J Psychosom Obstet Gynecol* 1999; **20:** 216-225.

16. Taylor, D. More than personal change: effective elements of symptom management. *Nurse Pract Forum* 2000; **11:** 79-86.

17. Smith JA. Evolving issues for qualitative psychology. In: Richardson J, eds. *Handbook of Qualitative Research Methods.* Leicester: BPS Books 1996: 189-202.

18. Elliott R, Fischer CT, Rennie DL. Evolving guidelines for publication of qualitative research studies in psychology and related fields. *Brit J Clin Psych* 1999; **38:** 215-229.

19. Yardley L. Dilemmas in qualitative health research. *Psychology and Health* 2000; **15:** 215-228.

20. Zadinsky JK, Boyle JS. Experiences of women with chronic pelvic pain. *Health Care Women Int* 1996; **17:** 223-232.

21. Chrisman NJ, Kleinman A. Popular health care, social networks, and cultural meanings. In: Mechanic D, eds. *Handbook of health, health care, and the health professions.* New York: Free Press 1983: 569-590.

22. Fry RP, Crisp AH, Beard RW. Patients' illness models in chronic pelvic pain. *Psychother Psychosom* 1991; **55:** 158-163.

23. Kleinman A, Eisenberg L, Good B. Culture illness and care – clinical lessons from anthropologic and cross cultural research. *Ann Intern Med* 1978; **88:** 251-258.

24. Savidge CJ, Slade P, Stewart P, Li TC. Women's perspectives on their experiences of chronic pelvic pain and medical care. *J Health Psychol* 1998; **3:** 103-116.

25. Grace VM. Problems women patients experience in the medical encounter for chronic pelvic pain: a New Zealand study. *Health Care Women Int* 1995; **16:** 509-519.

26. Grace VM. Problems of communication, diagnosis, and treatment experienced by women using the New Zealand health services for chronic pelvic pain: a quantitative analysis. *Health Care Women Int* 1995; **16:** 521-535.

27. Selfe SA, Van Vugt M, Stones RW. Chronic gynaecological pain: an exploration of medical attitudes. *Pain* 1998; **77:** 215-225

28. Hodgkiss AD, Watson JP. Psychiatric morbidity and illness behaviour in women with chronic pelvic pain. *J Psychosom Res* 1994; **38:** 3-9.

29 Slocumb JC, Kellner R, Rosenfeld RC, Pathak D. Anxiety and depression in patients with the abdominal pelvic pain syndrome. *Gen Hosp Psychiatry* 1989; **11:** 48-53.

30. Collett BJ, Cordle CJ, Stewart CR, Jagger C. A comparative study of women with chronic pelvic pain, chronic non-pelvic pain and those with no history of pain attending general practitioners. *Br J Obstet Gynaecol* 1998; **105:** 87-92.

31. Walling MK, O'Hara MW, Reiter RC, Milburn A, Lilly G, Vincent SD. Abuse history and chronic pain in women: I: Prevalences of sexual abuse and physical abuse. *Obstet Gynecol* 1994; **84:** 193-199.

32 Walker EA, Katon W, Harrop-Griffiths J, Holm L, Russo J, Hickok LR. Relationship of chronic pelvic pain to psychiatric diagnoses and childhood sexual abuse. *Am J Psychiat* 1988; **145:** 75-79.

33. Beard RW, Belsey EM, Lieberman BA, Wilkinson JCM. Pelvic pain in women. *Am J Obstet Gynecol* 1977; **128:** 566-570.

34. Fry RPW, Crisp AH, Beard RW, McGuigan S. Psychosocial aspects of chronic pelvic pain, with special reference to sexual abuse. A study of 164 women. *Postgrad Med J* 1993; **69:** 566-574.

35. Osborne M, Smith JA. The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *B J Health Psychol* 1998; **3:** 65-83.

36. Kellner R, Slocumb JC, Rosenfeld RC, Pathak D. Fears and beliefs in patients with the pelvic pain syndrome. *J Psychosom Res* 1988; **32:** 303-310.

37. Cohen S, Wills TA. Stress, social support and the buffering hypothesis. *Psych Bulletin* 1985; **98:** 310-357.

38. Jensen MP, Turner JA, Romano JM, Karoly P. Coping with chronic pain: a critical review of the literature. *Pain* 1991; **47:** 249-283.

39. Gijsbers K, Niven CA. Women and the experience of pain. In Niven C & Carroll D. eds. *The Health Psychology of Women.* Switzerland: Harwood Academic Publishers 1993: 55-56.

40. Lennane KJ. Lennane RJ. Alleged psychogenic disorders in women – A possible manifestation of sexual prejudice. *N Engl J Med* 1973; **288:** 288-292.

41. Dolan JG, Howard FM. A survey of gynecologists' attitudes regarding decision making in the management of non-cancerous conditions that frequently result in hysterectomy. *Med Decis Making* 1999; **19:** 186-192.

42. Ong LM, de-Haes JC, Hoos AM, et al. Doctor-patient communication: a review of the literature. *Soc Sci Med* 1995; **40:** 903-918.

43. McGowan L, Pitts M, Clark-Carter D. Chronic Pelvic Pain: The general practitioner's perspective. *Psych Health Meds* 1999; **4:** 303-317.

44. Reiter RC. Evidence-based management of chronic pelvic pain. *Clin Obstet Gynecol* 1998; **41:** 422-435.

CHAPTER TWO

SOCIAL SUPPORT FOR WOMEN WITH CHRONIC PELVIC PAIN: WHAT IS HELPFUL FROM WHOM?

ABSTRACT

The aim of this exploratory study was to gain a detailed description of chronic pelvic pain (CPP) patients' experiences of social support transactions, and to assess the importance of the source of support in conjunction with the specific behaviour provided. Eight women with CPP were asked by means of semi-structured interview, what had been helpful and unhelpful in terms of social support from their partners, families, friends, acquaintances, doctors, nurses and other women with CPP. Interpretative phenomenological analysis (IPA) of interview transcripts revealed that emotional and informational support was appreciated from all support providers but particular forms of tangible support were preferred from specific support providers. Participants required sustained support and appreciated efforts to facilitate coping. Support was less helpful when privacy and autonomy were not respected and the reality of women's experiences was denied. Anger and frustration from support providers undermined their intended support.

2.1 INTRODUCTION

Chronic Pelvic Pain (CPP) is a surprisingly common (Zondervan, Yudkin, Vessey, Jenkinson, Dawes, Barlow, & Kennedy, 2001), disabling condition which women may endure for years despite long term treatment by general practitioners and gynaecologists. It is defined as pain suffered by women in the lower abdomen or pelvis, that is of at least 6 months duration, occurring continuously or intermittently, not associated exclusively with the menstrual cycle or sexual intercourse (Moore & Kennedy, 2000). This pain problem has proved difficult to diagnose and treat because underlying, physical pathology can be hard to detect (Moore and Kennedy, 2000), and may not explain the pain even when it is detected. Physical pathology has been found in women with and without pain (Balasch, Creus, Fabregues, Carmona, Ordi, Martinez-Roman & Vanrell, 1996). Studies have suggested that the pelvic pain suffered by women without obvious pathology must be due to psychological and social factors. However, a meta-analytic review of CPP (McGowan, Clark-Carter & Pitts, 1998) concluded that it is scientifically questionable and clinically unhelpful to attribute CPP either to physical pathology in those women where it is detected, or to psychological factors in those women where it is not. Generally, researchers now acknowledge a much more complex interrelationship of social, psychological, and physical factors that account for the experience of chronic pain (e.g. Gamsa, 1994; Melzack, 1999).

Grace (2000) comments that despite repeated reference in the literature to the importance of understanding the psychosocial dimensions of CPP, the number of published articles addressing these issues from a psychosocial disciplinary base, in recent literature, is remarkably few. This study will therefore examine a psychosocial aspect of CPP, namely that of social support. Social support has been defined as information that one is loved and cared for, esteemed and valued, and part of a network of communication and mutual obligations (Cobb, 1976). There is evidence to suggest that social support may reduce the effects of stress and help individuals to cope (see Cohen & Wills, 1985). Problems in the measurement of social support have made the relationships among stress, social support, and psychological and health outcomes unclear (Taylor, 1995). This may be because early research tended to treat social support as a uni-dimensional construct (Cutrona and Russell, 1990) with little regard for the specific types of stress that individuals encounter, thus obscuring the effects of specific stressor and support interactions (Cohen and Wills, 1985).

An exception to this, is a study by Dakof and Taylor (1990) who hypothesised that the usefulness of social support would depend not only on a match between stressor and type of support but would also depend on the source of the support. Trained interviewers asked 55 cancer patients what were the most and least helpful things that each of 7 support providers had done for them since diagnosis. The group of support providers consisted of spouse, other family member, friend, acquaintance, fellow cancer patient, physician and nurse. Results showed that there were significantly more reports of helpful rather than unhelpful efforts to support. The data suggested that emotional support was most important from intimate others whereas informational support was more valuable from physicians and nurses.

It is not social support per se, but subjective experiences of social support that have been related to health outcomes (Dunkel-Schetter & Bennet, 1990). The argument for investigating women's subjective experiences of CPP was put by Savidge, Slade, Stewart and Li (1998), who suggested that dichotomous approaches to studies of CPP have led to women being blamed for their pain, and the reality of their experience being challenged, as a consequence their needs have remained largely unexplored. This position is further endorsed by Grace (2000) who comments that although the importance of a biopsychosocial approach is highlighted in the CPP literature, the biopsychosocial model has been purged of the subjective. There are relatively few studies that have been concerned with exploring women's experiences of CPP from the perspective of the 'insider' although it has been argued that such a perspective is essential for improved understanding of chronic health problems and their treatment (Conrad, 1987; Turk and Rudy, 1987).

This study will therefore examine subjective experiences of social support through the use of interpretative phenomenological analysis (IPA) (Smith, Jarman & Osborn, 1999). This involves the analysis of verbatim transcripts derived from in-depth semi-structured interviews with participants. We would argue that such an intensive qualitative approach is necessary given that the 'insiders' perspective is a new and emerging perspective in CPP research and no previous studies of social support have been identified in this field. The aim of this exploratory research is to gain a detailed behavioural description of CPP patients' experiences of social support transactions. The objective is to examine what has been helpful and unhelpful in terms of social support from partners, families, friends, acquaintances, doctors, nurses and other women with CPP and also to assess the importance of the source of support in conjunction with the specific help provided.

2.2 METHOD

2.2.1. Procedure

Research ethical approval was gained for this study from Leicestershire and Gloucestershire Health Authority Ethics Committees. Access to participants was gained via consultants at hospitals in Gloucester and Leicester. They identified patients who met the inclusion criteria of having continuous or intermittent pain in the pelvic or lower abdominal region which had lasted for at least 6 months and was not exclusively associated with sexual intercourse or menstruation. Women whose pain was associated with malignancy or pregnancy, or who were unable to speak English, were excluded. Identified patients were administered questionnaires which included questions about demographics, diagnosis and treatment. The questionnaire also included standardised measures for the purposes of a companion study reported elsewhere. Participants could indicate on the questionnaires if they were prepared to be contacted for interview. The first 8 questionnaires returned with such an indication provided the participants for this study. Informed consent was obtained and interviews were arranged to take place in participants' homes or at one of the participating hospitals.

2.2.2 Participants

Seven of the women were Caucasian and one woman was Indian. Their ages ranged from 21 to 61 years. Five of the participants were living with their partners, 2 had partners whom they did not live with and 1 was single. Five of the participants had children. Four participants were employed outside the home in a full or part-time capacity, 1 remained at home to care for family and 3 were unable to work due to illness or disability. The women had experienced pain ranging from between 2 to 14 years with a mean pain duration of 5.72 years. In addition to CPP, 5 of the women experienced pelvic pain with menstruation, and 6 experienced pelvic pain during or in the 24 hours after sexual intercourse. All the participants stated that they had had surgery more than a year ago, 5 stated that they were still undergoing medical treatment, 3 were not currently receiving medical treatment. Each of the women indicated that they had been given 1 or more of the following reasons for their pain by doctors: endometriosis; pelvic infection; adhesions; uterine fibroid; ovarian cyst; uterine/vaginal prolapse; cystitis; stress; irritable bowel syndrome; and back problems.

2.2.3 Semi-structured Interview

The semi-structured interviews varied in duration from 1 to 2 hours, they were audiotaped and transcribed verbatim. An interview schedule was designed as a flexible guide for the interviewer. Unlike with structured interviews, the ordering of questions was less important than establishing rapport with the respondent whose personal world we were trying to access. The interviewer was free to probe interesting areas that arose and follow the respondents' interests or concerns (Smith, 1995).

Interview schedule

Introductory points: *I'd like to ask you some questions about how people have been helpful to you. Since your pain first began people may have behaved towards you in a number of different ways, both helpful and unhelpful. I would like to know about your experiences with seven different groups of people: your partner if you have one, other family members, your friends, others you know who have had chronic pelvic pain, your doctors, nurses and, finally, acquaintances or strangers.*

Then the following set of questions was asked about each of the seven potential support providers.

1. *In the time since your pain began what is the most helpful thing that (support provider) has said or done to help you?*

2. *Sometimes people who are close to us may say or do things that make us feel bad. They may have had the best intentions, or maybe they just weren't thinking at the time. In the time since your pain began what has (support provider) said or done that you experienced as most annoying or that upset you, made you angry, or just somehow rubbed you up the wrong way?*

2.3 ANALYSIS

IPA is concerned with an individual's personal perception or account of an object or event as opposed to an objective statement of the object or event itself. It is recognised that although one is trying to get close to the participant's personal world, access to that world depends on, and is complicated by the researcher's own conceptions which are nonetheless required to make sense of that other personal world through a process of interpretative activity. A case study approach to interpretative phenomenological analysis was used (Smith, Jarman and Osborn, 1999) with some techniques borrowed from Moustakas (1994, pp. 120-121). Each stage of the analysis procedure is outlined in Table I below.

Table 2.1 – Analysis Process

Stage one	The first transcript (Appendix 2) was read a number of times. A list was made of every expression of the experience described by the respondent. This list only included those expressions that contained a moment of the experience that was a necessary and sufficient constituent for understanding it, and those expressions that were amenable to being abstracted and labelled. Overlapping, repetitive, and vague expressions were eliminated or presented in more exact descriptive terms. Each expression was given a page reference indicating where it could be found in the raw data (Appendix 3).

Stage two	Similar expressions were clustered together in relation to types of support provided by specific support providers. These clusters were given theme labels or codes (Appendix 4). This stage of analysis could be described as theory or prior-research driven (Boyatzis, 1998). Continual checks were made with the transcript to ensure the themes connected with what the respondent had actually said.
Stage three	Comprises an additional and alternative level of analysis which could be described as 'data-driven' (Boyatzis, 1998). The expressions from stage one were re-examined and again similar expressions were clustered together. This time, less emphasis was placed on pre-conceived categories and more attention was placed on impressions of the respondent's unique experience, different themes were the result (Appendix 5). The act of looking at the data from this additional perspective ensured thorough engagement with the data and helped to guard against bias towards pre-conceived categories.
Stage 4	Stages 1 to 3 were then repeated for each of the remaining 7 respondents until 2 lists of themes had been constructed for each respondent.
Stage 5	The lists of themes for all the respondents were read together and consolidated into a master list of themes (Appendix 6).
Stage 6	The themes in the master list were each given a definition and page references were checked to ensure that all the expressions appropriately fitted the themes in which they were clustered. Consequently, some re-arrangement took place until a hierarchy of themes were established.
Stage 7	The final master list was used as a basis for weaving a narrative about the women's experiences. By means of the page references instances of data were selected to illustrate this narrative. Participants' names were altered for purposes of confidentiality.

2.4 VALIDITY

Independent audits (Smith, 1996) of one of the case studies were conducted by the second author and by a member of a qualitative research collective, formed for this purpose. This audit was not designed to produce an inter-rater reliability score but rather to verify that the analysis presented was systematically achieved and was supported by the data. In addition, at every stage of the project the second author acted as a check on the emerging analytic account. Furthermore, reported results were illustrated with examples of raw data so that readers might be able to interrogate the interpretations made by the first author.

Member validity was sought; a draft of the manuscript was given to one of the participants, and a woman with CPP who was independent from the study. They confirmed that the results were consistent with their experiences of CPP.

2.5 RESULTS

The themes which emerged from the analysis, comprised helpful and unhelpful types of support with respect to each of the seven support providers. Types of support were defined as follows: *tangible support* was concrete, instrumental assistance e.g. physical help or financial assistance; *emotional support* was the ability to turn to others for comfort and support during times of stress so that one feels cared for, and also represented the bolstering of a person's sense of self-esteem by other people; and finally, informational support was the provision of advice or guidance concerning possible solutions to a problem. These categories were further divided into sub-categories as can be seen in Tables 2.2 - 2.8 which illustrate the structure of themes with respect to each support provider.

2.5.1 Support from Partners

Table 2.2 Perceptions of support from partners

	Helpful	Unhelpful
Tangible support	Child care House work Meal preparation	Consumed by own problems Self interest
Emotional support	Listening and understanding Believing the pain Reassurance	Lack of attentiveness/ understanding Disbelief/denying of pain Anger and frustration
Informational support	Getting books and information	Helplessness/anxiety

Tangible support from partners

Participants suggested a number of ways that their partners gave them tangible support. Alice explained that:

> When the pain has been bad he will do things like say have a lay down or have a cup of tea or help with practical things.

Marilyn described how her husband cared for her through the night, Jackie said her partner brought her a hot water bottle, Daphne said he would fetch things, look after the children and get meals. However, participants also described ways that their partners failed in providing tangible support. Anthea explained that her husband had stresses of his own associated with bereavement and alcohol. She suggested he was too weak to offer her resources for coping:

> He is not a strong man….if something happens he just panics.

Amy suggested her partner was not motivated to help improve her situation because:

> He quite likes the fact that I'm at home looking after him and his children….If it was by choice I would have gone back to work after my first child but I've not been fit enough to work.

Emotional support

Alice got emotional support from her partner through his:

> Listening and understanding how I feel.

She liked it when he remembered when her hospital visits were and asked how they had gone. Not only listening but also talking about the problem was appreciated by Sheila who described her partner as:

> A great one for talking things through.

Emotional support was clearly appreciated and gaps or failures in this type of support were keenly felt. Marilyn said:

> Although he will still do everything that I want and need.....sometimes he doesn't ask me everyday how I feel and that does hurt.

Daphne described how emotionally supportive it was to have her partner believe that she was in pain. Initially he had construed her reduced ability to work as laziness. She claimed that he did not take her pain seriously until her first operation. Similarly, Amy found her partner's continued lack of understanding and belief difficult:

> If I had a broken leg or something then he could see it and he could understand it, but because it's internal. I mean I say to him, 'oh I'm in a lot of pain', or, 'I've had a bad day', and nothing is said.

Anthea felt that her husband's lack of understanding and belief was demonstrated with these words:

> Every woman suffers don't worry about it.

Another form of emotional support described by participants was gaining reassurance from their partners. Sheila explained that her problem:

> Doesn't affect the way he feels about me, he loves me.

She also felt supported by her partner's reassurance that a solution to the problem would be found. However, the opposite of such reassurance was the anger and frustration of a partner in response to the pain. Jackie revealed that:

> Sometimes my belly is hurting and he gets quite angry.

Informational support from partners

Jackie described both positive and negative dimensions of informational support from her partner. She felt supported by her partner buying her books about how to deal with the pain and then troubled by his feelings of helplessness and anxiety in the face of her pain:

> He gets very frustrated that he can't help me, he cannot take the pain away, there is not a lot he can do, bar get me a hot water bottle, and he gets so frustrated with me and that kind of turns into anger.

Pressures on the main relationship

Participants suggested that some of the failures in support from partners were due to the stresses that the pain placed on their relationship. Jackie described the disruption to their sexual relationship:

> I know that the sex issue is kind of big on his part. I can block off but obviously if there's pain there you can't do it. He gets very frustrated about that.

Sheila described similar difficulties:

> I cannot have sex properly which to me is a major part of our relationship....I mean I am going to be quite graphic now, if I have penetration I feel like I am having a bowel movement....This whole area of my body has become out of bounds completely. I can't bear any thought of intimacy because of it.

Participants felt guilty about the impact of their pain on their partners. Jackie worried that she was:

> Completely ruining my partner's life, he would be better off with other people.

She remarked on the chronicity of the problem:

> It's unfair to tell him to keep silent but to keep silent about it for years!

Sheila explained that her partner had to cope with her being overly sensitive to his comments and Marilyn felt her husband had to cope with her irritability:

> Because I'm in this pain it's him I'm going to pick on all the time.

Alice commented that her own lack of communication may be partly responsible for her partner's occasional lack of attentiveness:

> At times when I get a stabbing pain, he doesn't know when that's happened, and I might just not be communicating about it.

Daphne was very clear that she communicated very little about her pain:

> Last time obviously he didn't know what was going on and I didn't tell him how I felt. I think women tend to keep a lot to themselves pain wise.

2.5.2 Support from family members

Table 2.3 Perceptions of support from family members

	Helpful	Unhelpful
Tangible support	Paying for private health care Help with housework Help with child care	Consumed by own problems Patchy/unsustained support
Emotional support	Regular contact Listening Taking problem seriously Caring/worrying	Apportioning blame Bossiness Sympathy
Informational support	Gathering information Encouraging help seeking Suggesting coping strategies	Intrusiveness Negativity

Tangible support from family

Alice and Sheila's parents paid for them to see private specialists. Marilyn, Anthea and Amy found their children helpful with household chores. Amy commented that her young children behaved out of character and tried hard to help whenever she said she felt poorly. Anthea appreciated her sister offering to look after her daughters when she was in hospital and Amy was grateful to her parents for child care. Although Amy appreciated such support she wished it could be more sustained to match the continuing nature of her pain:

> When I was in hospital last week, they were absolutely brilliant but now I'm home it's as though nothing has happened.

She also found that her family's own needs thwarted their best intentions, she described the problem:

> If I'm in pain or having a bad day it's like, 'well you must slow down, you must learn to say no', and all this but 'by the way can you do this for me?'

In a similar vein, Daphne described how her sister was too absorbed in her own problems to want to hear hers. Furthermore, she wasn't prepared to bother her siblings, judging that they had troubles enough of their own.

Emotional support from family

Marilyn appreciated frequent visits and daily phone conversations with multiple members of her family. Sheila spoke daily on the phone to her father and felt she could talk to him about anything and everything. Daphne also liked to be able to discuss her problem with her father. Both Sheila and Anthea appeared to gain comfort from the fact that their parents worried about them. However, participants felt less helped when family's concern for them led to the apportioning of blame. Daphne's mother, for example, held the demands of her children or her partner's lack of support as responsible for Daphne's return to hospital. Sheila's father blamed doctors and hospitals for her continuing difficulties and Deirdre felt that, on occasion, her sister blamed her for not recovering. She described her response to this:

> And well you think to yourself, well it's not my fault, it's not the hospitals fault....it's nobody's fault, it's just life.

Daphne felt greatly supported by her father who listened with respect to her views. By contrast, Jackie struggled when her parents attempted to decide her options for her:

> My dad tends to get involved when he has a strong idea about something...he is really quite forceful if he's got an idea....so he can be quite unhelpful and my mum, when they really do try and push things on me.

Sheila found her sister's bossiness equally difficult to cope with.

Although participants felt that they gained considerable emotional support from their families, sometimes their solicitousness was not appreciated. Daphne described her mother in comparison to her father:

> Mum's very good but she's more sympathetic and sometimes you don't want sympathy, you want somebody to be strong.

Informational support from family

Deirdre values the fact that her family had researched and learned about endometriosis so that they could better support her. Jackie similarly appreciated her mother's research and her uncle sending books from America. Alice's mother helped by encouraging her to seek help:

> She has been helpful in terms of saying 'you've got to get something done, you've got to get it sorted out, make sure you get to the doctor, make sure you tell him this and that'.

However this type of informational support can quickly become intrusive, as Alice explains:

> The unhelpful bit is, you know at times when I'm feeling better, 'Have you had pains today?', or you know, 'Has your period started?', or 'Have you had discharge this week?'. You know, she will go into details about things that are obviously personal or difficult. I feel bloody reminded of it every second and it's a little bit over intrusive.

Daphne's father helped by offering the following strategy for coping with the worry about what might lie behind the pain. He told her:

> Don't think on the black side, think positive until you know, and then deal with the situation when you come to it.

In contrast, negativity from Sheila's father was unhelpful:

> It can depress me because he is very negative. I need his security but on the other hand sometimes I come away completely drained because all we ever talk about are my nether regions and my health problems.

2.5.3 Support from friends

Table 2.4 Perceptions of support from friends

	Helpful	Unhelpful
Tangible support	Providing a bed when in crisis Accompanying hospital visits Providing distractions	
Emotional support	Being available to help Providing opportunity to vent frustration Unconditional positive regard	Lack of interest or concern Consumed by own problems/lack of reciprocity Undermining self esteem
Informational support	Solution focused advice	

Tangible support from friends

Amy was grateful to a friend who took her and her baby in, when she was in crisis with the pain. A friend helpfully accompanied Alice on hospital visits.

Her friends also helped by distracting her from the problem. Alice explained how a friend would say:

> 'Alright get in the car we're going out...I'm not having you sitting here feeling sorry for yourself'...That'd be quite helpful because I think sometimes you feel so horrible with it, that you don't want to do anything.

Emotional support from friends

Marilyn said it helped to know that her friend would come round if she was needed. Similarly, Deirdre commented that it was helpful to know that her friend represented:

> Someone else out there apart from your family that does understand.

However, some friends did not appear genuinely interested or concerned. Daphne suggested that:

> People don't want a misery guts hanging about do they? And when people ask you how you are they don't really want to know.

In a similar vein, Deirdre commented that:

> You know really that they are not asking because they want to know, they are just asking to be basically nosy.

Deirdre's close friend made her feel better by listening and letting her vent her frustration. However, some friends were too consumed by their own problems to provide such an opportunity. Sheila described one such friend:

> You could never talk to her about problems because she is too into her, its all about her, so you do get friends when it's like a one-sided thing.

Amy valued the fact that particular friends held her in unconditional positive regard:

> So it's just that I know I can say anything to my friends and they will sort of, they are on my side.

However, just as friends can build self-esteem they can also undermine it. Alice was hurt by a friend saying:

> 'Oh God, you've always got something wrong', or 'you're always ill'.

Deirdre said it made her feel more useless than usual when friends implied that she should have returned to work by now. Furthermore she told of how she had lost friends who took it personally that she did not feel well enough to go out at night with them.

The fear that friends will tire of hearing about the pain prevents participants from discussing it with them to any extent. Jackie explained her strategy:

> You just pretend it doesn't exist.

Sheila said she avoided telling some friends about her pain because it would entail going into embarrassing personal details, and Daphne said:

> I don't really confide in friends. If they ask me how I am, I'd say I'm well thank you very much.

<u>Informational support from friends</u>

One of Anthea's friends advised her about how to negotiate more manageable working conditions with her employer in order to cope better at work.

2.5.4 *Support from women in similar situations*

Table 2.5 Perceptions of support from women in similar situations

	Helpful	Unhelpful
Emotional support	Reducing feeling of isolation Shared experience/ understanding	Increasing feeling of isolation Experiences not similar enough
Informational support	Anecdotal information about symptoms Pain management tips	Difficulty of deciphering pertinent information Insufficient local contacts

Emotional support from women in similar situations

Women in similar situations reduced participants' sense of isolation. Jackie explained that:

> When somebody your age gets the same, similar kind of pain and has similar kinds of restrictions it is helpful to think that I'm not really that weird.

Amy found it:

> Such a relief that somebody else, that there are other people who have these problems.

Deirdre had become a member of the National Endometriosis Society (NES) and described how helpful it was to share experiences with fellow members:

> When you explain a bad day and how you feel low, they know exactly why you feel low because they have gone through the same thing.

Daphne on the other hand knew only one woman who had had a hysterectomy, she was older than Daphne and her symptoms were not as extreme, thus Daphne's feeling of isolation remained.

Informational support from women in similar situations

Both Daphne and Sheila found it useful to refer to anecdotal information from other women who had experienced hysterectomies in order to ascertain that their own recoveries were not as they should be. However, Alice found it wasn't easy to decipher which bits of information from a friend with irritable bowel syndrome were pertinent to her problem and which were not.

Deirdre gained pain management information from fellow (NES) members:

> They give you tips on what they tried to do to ease the pain...things like that, little bits of information and you try it and realise it does work.

However, it was expensive to maintain telephone contact with members all over the country and she longed for more contact with local women in similar situations.

2.5.5 Support from acquaintances and strangers

Table 2.6 Perceptions of support from acquaintances or strangers

	Helpful	Unhelpful
Tangible support	Carrying shopping bags	
Emotional support	Increasing self esteem Providing opportunity to vent frustration Anonymity	Disbelief/denying of pain Insensitive comments Unhelpful assumptions
Informational support	Encouraging help seeking	

Tangible support from acquaintances or strangers

Marilyn found strangers surprisingly helpful in doing things like carrying her shopping bags to the car.

Emotional support from acquaintances or strangers

Anthea said a work client had complimented her ability to continue working, and this boosted her self-esteem. The respect and concern of her employers had a similar effect. In contrast, Daphne's manager undermined her self-esteem by being critical that she had taken time off sick. This problem was compounded because Daphne had no diagnosis to offer in explanation. Disbelief from acquaintances and strangers was a common problem, as Anthea describes:

> Strangers you know, when you say (about) the pain, sometimes (they say), 'What pain, nothing pain, you are just making it up.'

Participants were also troubled by simplistic assumptions made by strangers or acquaintances. Amy explained that she had put on weight as a side effect of her medication. She felt that people's prejudices about weight prevented them from understanding the reality of her problem:

> If I was size 12/14 people would look at me and see me in obvious pain, or limping or whatever and they'd say, 'Oh whatever's wrong, what's the problem?', but because of my size they think I'm just out of breath.

Insensitive comments were also a problem, a stranger asked Daphne if she had cancer which exacerbated her fear of this possibility.

On the other hand, Sheila found strangers helped by providing her with opportunities to talk about the problem:

> Someone totally out of the scenario of your personal life, just a voice on the end of the phone. It's like a vent really, it's like letting off steam. Just to talk about it.

And Amy acknowledged that the anonymity of strangers made it easier to talk to them about the problem.

Informational Support from acquaintances and strangers

A professional acquaintance, Sheila's solicitor, helped by encouraging her to seek further help from a counsellor and a doctor.

2.5.6 *Support from nurses*

Table 2.7 Perceptions of support from nurses

	Helpful	Unhelpful
Tangible support	Competence Safeguarding privacy	Incompetence Invasion of privacy
Emotional support	Listening and understanding Shared experience Physical comfort Encouragement and reassurance	Rudeness/intolerance
Informational support	Thorough explanation of procedures	

Tangible support from nurses

The competence of nurses, particularly in doing uncomfortable procedures, was important to participants. Alice was grateful to a nurse for being gentle when taking her blood and Anthea felt nurses were kind after her operation when they took her clips out with care. However, she recalled that a particular nurse had been incompetent by removing her catheter too early and expecting her to get to the toilet by herself before she was able. This nurse was later reprimanded by a superior, for her mistake.

The safeguarding of privacy was also valued. Alice found such consideration helpful:

> Simple things like giving a sheet to put over you to give you some kind of dignity.

She found it discomforting on another occasion when a nurse was less considerate:

> The nurse just gave me a tatty gown and told me to wrap it round my bottom half and walk down the corridor. The corridor was opposite the waiting room, and people sitting there can see down the corridor. I said, 'No thank you I'd rather put my clothes back on.' Well it's only down the corridor', she said and actually quite insisted.

Emotional support from nurses

Several of the participants found the nurses to be understanding and caring. Deirdre explained that:

> They seem to understand what you are going through. They are very caring and will stand there and talk to you for ages. They don't seem to think, 'Right I've got to do this, I've got to do that.' I've never had a bad experience with nurses at all.

Sheila concurred with this:

> I don't think I've ever had any problem with nurses. Comforting, they listen to you.

She appreciated their ability to provide 'hands on' care:

> I mean there are times when I'm very tactile, so with a nurse you feel you ~~can~~ perhaps get a cuddle off them if you feel upset, or they'll hold your hand.

Daphne found one nurse to be all the more supportive because she had also gone through a hysterectomy:

> She had gone through the same thing herself and she was excellent.

Anthea appreciated nurses who told her that she would recover soon and would be feeling better before long. However, Marilyn observed on one occasion that nurses were less tolerant and supportive:

> One lady did start to complain one night and this is when the night staff were a bit off with her. To me they were alright.

Informational support from nurses

When Daphne was told she was to have a hysterectomy she knew nothing of what this would entail. A nurse relieved her anxiety by explaining the procedure in a lot of detail and answering all her questions.

2.5.7 Support from doctors

The biggest proportion of all the interviews was concerned with interactions with doctors. Considerable dissatisfaction was voiced about this group of support providers.

Table 2.8 Perceptions of support from doctors

	Helpful	Unhelpful
Tangible support	Safe guarding privacy	
	Swift referral process	Reluctance to refer
	Competence	Doctors at a loss
		Mistakes/Negligence
		Handed round to different doctors
		Unsatisfactory medical treatment
Emotional support	Showing genuine concern	Lack of respect/concern
		Causing upset
		Insensitivity
	Believing the pain	Minimising/denying problem
		Implying problem is all in the mind
Informational support	Giving detailed information	Giving inadequate information
	Providing explanation for pain	Misdiagnosis / no diagnosis

Tangible support from doctors

Alice was impressed with a consultation with a private specialist who took steps to safeguard her privacy and gave her his time:

> Just simple things like drawing the curtains round the bed properly making sure there is a nurse in the room, things like that, that make you feel not rushed, a bit kind of safer.

Both Sheila and Daphne praised particular GPs for referring them to specialists swiftly and decisively. In contrast, Marilyn was greatly perturbed by a GP's reluctance to refer:

> It was when it (vaginal wall) collapsed after the first operation. It was like being in labour 24 hours a day....I went to see him to ask him if he could send me to a different specialist urgently...and he said, 'No I don't class you as an emergency'.

Marilyn regarded a particular GP highly because she felt he was competent and trustworthy. Similarly, Anthea chose always to see one particular GP whenever possible because she felt he was competent and understood her problem well. In stark contrast, they both described suffering unnecessary traumas as a result of mistakes and negligence by other doctors.

With regard to the competence of doctors, some participants had the impression that they drained doctors of their expertise. Daphne said she had gone through every doctor in her local practice. Alice explained that:

> The more I kept going back and saying actually I'm still having this, it hasn't gone away, the more he despaired and didn't know what to do.

Jackie described one GP:

> I think she kind of got a bit lost for ideas, and was tearing her hair out about what was wrong with me.

Being passed from doctor to doctor results in a lack of continuity of care as Jackie described:

> I just kept getting passed around...I don't feel like anybody's really concentrating on me.

Participants felt their medical treatment was unsatisfactory. Alice was given medication for irritable bowel syndrome and for depression, she did not believe she was suffering from either and therefore did not take the medication. Sheila stopped taking anti-depressants after 3 days because they gave her panic attacks. She described a whole catalogue of surgical treatments that she had received, none of which she found effective. Jackie said that no treatment had helped except powerful pain-killers which she did not want to take long-term. Daphne was similarly concerned about the powerful medication she had been prescribed, it made a difference to the pain but the side-effects rendered normal everyday activities impossible.

Emotional support from doctors

Participants were helped when doctor's showed genuine concern. Marilyn felt that a particular GP listened, cared and took her seriously. Jackie described one GP:

> He obviously cares, he does get quite passionate about it, and when I tell him about things the gynaecologist has said or done, he gets quite angry.

Deirdre's gynaecologist had the opposite effect on her:

> It made me feel every time that I went to see him that I was wasting his time. I wasn't important, you know.

Alice commented that she was never sure which doctor she would see on hospital visits and doctors rarely introduced themselves. This reinforced the impression that they had little respect for her as a patient. A number of participants described being reduced to tears because of a doctor's manner or attitude.

Jackie found one gynaecologist insensitive, with little understanding for her perspective:

> The first thing he offered me actually when I first went to see him, bearing in mind I was 18 at the time, he said, 'Hysterectomy, it's the only real way to get rid of it.' And he was quite adamant that that's how it was, and I went absolutely mad.

Deirdre found that a gynaecologist just assumed she wanted a hysterectomy when she was adamant that she didn't. Alice commented that a gynaecologist seemed to have no consideration for how she felt.

Having their pain believed and taken seriously by doctors was important to participants. Amy described what a difference it made when doctors and a psychologist at a multi-disciplinary clinic reviewed all her case notes and acknowledged her problem:

> This was the first time that somebody had said, 'It wasn't your fault, it shouldn't have happened. Yes all these terrible things that happened to you, did happen.' I knew then that it wasn't in my head. It was almost as if I was able to put it to bed.

She subsequently saw the psychologist on a number of occasions to learn pain management techniques which proved helpful. The psychologist also helped her come to terms with the trauma she had suffered and disentangle the repercussions it had had on her children. Marilyn also received this sort of help.

Participants found it much more difficult when their pain was minimised or denied by doctors. Alice described how a GP wrongly assumed that:

> I was just being anxious about sex or not having good enough sex.

She explained that she had bled everyday for 6 weeks only to be told that women were bound to get their ups and downs in the cycle. She recalled one gynaecologist saying:

> 'Before we start let me just tell you that there's nothing wrong with you' and then proceeded to give me a big speech about why women worry too much about their symptoms and women under 30 don't have any serious problems.

Jackie was told by a GP that she had growing pains, and Sheila was told by a bowel specialist to go away and try not to think about the pain. She worried that doctors thought the pain was 'psychosomatic' and that they would write this in her notes. Amy said doctors implied that her problem was all in her mind:

> I know that the pain I've got there 99% of my life is not in my head, its physically in my stomach, and for somebody to say that its because of stress makes it a hundred times worse.

Alice complained that anxiety was suggested as a cause rather than as a consequence of her pain. She found it unhelpful when doctors suggested her pain was due to stress:

> I think that if someone's going to give you the message that it's stress or whatever, you also need to understand the rationale for that, and for that to be helpful, rather than kind of, 'Oh look you are just stressed.'

Informational support from doctors

Participants appreciated detailed explanations about procedures and treatment. Alice offered this view:

> I think the doctors who've taken time to try and explain how things work, if you like, try to say, 'This is the problem you've got', and draw diagrams and, 'This is what's happened, and this is why we're doing this'. To actually give a rationale and information about what's going on, that's helpful.

Deirdre praised the informational support she got from her G.P:

> If he can't answer you when you see him he will get an answer for you in the next time you go and see him.

He had also informed her about NES, which provided further informational and emotional support. She had a different experience with her gynaecologist who:

> Told me I got 'Endometriosis, its to do with the womb', and that was it...I was told I got a disease that I didn't know anything about. I thought I was dying, to be honest.

Alice, Sheila, Amy and Jackie observed that they would only get their questions answered, if they were well informed themselves and very assertive with their doctors.

Having an explanation for the pain helped Anthea who was told that the pain was due to adhesions from her operation. Amy also appreciated an explanation, if not a diagnosis:

> They can't explain to me what is causing the pain but they can say to me why they think it's happening.

On the other hand, Daphne was troubled by multiple and conflicting diagnoses:

> One day I had 3 different diagnoses by 3 different doctors.

Also a serious misdiagnosis:

> He turned round and said we didn't find any endometriosis in the end. He said it was misdiagnosed and we didn't really have to have a hysterectomy.

She described how helpful it would be to have an explanation for her pain:

> All I want is for them to diagnose it so I can deal with it...If you know what the monster is you can deal with it. If you don't know what it is your brain just makes a bigger one.

2.6 DISCUSSION

On the whole participants valued tangible, emotional and informational support from all the support providers. However, some types of support were specific to particular support providers. Financial assistance, help with housework and child-care were only received from partner and family rather than friends. Another qualitative study of CPP also found that support was preferred from family rather than friends (Zadinsky and Boyle,1996). Participants in this study sometimes masked the extent of their problem from friends for fear of exhausting their support. Participants did not describe any form of tangible support from women in similar situations. A form of tangible support that was specific to doctors and nurses was their competent use of medical skills.

It appears important for support providers to offer support whilst at the same time respecting privacy. Small considerations such as drawing a curtain around the bed could affect whether a participant felt valued or disrespected by medical practitioners. Furthermore, a mother's support for her daughter was experienced as helpful or unhelpful depending on whether she felt her privacy was invaded. It would seem reasonable to assume that privacy is a sensitive issue for women with CPP given that their genital and reproductive organs are often the focus of investigation.

The undermining of autonomy was also a problem, with participants complaining of bossiness or overly strong recommendations from family or doctors. The danger of such efforts to 'take over' is of a woman's sense of control or self-efficacy (Bandura, 1986) being undermined. There is evidence that people with a strong sense of self-efficacy show less psychological and physiological strain in response to stress than those with a weak sense of self-efficacy (Bandura, Taylor, Williams, Mefford & Barchas, 1985).

Participants described the relentlessness of CPP and expressed a desire for support to match the chronicity of the pain. This shortfall in support may in part be due to the dominance of an acute model for managing pelvic pain, where the focus is on finding 'cause' and 'cure': an understandable approach, if there was evidence for its effectiveness. Participants complained of ineffective medical treatment. The fact is that procedures designed to identify 'cause' are not themselves without risk and even when pathology is found, there is little evidence that surgical treatment effectively removes pain (Reiter, 1998). An alternative model for managing CPP should therefore be considered (e.g. Collett, Cordle and Stewart, 2000). The focus of this model is on reducing the impact of pain on daily functioning, with the understanding that the identification of 'cause' and 'cure' may not be possible. Multidisciplinary pain management approaches using this model have proved effective for CPP (e.g Peters, Van Dorst, Jellis, Hermans and Trimbos, 1991), and two participants who encountered this approach, deemed it beneficial.

Family members, women in similar situations and psychologists helped participants to cope with their pain in the absence of a 'cure' by encouraging them to develop techniques and strategies consistent with the cognitive behavioural approach to pain management (Turk, Meichenbaum and Genest, 1983). Participants were helped by advice which encouraged a positive and constructive approach to the problem and were troubled by negativity which left them feeling overwhelmed by it. One participant described the benefits of having friends take her out to distract her from the problem, another described the difficult consequences of withdrawing from usual social contact.

Women in similar situations were considered particularly helpful in terms of providing information about shared experience. The finding was also reported in two other qualitative studies of CPP (see Savidge et al, 1998; Selfe et al, 1998). Comparison with others can be used to form attitudes which help in coping with uncertainty and anxiety when information is limited, as in the case of chronic illness (Festinger, 1954; Molleman, Pruyn & Van Knippenberg, 1986). Festinger proposed that people preferred to compare themselves with similar others rather than those who were different in order to judge their own abilities precisely. Although this was true for some participants, others found the differences between themselves and similar others too great, or found that they compared unfavourably, thus increasing their anxiety and sense of isolation.

Participants felt supported by those who they perceived to have genuine care for them. The feeling of being loved, valued and unconditionally accepted has been shown to be central to the construct of social support (Sarason, Pierce & Sarason, 1990). It has long been argued that this type of support serves to validate one's sense of worth (Rogers, 1951). However, when caregivers apportioned blame, the opposite effect was achieved. Anger and frustration expressed by caregivers was equally unhelpful. This finding is consistent with research, which has found an association between upsetting communication of this sort and depression for chronic pain sufferers generally (Fiore, Becker & Coppel, 1983; Kerns, Haythornthwaite, Southwick & Giller, 1990).

Participants wanted support providers to believe in their pain. They described the burden of not only being faced with the pain but also the disbelief of their partners, acquaintances, friends and doctors. Participants found that doctors implied their pain was psychosomatic or 'all in the mind'. There is now considerable research evidence to suggest that the idea of CPP as psychogenic is both ill founded and unhelpful (Grace, 1998). The lack of belief in CPP may represent a feminist issue. There is evidence to suggest that women are more likely than men to be diagnosed as suffering from a number of painful 'syndromes' which by default rather than good evidence are considered to be psychogenic (Gijsbers & Niven, 1993). Moore and Kennedy (2000) contend that it is theory that should be discounted when the patient's symptoms refuse to fit, not the patient's account of reality.

Research suggests that CPP patients may use pain behaviours in an effort to get their pain heard (McGowan et al, 1998). However, some participants from this study attempted to keep their pain to themselves. This apparent stoicism may in fact prevent communication. How are support providers to understand about the pain if they are not told about it? There may be scope for providing preventative therapy for couples faced with CPP such that they can better resolve the conflicts that often arise as a consequence of the pain, and can communicate more effectively about their difficulties (Cutrona, 1996).

One important aspect of communication is the giving and receiving of information. Participants felt that the information given by doctors was largely inadequate. This dissatisfaction has also been revealed by other CPP studies (Grace, 1995; Savidge et al, 1998). According to participants, the doctor-patient interaction had considerable influence. Research into doctor-patient communication (Ong, de Haes, Hoos & Lammes, 1995) suggests that it can affect patient's behaviour and well being in terms of dissatisfaction with care, adherence to treatment, recall and understanding of medical information, coping with disease, quality of life and even state of health. There is a need for more research exploring the interaction between doctors and women with CPP. Previous research has assumed that patients' attitudes rather than doctors' attitudes were responsible for difficult consultations. Only recently has research attention turned to the attitudes of doctors working in this field (Selfe, Van Vugt & Stones, 1998; Dolan and Howard, 1999; McGowan, Pitts & Clark-Carter, 1999) this at least represents a start to this line of enquiry.

As well as looking at doctor patient interaction, there may be scope for tailoring interventions not only at the woman with CPP but at her family as a whole. A woman's social context may substantially influence her pain experience. For example, one participant claimed that her partner had a vested interest in maintaining her in a sick role. Two participants described considerable disruption to sexual relations, and another was concerned about the impact of her pain on a child. Interestingly, there may be a role for psychology here, as two participants described how psychologists had helped them to understand their pain in the context of their social environments.

In summary, the main findings from this study suggest that most types of support are helpful from all potential support providers, although particular forms of tangible support were preferred from specific support providers. For support to be experienced as helpful: the woman's account of reality needs to be heard and believed; autonomy and privacy must be respected and it should be noted that anger, frustration and blaming from support providers runs counter to the support they offer. Support needs to be sustainable over time and efforts to facilitate coping need to be positive and constructive with an emphasis on management rather than cure.

This exploratory study has been concerned with gaining an in depth description of the support needs particular to a small group of women with CPP. The results could prove useful in terms of providing hypotheses for further exploration. For example, what relative importance do the different types of support have, and how true are the findings for women with CPP in general?

Participants used the interviews to tell poignant stories of the traumas they had experienced in relation to this pain. The fact that a relatively large number of women experience this distressing long-term pain, should be sufficient justification for it to have a high priority on the research agenda.

2.7 REFERENCES

Balasch, J., Creus, M., Fabregues, F., Carmona, F., Ordi, J., Martinez-Roman, S.. Vanrell, J.A. (1996). Visible and non-visible endometriosis at laparoscopy in fertile and infertile women and in patients with chronic pelvic pain: a prospective study. Human Reproduction, 11, 387-391.

Bandura, A. (1986). Social foundations of thought and action: A social cognitive theory. Englewood Cliffs, NJ: Prentice Hall.

Bandura, A., Taylor C.B., Williams, S.L., Mefford, I.N., & Barchas, J.D. (1985). Catecholamine secretion as a function of perceived coping self-efficacy. Journal of Consulting and Clinical Psychology, 53, 406-414.

Boyatzis, R.E. (1998). Transforming Qualitative Information: Thematic Analysis and Code Development. Thousand Oaks, California; London: Sage.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.

Cohen, S., & Wills, T.A. (1985). Stress, social support and the buffering hypothesis. Psychological Bulletin, 98, 310-357.

Collett, B.J., Cordle, C., & Stewart, C.S. (2000). Setting up a multi-disciplinary clinic. Baillieres Clinical Obstetrics and Gynaecology, 14, 541-556.

Conrad, P. (1987). The experience of illness: Recent and new directions. Research in the Sociology of Health Care, 6, 1-31.

Cutrona, C.E., & Russell, D.W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In G. Sarason, B. R. Sarason, & G. R. Pierce (Eds.), Social support: An interactional view (pp. 319-366). New York: Wiley.

Cutrona, C.E. (1996). Social support in couples. Thousand Oaks, California: Sage.

Dakof, G.A., & Taylor, S.E. (1990). Victims perceptions of social support: What is helpful from whom? Journal of Personality and Social Psychology, 58, 80-89.

Dolan, J.G., Howard, F.M. (1999). A survey of gynecologists' attitudes regarding decision making in the management of non-cancerous conditions that frequently result in hysterectomy. Medical Decision Making, 19, 186-192.

Dunkel-Schetter, C., & Bennet, T.L. (1990). Differentiating the cognitive and behavioural aspects of social support. In G. Sarason, B. R. Sarason, & G. R. Pierce (Eds.), Social support: An interactional view (pp. 267-296). New York: Wiley.

Festinger, L. A. (1954). A theory of social comparison processes. Human Relations, 7, 117-140.

Fiore, J., Becker, J., & Coppel, D. (1983). Social network interactions: A buffer or a stress? American Journal of Community Psychology, 11, 423-439.

Gamsa, A. (1994). The role of psychological factors in chronic pain II: A critical appraisal. Pain, 57, 17-29.

Gijsbers, K., & Niven C.A. (1993). Women and the experience of pain. In C. Niven & D Carroll (Eds.), The Health Psychology of Women (pp.55-56). Switzerland: Harwood Academic Publishers.

Grace, V.M. (1995). Problems of communication, diagnosis and treatment experienced by women using the New Zealand health services for chronic pelvic pain: a quantitative analysis. Health Care For Women International, 16, 521-535.

Grace, V.M. (1998). Mind/body dualism in medicine: The case of chronic pelvic pain without organic pathology: a critical review of the literature. International Journal of Health Services, 28, 127-151.

Grace, V.M. (2000). Pitfalls in the medical paradigm in chronic pelvic pain. Bailliere's Clinical Obstetrics and Gynaecology, 14, 525-539.

Kerns, R.D., Haythornthwaite, J., Southwick, S., & Giller, E.L. (1990). The role of marital interaction in chronic pain and depressive symptom severity. Journal of Psychosomatic Research, 34, 401-408.

McGowan, L.P.A., Clark-Carter, D.D., & Pitts, M.K. (1998). Chronic pelvic pain:

a meta-analytic review. Psychology and Health, 13, 937-951.

McGowan, L.P.A., Pitts, M.K., Clark-Carter, D.D. (1999). Chronic Pelvic Pain: The general practitioners perspective. Psychology Health and Medicine, 4, 303-317.

Melzack, R. (1999). Pain and stress: a new perspective. In R.J. Gatchel & D.C. Turk (Eds.), Psychosocial Factors in Pain: Critical Perspectives, (pp 89-106.) New York: Guilford Press.

Molleman, E., Pruyn, J. & Van Knippenberg, A. (1986). Social comparison processes among cancer patients. British Journal of Social Psychology, 25, 1-13.

Moore, J., & Kennedy, S. H. (2000). Causes of chronic pelvic pain. Baillieres Clinical Obstetrics and Gynaecology, 14, 389-402.

Moustakas, C. (1994). Phenomenological Research Methods. Thousand Oaks, California; London: Sage.

Ong, L.M., de Haes, J.C.J.M., Hoos, A.M., & Lammes, F.B. (1995). Doctor-patient communication: a review of the literature. Social Science and Medicine, 40, 903-918.

Peters, A.A.W., Van Dorst, E., Jellis, B., Van Zuuren, E., Hermans, J., & Trimbos, J.B. (1991). A randomised clinical trial to compare two different approaches in women with chronic pelvic pain. Obstetrics and Gynecology, 77, 740-744.

Reiter, R.C. (1998). Evidence-based management of chronic pelvic pain. Clinical

Obstetrics and Gynecology, 41, 422-435.

Rogers, C.R. (1951). Client centred therapy: Its current practice, implications, and theory. Boston: Houghton Mifflin.

Sarason, B.R., Pierce, G.R., & Sarson, I.G. (1990). Social support: the sense of acceptance and the role of relationships. In G. Sarason, B. R.. Sarason, & G. R.. Pierce (Eds.), Social support: An interactional view (pp. 97-128). New York: Wiley.

Savidge, C.J., Slade, P., Stewart, P. & Li, T.C. (1998). Women's perspectives on their experiences of chronic pelvic pain and medical care. Journal of Health Psychology, 3, 103-116.

Selfe, S.A., Van Vugt, M., & Stones, R.W. (1998). Chronic gynaecological pain: an exploration of medical attitudes. Pain, 77, 215-225.

Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith & R. Harre (Eds.), Rethinking Methods in Psychology (pp.9-26). London: Sage.

Smith, J.A. (1996). Evolving issues for qualitative psychology. In J.T.E. Richardson (Eds.), Handbook of Qualitative Research Methods (pp. 189-202). Leicester: BPS Books.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing Interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), Qualitative Health Psychology: Theories and Methods (pp.218-240). London: Sage.

Taylor, S.E. (1995). Health Psychology. United States: McGraw-Hill.

Turk, D.C., & Rudy, T.E. (1987). Towards a comprehensive assessment of chronic pain patients. Behavioural Research and Therapy, 25, 237-249.

Turk, D.C., Meichenbaum, D., & Genest, M. (1983). Pain and Behavioural Medicine: A Cognitive Behavioural Perspective. New York: Guilford Press.

Zadinsky, J.K., & Boyle J.S. (1996). Experiences of women with chronic pelvic pain. Health Care for Women International, 17, 223-232.

Zondervan, K.T., Yudkin, P.L., Vessey, M.P., Jenkinson, C.P., Dawes, M.G., Barlow, D.H., & Kennedy, S.H. (2001). The community prevalence of chronic pelvic pain in women and associated illness behaviour. British Journal of General Practice, 51, 541-547.

CHAPTER THREE

SOCIAL SUPPORT FROM PARTNERS: ASSOCIATIONS WITH PSYCHOLOGICAL WELL BEING AND PAIN EXPERIENCE IN WOMEN WITH CHRONIC PELVIC PAIN

ABSTRACT

Social support has been shown to reduce the effects of stress and help individuals to cope. However, research into social support for chronic pain patients has found associations between partner's responses and increased symptoms of pain and depression. This correlation study aimed to explore social support from partners of women with chronic pelvic pain (CPP). Solicitous responses, punishing responses, empathy, level of regard, unconditionality and congruence from partners were examined in relation to anxiety, depression and pain experience in women with CPP. Punishing responses from partners were positively associated with depression and pain severity. Empathy, level of regard, unconditionality and congruence from partners were negatively associated with depression. No association was found between solicitous responses from partners and any of the dependent variables. Clinical implications for supporting women with CPP were discussed with reference to these findings.

3.1 INTRODUCTION

Chronic Pelvic Pain (CPP) is a common (Zondervan, Yudkin, Vessey, Jenkinson, Dawes, Barlow & Kennedy, 2001) and distressing pain problem suffered by women, that has proved difficult to diagnose and treat (Beard, 1998). CPP can be defined as pain in the lower abdomen or pelvis, that is of at least 6 months duration, occurring continuously or intermittently, not associated exclusively with the menstrual cycle or sexual intercourse (Moore & Kennedy, 2000). Generally, researchers now acknowledge that there is a complex interrelationship of social, psychological, and physical factors that account for the experience of chronic pain (e.g. Gamsa, 1994; Melzack, 1999).

This study will therefore examine a psychosocial aspect of CPP that has not been addressed in the CPP literature, namely that of social support. Social support has been defined as information that one is loved and cared for, esteemed and valued, and part of a network of communication and mutual obligations (Cobb, 1976). Psychological research into stress has found evidence to suggest that social support may reduce the effects of stress and help individuals to cope (Cohen & Wills, 1985). However, it is suggested that social support can only reduce the effects of stress when there is a match between the needs demanded by a particular stressor, like chronic pelvic pain, and the type of support offered (Cutrona & Russell 1990). It may also depend on who is offering the support; in the case of cancer patients, informational support was valued from physicians and nurses whereas emotional support was found to be most important from intimate others (Dakof &Taylor, 1990).

This study aims to gain an understanding about what intimate others, in this case partners, effectively offer women with CPP in terms of emotional support. Emotional support appears to represent the ability to turn to others for comfort and security during times of stress, leading the person to feel she is cared for by others (Cutrona & Russell, 1990). What is it that partners do to get this feeling across? Rogerian person-centred theory (see Barrett-Lennard, 1998) would suggest that such feelings are fostered in relationships by empathy, or an active process of desiring to know the full present and changing awareness of the other person; a positive level of regard for each other; unconditionality of regard, that is a level of regard which remains consistent irrespective of what the partners reveal to each other about themselves; and finally congruence, in other words a perception that the other is genuine, transparent and honest about him/herself. This person-centred perspective has not featured in investigations of spouse support in the context of chronic pain. In fact most investigations of this sort have been concerned with the negative rather than positive effects of partner support.

The predominant theory behind most investigations of spouse support has been the behavioural formulation of chronic pain (Fordyce, 1976). According to this theory, the partner is a primary source of social contingencies for the patient, and serves as a discriminative cue and selective reinforcer for the behavioural expression of pain. Flor, Kerns and Turk (1987) found that frequency of solicitous responses from wives of chronic pain patients was positively related to patients' pain behaviours and reports of pain severity. It was suggested that the solicitous partner unwittingly contributed to a patient's pain experience through the selective and specific reinforcement of pain behaviours. Flor, Turk and Rudy (1989) reported differences in the association between pain report and spouse responses for male and female patients. They found that it was only for married male patients that spouse support was associated with reported pain severity.

The behaviour of partners has also been related to depression in chronic pain patients. Aversive communication from spouses was found to be predictive of depressive symptom severity in a predominantly male sample of chronic pain patients (Kerns, Haythornthwaite, Southwick & Giller, 1990). However, spouse criticisms have been associated with maladaptive coping behaviours and poor psychological adjustment in female rheumatoid arthritis patients (Mann & Zautra, 1989). In this case, spouse responses perceived as supportive, were associated with the use of more adaptive coping strategies. Altogether results into investigations of spouse support in the context of chronic pain are somewhat confusing, with spouse support being associated with deleterious as well as stress buffering effects.

The aim of this study is to disentangle some of this complexity in the specific case of women with CPP. The objectives are to test whether:

1. Solicitous responses from partners are positively associated with pain severity and interference
2. Punishing responses from partners are positively associated with depression.
3. Empathy, level of regard, unconditionality and congruence are negatively associated with anxiety, depression, pain severity and interference.

3.2 METHOD

3.2.1 Procedure

Access to participants was gained via consultants at hospitals in Gloucester and Leicester, where ethical approval was gained from the respective research ethics committees. Further access to participants was via the National Endometriosis

Society (NES) who permitted a message on their web site asking for participants who met the inclusion criteria (Appendix 13). Participants had to be female, aged 18 years or over, with continuous or intermittent pain in the pelvic or lower abdominal region of at least 6 months duration, which was not exclusively associated with sexual intercourse or menstruation. Women whose pain was associated with malignancy or pregnancy were excluded. A total of 91 questionnaires were sent out and 38 completed questionnaires were returned, a response rate of 42 %. Data from one of the completed questionnaires were not used because the questionnaire did not contain sufficient indication that inclusion criteria were met. The data from a further 8 questionnaires were also not used as the respondees indicated that they did not have partners. Therefore data were provided from 29 participants in all.

3.2.2 Participants

The sample of 29 women were aged between 21 and 61 years, with the mean age being 35.43 years. Seven were single and living with their partners, 1 was divorced and living with a partner, 2 were living in separate accommodation from their current partners, and 19 were married. Nineteen of the participants (64.3%) had children. Twelve of the women (41.4%) were employed full-time, 10 (34.5%) were employed part-time, 1 (3.4%) was a student, 2 (6.9%) cared for home and family, 3 (10.3%) were unable to work due to their disabilities and 1 (3.4%) did not give information about her employment.

The minimum pain duration indicated by a participant was 6 months and the maximum was 25 years. The mean pain duration was 9 years with a mode of 3 years. All participants indicated that they had continuous or intermittent pain which was not related to periods or sexual intercourse. In addition to CPP, 29 of the participants (76.3%) indicated that they had pain with their periods and 28 participants (73.8%) said they had pain during or in the 24 hours after sexual intercourse. Participants indicated that they were given one or more of a selection of reasons for their pain by doctors, see Table 3.1. This list illustrates the multiple diagnoses that women receive when presenting with CPP (Moore & Kennedy, 2000). The most common reason indicated was endometriosis, this may reflect the fact that a large proportion (59%) of participants were recruited via the National Endometriosis Society.

Table 3.I Reasons given by doctors for the pain

Possible reasons given by doctor	N. (Participants could indicate more than 1 reason)	%
Endometriosis	22	75.9
Pelvic infections	5	17.2
Adhesions	11	37.9
Fibroids	2	6.9
Ovarian cyst	9	31.0
Prolapse	2	6.9
Pelvic congestion	1	3.4
Cystitis	3	10.3
Stress	4	13.8
Appendicitis	2	6.9
Back pain	2	6.9
Constipation	2	6.9
IBS	13	44.8
Bowel disease	1	3.4
Other reason given	4	13.8

Participants indicated that one or more of a selection of tests or investigations had been carried out in relation to their pain, see Table 3.2.

Table 3.2 Tests and investigations in relation to the pain

Investigation	N. (Participants could indicate more than 1 investigation)	%
Laparoscopy	21	72.4
Colonoscopy	4	13.8
Ultrasound	23	79.3
X-ray	4	13.8
Other	10	34.5
No tests	3	10.3

Participants indicated their stage of treatment and when they had received medication or surgery, see Table 3.3.

Table 3.3 Stage of treatment

		N	%
Stage of treatment	Currently having treatment	12	41.4
	No treatment as yet	2	6.9
	No treatment currently	15	51.7
Tablets or medicines	Had medicine in last 12 months	27	93.1
	Had medicine more than a year ago	2	6.9
Surgery	Surgery in last 12 months	10	34.5
	Surgery more than a year ago	14	48.3
	Surgery is planned	2	6.9
	No surgery	2	6.9

3.2.3 Measures (Appendix 7)

The West Haven-Yale Multidimensional Pain Inventory (WHYMPI) (Kerns, Turk & Rudy, 1985)

This inventory was designed to provide a brief assessment of the subjective experience of pain. Two of its 3 parts were used in this study. Part I comprises 5 scales to measure: (a) pain severity and suffering e.g. *On the average how severe* *has your pain been during the last week?*; (b) pain related life interference, including interference with family and marital functioning, work and work related activities, social recreational activities as well as dissatisfaction with levels of functioning in these areas e.g. *In general how much does your pain problem interfere with your day to day activities?*; (c) appraisal of support received from spouse, family and significant others e.g. *How worried is your partner about you in relation to your pain problem?*; (d) perceived life control, incorporating the perceived ability to solve problems and feelings of personal mastery and competence e.g. *During the past week how much do you feel that you've been able to deal with your problems?* ; and (e) affective distress, including ratings of depressed mood, irritability, and tension e.g. *During the past week how tense and anxious have you been?* Participants are required to record their responses to each of 20 questions on a 7-point scale. Part II examines patients' perceptions of the range and frequency of responses by significant others to displays of pain and suffering. It comprises 3 scales to measure: (a) spouse punishing responses e.g. *Expresses irritation at me*; (b) spouse solicitous responses e.g. *Gets me something to eat or drink*; and (c) spouse distracting responses e.g. *Talks to me about something else to take my mind off the pain.* Patients are required to record their responses to each of 14 questions on a 7-point scale.

Estimates of internal consistency (alphas ranged from 0.74 to 0.84) and test-retest reliability (r = 0.62-0.89) are all good to excellent. Kerns and colleagues (1985) found converging evidence for the internal and external construct validity of the 12 WHYMPI scales.

The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)

This is a widely used 14-item measure of depressed mood, emotional distress, anxiety and depression and emotional disorder in clinical populations with symptoms of physical disease. Scores are produced for the 2 subscales of anxiety and depression. Scores of 8-10 are regarded as borderline and scores of above 10 as clinically significant. Johnston, Pollard and Hennessey (2000) reported that the HADS showed high levels of internal consistency although one or two items performed poorly for some clinical groups. They found evidence to support its validity and concluded that it is an easily administered measure, which is not unduly burdensome to patients who may be ill, and thus continues to be useful in measuring emotional distress in clinical populations.

Barrett-Lennard Relationship Inventory - Form OS-40 (Barrett-Lennard, 1978, 1986)

This measure is based on Rogerian person-centred theory (see Barrett-Lennard, 1998) and it aims to assess a dyadic relationship for (a) empathic understanding, that is an active process of desiring to know the full present and changing awareness of the other person e.g *He usually senses or realises what I am feeling*; (b) a positive or negative level of regard for each other e.g. *He respects me*; (c) an unconditionality of regard, that is a level of regard which remains consistent irrespective of what the partners reveal to each other about themselves e.g. *Whether I am feeling happy or unhappy about myself makes no real difference to the way he feels about me*; and (d) congruence, in other words a perception that the other is genuine, transparent and honest about self e.g *I feel that he is genuine with me.* Participants are presented with 40 statements and are required to state how strongly they feel that each statement is true on a 6 point scale. Scores can range from 0 to 60 for each of the 4 scales, with higher scores representing more empathy, for example, than lower scores. The inventory has been shown to have good internal and test-retest reliability and various levels of validity (see Gurman, 1977, for a review)

3.3 RESULTS

Table 3.4 shows the mean scores, standard deviations, and internal consistency (Cronbach's alpha) for all the scales

Table 3.4 Mean scores, standard deviations, and internal consistency

Scale	Mean	Sd	Alpha
WHYMPI pain severity	10.41	4.42	.90
WHYMPI pain interference	30.31	12.30	.93
WHYMPI negative mood	10.65	4.00	.80
WHYMPI self control	6.17	2.58	.77
WHYMPI spouse support	12.51	3.66	.80
WHYMPI punishing spouse	6.07	5.16	.67
WHYMPI distracting spouse	8.21	4.95	.66
WHYMPI solicitous spouse	22.62	9.69	.88
BL level of regard	50.90	8.19	.91
BL empathy	40.24	8.74	.86
BL unconditionality	41.93	7.79	.78
BL congruence	42.03	8.77	.85
HADS anxiety	10.45	4.74	.88
HADS depression	8.24	4.37	.70

3.3.1 Correlations

Table 3.5 shows that significant correlations were only found between solicitous spouse responses and other measures of spouse support. No association was found between solicitous spouse responses and pain severity or interference. Punishing spouse responses were positively associated ($p<.01$) with depression, and to a lesser extent ($p<.05$) with pain severity. Depression was negatively associated ($p<.01$) with positive level of regard; empathy; unconditionality; and congruence. There was no association between any of these four factors and anxiety or pain severity. However there were negative associations ($p<.05$) between pain interference, congruence and level of regard.

Table 3.5 Correlations between, social support, pain experience, anxiety and depression

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. pain severity														
2. pain interference	.802**													
3. spouse support	.245	.204												
4. negative mood	.519**	.578**	.337*											
5. self control	-.502**	-.450**	-.150	-.610**										
6. punishing spouse	.368*	.357*	-.112	.174	-..267									
7. solicitous spouse	-.010	.196	.702**	.171	.143	-.069								
8. distracting spouse	.065	.061	.390*	-.029	-.224	.044	.465**							
9. level of regard	-.282	-.329*	.458**	-.202	.211	-.438**	.447**	.359*						
10. empathy	-.124	-.284	.643**	-.011	.093	-.377*	.438**	.272	.748**					
11. unconditionality	-.033	-.293	.279	-.172	.241	-.444**	.155	.050	.681**	.625**				
12. congruence	-.167	-.324*	.320*	-.264	.194	-.158	..299	..273	.662**	.764**	.609**			
13. anxiety	.419*	.494**	-.014	.679**	-.384*	.035	.057	-.027	-.148	-.045	-.080	-.168		
14. depression	.645**	.793**	-.204	.568**	-.476**	.430**	-.099	-.060	-.580**	-.502**	-.439**	-.523**	.524**	

** Correlation is significant at the 0.01 level (1-tailed). *. Correlation is significant at the 0.05 level (1-tailed).

3.4 DISCUSSION

The results of this study must be interpreted with some caution given the possibility of type one errors due to the large number of correlations, it should also be noted that no directional causality can be ascertained from correlations.

With regard to social support from partners, findings were not consistent with the behavioural formulation of chronic pain (Fordyce, 1976), as no association was found between solicitous spouse responses and pain severity, or indeed any of the dependent variables. One of the reasons for this disparity in findings may be the gender of participants. CPP patients are female and there is evidence to suggest that solicitous spouse responses are less likely to be associated with pain severity and somatisation in female, compared to male patients (Flor et al, 1989). This difference may be because women traditionally assume the nurturing or caring role. It is unlikely that this role would be entirely relinquished by women who have CPP, and even more unlikely that their partners who are generally less accustomed to the caring role become so adept in it that their proficiency errs on the side of over protectiveness or excessive solicitousness.

Aversive responses from partners may represent more of a problem to women with CPP than solicitous responses. Results were consistent with the research evidence that suggests an association between aversive spouse responses and depression (e.g. Kerns et al, 1990). Furthermore, there was also an association between reports of partners' aversive responses and pain experience. 'Punishing spouse' was the only social support measure in this study that was also associated with pain severity. Anger has been found to be a problem both for patients with chronic illness and their spouses. Lane & Hobfoll (1992) found that the severity of symptoms in patients with chronic pulmonary disease was a significant predictor of how angry they were, and a significant link was found between anger in the patient and anger in the well spouse. Partners of women with CPP may feel helpless when witnessing the pain, they may have their usual activities restricted and their sex lives disrupted as a consequence of the pain. This may lead to feelings of resentment and frustration aimed at the woman. Whatever the reasons for it, the perception of anger from partners does not appear to have healthy associations for women with CPP.

By contrast, and perhaps not surprisingly, unconditional positive regard, empathy and genuineness from a partner were associated with fewer symptoms of depression. This finding suggests a potentially more positive role for partners in supporting women with CPP, than has been indicated by behavioural investigations of spouse support in chronic pain. The BLRI (Barrett-Lennard, 1986) offers a means of exploring what constitutes emotional support from partners. This measure was designed to investigate a dyadic relationship and as such it could be used in future investigations to explore not only the perceptions of women with CPP about the support they receive but also the perceptions of their partners about the support they provide. This might provide a more comprehensive view of the social support interactions that can help couples to cope with this pain problem.

It is worthy of note that BLRI scores were not found to be associated with pain severity, although level of regard and congruence were negatively related to pain interference. It may be that empathy, level of regard, unconditionality and congruence are more influential in terms of psychological well being than pain experience. On the other hand, the lack of association with pain may be due to problems with the pain measure.

A weakness of this study design was the use of the WHYMPI as a measure of pain severity. The WHYMPI proved to be an inadequate pain measure because of the intermittent nature of CPP, participants were asked to rate their pain levels either at the present moment or in the past week, and it is possible that neither of these time intervals would adequately gauge their pain experiences. The standardised measurement of CPP severity has been reported to be problematic because of the episodic nature of this pain (Stones & Selfe, 2000). Participants in the present study commented that the WHYMPI was inadequate for assessing their pain because items were concerned with pain in the previous week, whereas they might experience one month of pain, followed by a pain free month. Future investigations may therefore need to tailor pain measures specifically to CPP in order to account for its episodic nature.

3.4.1 Clinical implications

The results of this study are exploratory and conclusions must therefore be tentative, but there is indication that perceptions of partners' attitudes and behaviour may represent an important influence on women's experience of CPP. Hence there may be scope for providing social support therapy to couples who face this pain problem. Cutrona (1996) describes how behaviourally oriented marital therapies can help to decrease the frequency with which couples engage in aversive behaviours such as criticism, name calling and sarcasm. However, she suggests that preventative interventions may be more effective because it is very difficult to restore goodwill and trust therapeutically, once they have been eroded. It may be helpful for multi-disciplinary CPP clinics (e.g. Collett, Cordle & Stewart, 2000) to see women with CPP alongside their partners so that strategies for helping the couple to cope with the pain together, can be discussed. In line with preventative social support therapy for couples when one partner is ill (Cutrona, 1996), efforts to improve communication, address inequities and resolve conflict may pay dividends in terms of improved social support from partners thus reducing symptoms of depression and perhaps even reducing symptoms of pain.

3.5 REFERENCES

Barrett-Lennard, G.T. (1978). The Relationship Inventory: later development and adaptations. JSAS Catalogue of Selected Documents in Psychology, 8, 68.

Barrett-Lennard, G.T. (1986). The Relationship Inventory now: issues and advances in theory, method and use. In L.S. Greenberg, & W.M. Pinsof (Eds.), The Psychotherapeutic Process: A Research Handbook (pp. 439-476). New York: Guilford Press.

Barrett-Lennard, G.T. (1998). Carl Rogers' Helping System. London: Sage Publications.

Beard, R.W. (1998). Chronic Pelvic Pain. British Journal of Obstetrics and Gynaecology, 108, 8-10.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine, 38, 300-314.

Cohen, S., & Wills, T.A. (1985). Stress, social support and the buffering hypothesis. Psychological Bulletin, 98, 310-357.

Collett, B.J., Cordle, C., & Stewart, C.S. (2000). Setting up a multi-disciplinary clinic. Baillieres Clinical Obstetrics and Gynaecology, 14, 541-556.

Cutrona, C.E. (1996). Social Support in Couples. Thousand Oaks, California: Sage.

Cutrona, C.E., & Russell, D.W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In G. Sarason, B. R. Sarason, & G. R. Pierce (Eds.), Social support: An interactional view (pp. 319-366). New York: Wiley.

Dakof, G.A., & Taylor, S.E. (1990). Victims perceptions of social support: What is helpful from whom? Journal of Personality and Social Psychology, 58, 80-89.

Fiore, J., Becker, J., & Coppel, D. (1983). Social network interactions: A buffer or a stress? American Journal of Community Psychology,11, 423-439.

Flor, H., Kerns, R.D., & Turk, D.C. (1987). The role of the spouse in the maintenance of chronic pain. Journal of Psychosomatic Research, 31, 251-259.

Flor, H., Turk, D.C., & Rudy, T.E. (1989). Relationship of pain impact and significant other reinforcement of pain behaviours: the mediating rôle of gender, marital status, and marital satisfaction. Pain, 38, 45-50.

Fordyce, W.E. (1976). Behavioural Methods in Chronic Pain and Illness. St Louis: Mosby.

Gamsa, A. (1994). The role of psychological factors in chronic pain. II. A critical appraisal. Pain, 57, 17-29.

Gurman, A.S. (1977). The patient's perception of the therapeutic relationship. In A.S. Gurman & A.M. Razin (Eds.), Effective Psychotherapy: A handbook of research (pp. 503-543). Oxford: Pergamon.

Johnston, M., Pollard, B., & Hennessey, P. (2000). Construct validation of the hospital anxiety and depression scale with clinical populations. Journal of Psychosomatic Research,48, 579-584.

Kerns, R.D., Turk, C.C., & Rudy, T.E. (1985). The West Haven-Yale Multidimensional Pain Inventory (WHYMPI). Pain, 23, 345-356.

Kerns, R.D., Haythornthwaite, J., Southwick, S., & Giller, E.L. (1990). The role of marital interaction in chronic pain and depressive symptom severity. Journal of Psychosomatic Research, 34, 401-408.

Lane, C., & Hobfoll, S.E. (1992). How loss affects anger and alienates potential supporters. Journal of Consulting and Clinical Psychology, 60, 935-942.

Mann, S.L.& Zautra, A.J. (1989). Spouse criticism and support: their association with coping and psychological adjustment among women with rheumatoid arthritis. Journal of Personality and Social Psychology, 56, 608-617.

McGowan, L.P.A., Clark-Carter, D.D., & Pitts, M.K. (1998). Chronic pelvic pain: a meta-analytic review. Psychology and Health, 13, 937-951.

Melzack. R. (1999). Pain and stress: a new perspective. In R.J. Gatchel & D.C. Turk (Eds.), Psychosocial Factors in Pain. Critical Perspectives (pp 89-106). New York: Guilford Press.

Moore, J., & Kennedy, S. H. (2000). Causes of chronic pelvic pain. Baillieres Clinical Obstetrics and Gynaecology, 14, 389-402.

Zigmond, A., & Snaith, R. (1983). The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica, 67, 361-370.

Zondervan, K.T., Yudkin, P.L., Vessey, M.P., Jenkinson, C.P., Dawes, M.G., Barlow, D.H., & Kennedy, S.H. (2001). The community prevalence of chronic pelvic pain in women and associated illness behaviour. British Journal of General Practice, 51, 541-547.

CHAPTER FOUR

AN ASSESSMENT OF THIS PROJECT IN RELATION TO GUIDELINES FOR THE PUBLICATION OF QUALITATIVE RESEARCH

4.1 INTRODUCTION

The epistemological priorities and commitments of qualitative and quantitative research tend to be very different. It is therefore inappropriate for qualitative research to be evaluated according to the canons of validity that have evolved for quantitative research (Smith, 1996). Elliott, Fischer and Rennie (1999) have identified evolving guidelines for the publication of qualitative research studies in psychology. They propose seven guidelines which are common to both qualitative and quantitative research and another seven guidelines especially pertinent to qualitative investigations. These guidelines lend themselves as criteria for the review of this project which is predominantly qualitative (see Chapter 2) with quantitative elements (see Chapter 3). For the purposes of this research review, the fourteen guidelines as outlined in Table 1 will be discussed in relation to this project as a whole.

Table 4.1 Evolving guidelines for the publication of qualitative research studies in psychology and related fields (Elliot et al, 1999)

A. Publishability guidelines shared by both qualitative and quantitative approaches
    1. Explicit scientific context and purpose
    2. Appropriate methods
    3. Respect for participants
    4. Specification of methods
    5. Appropriate discussion
    6. Clarity of presentation
    7. Contribution to knowledge

B. Publishability guidelines especially pertinent to qualitative research
    1. Owning one's perspective
    2. Situating the sample
    3. Grounding in examples
    4. Providing credibility checks
    5. Coherence
    6. Accomplishing general vs. specific research tasks
    7. Resonating with readers

4.2 PROJECT ASSESSMENT

Specific scientific context and purpose. This guideline recommends that the manuscript should specify where the study fits within relevant literature and states the intended purposes of the study. This principle was followed for both studies in this project, which were designed in the context of theory and research about social support, chronic pelvic pain in particular, and chronic pain in general. Study aims were explicitly stated in relation to the literature.

Appropriate methods. This guideline is concerned that the methods and procedures used should be appropriate or responsive to the intended purposes of the study. Interpretative phenomenological analysis (IPA) (Smith, Jarman & Osborn, 1995) seemed an appropriate method for the qualitative study because of its commitment to the phenomenological perspective. I valued the method for its explicit acknowledgement that access to the personal worlds of participants depends on and is complicated by the researcher's own conceptions, because I believe this acknowledgement facilitates a commitment to transparency with regard to differentiating between data and interpretation. The method has a 'track record' in chronic pain (Osborn & Smith, 1998). Also, information about how to conduct this sort of analysis was accessible, through the literature (Smith, 1995; Smith et al, 1999; Moustakas, 1994) and through an opportunity I had to attend a workshop presented by Johnathan Smith, who developed the method for use in health psychology.

With regard to the quantitative study, the use of standardised measures provided a way of gaining information about the social support experiences of a larger number of women with CPP, such that relationships between these experiences and levels of pain and psychological well being could be explored through correlation analysis. It also provided an opportunity to examine aspects of social support which had received little attention in this field, namely dimensions of intimate relationships as measured by the Barrett-Lennard Relationship Inventory (Barrett-Lennard, 1986).

Respect for participants. This guideline recommends that researchers should creatively adapt their procedures and reports to respect both their participants' lives and fulfil other ethical principles. The process of gaining ethical approval from two research ethics committees (Appendix 8) was designed to safeguard participants in this project. All participants were sent letters of invitation (Appendix 9) and information sheets about the study (Appendix 10). Informed consent was obtained from interviewees (Appendix 11) and signatures of consent were required on all completed questionnaires (Appendix 12). Anonymity of participants was preserved through the use of pseudonyms or number codes, and data protection guidelines were followed. All participants were given the option to receive the research reports.

Specification of methods, appropriate discussion and clarity of presentation. These guidelines are concerned with the adequate reporting of all procedures for gathering data, including questions posed to participants, and with the specification of methods of analysis. The research data and the understandings derived from them should be discussed in terms of their contribution to theory, content, method, and practical domains, in suitably tentative and contextualised terms. Furthermore, the manuscript should be well-organised and clearly written with technical terms defined.

My intention was to specify methods in sufficient detail to allow reproducibility by other researchers; and to discuss the data in the terms specified above. The extent to which I achieved these goals was difficult to judge myself. I relied on the review process to facilitate the refinement of these aspects of reporting.

Manuscripts were passed between 3 supervisors for constructive criticism and were submitted for consideration for publication so that they would be subject to the peer review process.

Contribution to knowledge. This guideline recommends that manuscripts should contribute to an elaboration of a discipline's body of description and understanding. Findings from both studies about what is helpful and unhelpful in terms of social support for women with CPP could usefully inform the development of pain management programmes for this patient group. There is evidence that psychology has a useful role to play in multi-disciplinary pain management programmes (Peters, Van Dorst, Jellis, Van Zuuren, Hermans, and Trimbos, 1991; Collett, Cordle & Stewart, 2000), where the emphasis is on helping women to manage this long-term pain in the context of their lives.

However, while the dichotomous approach to CPP continues to dominate, i.e. pain is ascribed to either physical pathology or psychological pathology, this management role for psychology tends to be misunderstood. The process of conducting psychological research in this area may in itself serve to reinforce this misunderstanding. One consultant who helped to recruit participants for the study, asked me which of his patients would be suitable for inclusion, those who had responded to medical treatment, or those who had not, whom he called, 'the nutters'.

There is little evidence for the idea that women with visible pathology are psychologically different from those without (McGowan, Clark-Carter & Pitts). Although early psychological research in this field claimed that CPP was 'all in the mind' (Gidro-Frank, Gordon & Taylor, 1960) there is very little scientific support for the assertion that CPP is psychogenic (Grace, 1998). However, it is most likely that this assertion is responsible for participants reporting that their pain was disbelieved, denied and dismissed by others. In order to prevent psychological research from adding to the stress that women with CPP already suffer, it is essential that patients and practitioners are re-educated about the role of psychology in pain management. It should be emphasised that the focus is not on pre-existing psychological pathology but rather that psychology aims to facilitate coping in women faced with the stressful consequences of long-term pain. Furthermore, such management can take place in the absence of an identified cause for the pain. This is particularly important when there is evidence to suggest that diagnostic investigations may in themselves exacerbate the pain problem and even when the cause of pain has been diagnosed and treated, for example with endometriosis, the pain often remains.

Owning one's perspective. This guideline is concerned with authors' attempts to recognise their values, interests and assumptions, as such attempts may help to develop and communicate their understanding of the phenomenon under study. In an attempt to maintain my awareness of the effect I was having on the research and the effect it was having on me, I kept a research diary to record my reflections. I noted that participants' accounts of difficult encounters with GPs and Gynaecologists were similar to some of my experiences as a patient in the past, when I felt belittled and disempowered in unsatisfactory interactions with doctors. I identified with participants in this respect but at the same time, I was aware that I needed to prevent memories of my experiences from clouding my perception of their experiences. The tension between empathy and identification on the one hand, and the need to be aware of our differences on the other, was a tension that remained throughout the research process.

I observed that participants seemed eager to tell their stories and be heard. This seemed to illustrate how little they felt heard and understood, elsewhere. I noted my own discomfort in hearing the tales of relentless pain that invaded every aspect of participants' lives. It was frightening to think that I, as a woman, might find myself similarly stricken in the future. I tried to identify factors that set me apart from participants, and thus made me immune. Such efforts did little to subdue my fears; I had nightmares about surgery, and I suffered one sleepless night when I felt sure I was developing symptoms of CPP.

Some of the accounts were very shocking. Some of the women wept as they recounted particular traumas. In one interview, a participant's pain became almost visible when I observed her turn ashen as her pain medication began to wear off. To be a witness to such suffering was disturbing, but it gave the research a greater sense of purpose and made the responsibility of giving voice to these experiences, all the more great.

Results in chapter two reveal how easily efforts at support can begin to undermine self-esteem and autonomy. This finding struck me as important for my work as a clinical psychologist. While it is necessary to try to offer support and insight it is equally necessary to remain vigilant about the danger of becoming too prescriptive and 'taking over'.

Situating the sample. This guideline is concerned that participants and their life circumstances should be described in sufficient detail to aid the reader in judging the range of persons and situations to which the findings may be relevant. I provided detailed demographic information about participants. I also included information about pain, diagnosis and treatment. This was important because the definition and criteria for diagnosis of CPP has been surrounded by controversy (Howard, 1993).

Problems of diagnosis may lie behind the fact that far less women were recruited via the NHS than via the internet. Judgements about what constituted CPP tended to vary among consultants, who admittedly had little time to devote to the problem. The National Endometriosis Society web site advertisement (appendix 13) provided a more direct route of communication between myself and prospective participants. Questionnaires were designed to elicit sufficient diagnostic information so that a check could be made as to whether participants met the inclusion criteria. Interestingly it was an NHS recruit not an internet recruit who was excluded on the basis of this information.

The internet provided a way of finding women with CPP in the community, who may represent a group which is often missed in research. A community study of CPP revealed that 41% of women with CPP did not consult services (Zondervan, Yudkin, Vessey, Jenkinson, Dawes, Barlow & Kennedy, 2001). Furthermore, Savidge and Slade (1998) revealed that women complained of pain 18 months after negative laparoscopy and received little or no medical follow up.

Grounding in examples. As recommended by this guideline, the qualitative paper provided examples of data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them. It is hoped that the examples allowed readers to appraise the fit between the data and my understanding of it and provided opportunity for readers to find alternative meanings or understandings.

Providing credibility checks. This guideline suggests that researchers may use any one of several methods for checking the credibility of their categories, themes or accounts. This study used independent audit (Smith, 1996) rather than inter-rater reliability checks because the objectivity of a coding scheme is meaningless to researchers who believe that knowledge cannot be objective, but is always shaped by the purposes, perspectives and activities of those who create it

(Seidel & Kelle, 1995). Independent audit demanded that I filed data in such a way that my supervisor could follow the chain of evidence that led to the final report. This chain comprised the interview schedule, interview transcripts, notes and codes at each of 3 stages of analysis, draft reports and the final report. My supervisor's task was not to assess whether he would have provided the same analysis, but rather to check that the final report was a credible one in terms of the data collected and that a logical progression ran through the chain of evidence. In addition, a mini audit was carried out by a qualitative researcher, independent of the study, who followed the chain of evidence for a single case.

Another attempt at validity was based on the rationale that if you use a number of different methods to tackle a question, the resulting answer is likely to be more accurate. Hence this project employed both qualitative and quantitative methods to examine the social support needs of women with CPP, an example of triangulation.

'Testimonial' or 'member' validity was also sought. Initial drafts of the qualitative results section were given to a participant and to a woman with CPP who did not take part in the study. They were asked whether the findings were consistent with their experiences, and if there was anything about the results that they disliked or disagreed with. Both women said the findings resonated with their experiences.

Coherence. This guideline is concerned that the understanding is represented in a way that achieves coherence while preserving nuances in the data. Readers should not be confused by a mixture of categories referring to different levels of abstraction without an apparent underlying structure to the phenomenon .

I found the task of providing a coherent narrative about the women's experiences to be the most demanding aspect of the qualitative study. It was difficult to decide on a structure for the story which would reveal the themes, present the experiences in sufficient detail and still remain interesting and fluent. I used tables to illustrate the hierarchy of themes and hoped these would act as maps to guide the reader through my story.

Accomplishing general versus specific tasks. This guideline is concerned with ensuring that where a general understanding of a phenomenon is intended it is based on an appropriate number of instances. Limitations of extending the findings to other contexts should be specified. Where understanding a specific instance is the goal, it should be described comprehensively enough to provide the reader with a basis for attaining that understanding.

The qualitative component of this project was concerned with providing a 'thick' description of the experiences of a small group of women. Less detailed information about only one aspect of social support, that is support from partners, was gathered from a larger number of women and was analysed quantitatively. A closer match between these specific and more general tasks may have improved this study. For example, if I had used the findings from the qualitative study to design a more general investigation, as was done by Grace (1995a & b). She used focus groups to gain a detailed description of problems that a small number of women patients experienced in the medical encounter for CPP. This qualitative information was then used as a basis for designing a questionnaire to elicit views about problems of communication, diagnosis and treatment from 336 women with CPP. It was not possible to use such a model for this project, as time constraints demanded that the qualitative and quantitative components were conducted in parallel. However, there is scope for using the qualitative information as the basis for a quantitative investigation in the future.

Resonating with readers. This guideline recommends that material should be represented in such a way that readers judge it to have accurately represented the subject matter or to have clarified or expanded their appreciation and understanding of it. The only indication as yet that this has been achieved, has come from the women who provided member validation for the study. One participant gave feedback by telephone. She said she read the findings a number of times because she was so amazed that other women's experiences were just like hers. Before reading it she felt she was alone and unique in her problem, after reading it she realised that this was not the case. The other woman who validated the study gave feedback in writing as follows:

> Thank you for your study result notes. They have provided a fantastic insight. I generally agree with everything written. The examples were particularly helpful with getting to the root of meanings and provided great insight into other women's thoughts and experiences.....I have noticed that your study notes show more examples of dismissive than supportive doctors, perhaps it is THEIR attitude that should be studied, as well as ours!

4.3 CONCLUSION

This project has followed a number of the guidelines that have evolved for the evaluation of qualitative research (Elliot et al, 1999). Reports were explicit in giving a scientific purpose and context to the studies; reasons were offered for the choice of methods; steps were taken to ensure respect was shown to participants; examples of reflexivity were given; study samples were situated in terms of life circumstances but also in terms of pain experience and treatment; the qualitative report was grounded in examples; and credibility checks were taken. However, the jury is still out about the standard achieved in reporting methods, results, and discussion. It is only for readers, to comment whether my explanation of the social support experiences of women with CPP, was coherent. However, there is evidence to suggest that the explanation resonated with the experiences of two readers. The findings from this project could usefully inform the development of pain management programmes for women with CPP. However, for this to happen, an improved understanding of the biopsychosocial approach to chronic pain needs to be cultivated, along with a better appreciation of the new role for psychology with respect to CPP.

REFERENCES

Barrett-Lennard, G.T. (1986). The Relationship Inventory now: issues and advances in theory, method and use. In L.S. Greenberg, & W.M. Pinsof (Eds.), The Psychotherapeutic Process: A Research Handbook (pp. 439-476). New York: Guilford Press.

Collett, B.J., Cordle, C., & Stewart, C.S. (2000). Baillieres Clinical Obstetrics and Gynaecology, 14, 541-556.

Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. British Journal of Clinical Psychology, 38, 215-229.

Gidro-Frank, L., Gordon, T., & Taylor, H.C. (1960). Pelvic pain and female identity. American Journal of Obstetrics and Gynecology, 79, 1184-1202.

Grace, V.M. (1995a). Problems women patients experience in the medical encounter for chronic pelvic pain: a New Zealand study. Health Care for Women International, 16, 509-519.

Grace, V.M. (1995b). Problems of communication, diagnosis and treatment experienced by women using the New Zealand health services for chronic pelvic pain: a quantitative analysis. Health Care for Women International, 16, 521-535.

Grace, V.M. (1998). Mind/body dualism in medicine: The case of chronic pelvic pain without organic pathology: a critical review of the literature. International Journal of Health Services, 28, 127-151.

Howard, F.M. (1993). The role of laparoscopy in chronic pelvic pain: promise and pitfalls. Obstetrical and Gynecological Survey, 48, 357-387.

McGowan, L.P.A., Clark-Carter, D.D., & Pitts, M.K. (1998). Chronic pelvic pain: a meta-analytic review. Psychology and Health, 13, 937-951.

Moustakas, C. (1994). Phenomenological Research Methods. Thousand Oaks, California; London: Sage.

Osborn, M., & Smith, J.A.. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. British Journal of Health Psychology, 3, 65-83.

Peters, A.A.W., Van Dorst, E., Jellis, B., Van Zuuren, E., Hermans, J., & Trimbos, J.B. (1991). A randomised clinical trial to compare two different approaches in women with chronic pelvic pain. Obstetrics and Gynecology, 77, 740-744.

Savidge, C.J., Slade, P., Stewart, P. & Li, T.C. (1998). Women's perspectives on their experiences of chronic pelvic pain and medical care. Journal of Health Psychology, 3, 103-116.

Seidel, J. & Kelle, U. (1995). Different functions of coding in the analysis of textual data. In U. Kelle (Ed.), Computer-aided qualitative data analysis: theory, methods and practice (pp. 52-61). Thousand Oaks, CA: Sage.

Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith & R. Harre (Eds.), Rethinking Methods in Psychology (pp.9-26). London: Sage.

Smith, J.A. (1996). Evolving issues for qualitative psychology. In J.T.E. Richardson (Eds.), Handbook of Qualitative Research Methods (pp. 189-202). Leicester: BPS Books.

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing Interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), Qualitative Health Psychology: Theories and Methods (pp.218-240). London: Sage.

Zondervan, K.T., Yudkin, P.L., Vessey, M.P., Jenkinson, C.P., Dawes, M.G., Barlow, D.H., & Kennedy, S.H. (2001). The community prevalence of chronic pelvic pain in women and associated illness behaviour. British Journal of General Practice, 51, 541-547.

APPENDIX 1

JOURNAL INSTRUCTIONS TO AUTHORS

Journal of Psychosomatic Research

Guide for Authors

Papers must be written in English. They will be acknowledged on receipt, and then reviewed. The decision on acceptance will usually be conveyed to the authors within two months.

Full Length Papers. Full length research papers will not normally be more than 4000 words in length and will preferably be shorter. Submission of a paper to the **Journal of Psychosomatic Research** will be held to imply that it represents original research not previously published (except in the form of an abstract or preliminary report), that it is not being considered for publication elsewhere, and that if accepted by the **Journal of Psychosomatic Research** it will not be published elsewhere in the same form in any language without the consent of the Publisher. Major papers of topical content will be given priority in publication.

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Manuscripts should be typed with wide margins, double-spaced on one side of standard A4 or 8.5" x 11" paper. The format should be as follows:

Title page. This should contain (a) the **title** of the article; (b) a short **running head;** (c) name of **department** where the work was conducted; (d) **names of the each author** with highest academic degree; (e) name, address, phone and fax of **author responsible for correspondence** and to whom requests for reprints should be addressed; (f) up to six **keywords** should be listed in alphabetical order after the abstract. These terms should optimally characterize the paper.

Abstract. This should be subdivided under the headings *Objective, Methods, Results, Conclusion* and should not exceed 150 words.

Text. This should be divided into sections with main headings: Introduction, Method, Results and Discussion. Accepted papers will usually be between 2000 and 4000 words in length.

Acknowledgments. These must include mention of any source of funding outside the basic funding of the host institution.

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1. Ingham JC, Miller P McC. Self-referral to primary care: symptoms and social factors. J Psychosomatic Res 1986;30:49-56.

2. Berkenbosch F. Corticotrophin-releasing factor and catecholamines: a study on their role in stress-induced immunomodulation. In: Schneiderman N, McCabe P, Baum, A, eds. Perspectives in behavioral medicine. Hillsdale, New Jersey: Erlbaum 1992:73-91.

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>
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> 1. Johnston, M. (1984) Dimensions of recovery from surgery. *International Review of Applied Psychology*, **33**(4), 505-520.

2. Smith, A.P., Tyrrell, D.A.J., Coyle, K.B., Higgins, P.G. and Willman, J.J. (1990) Individual differences in susceptibility to infection and illness following respiratory virus challenge. *Psychology and Health*, **4**, 201-211.

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The following types of paper are invited :

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- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
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(a) Four copies of the manuscript should be sent to the Editor (Professor Douglas Carroll, BPS Journals Department, St. Andrews House, 48 Princess Road East, Leicester, LE1 7DR, UK). Submission of a paper implies that it has not been published elsewhere and that it is not being considered for publication in another journal. Papers should be accompanied by a signed letter indicating that all named authors have agreed to the submission. One author should be identified as the correspondent and that person's title, name and address supplied.

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a) Kanvil, N., & Umeh, K.F. (2000). Lung cancer and cigarette use: Cognitive factors, protection motivation and past behaviour. British Journal of Health Psychology, 5, 235-248.
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1. Supplementary data too expensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

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- A cover page with title/author(s)/affiliation
- Double spacing with wide margins
- Tables/figures at the end
- Complete reference list in APA format
- Four good copies of the manuscript (or an e-mail attachment)

APPENDIX 2

EXAMPLE OF INTERVIEW TRANSCRIPT

Subject 3 Interview

R: Since your pain began what is the most helpful thing your partner has said or done to help you?
J: Probably the best thing he's ever done is get me a hot water bottle and give me a hug that's the most effective thing that he has ever done because obviously there is nothing else that he can do he can't take it anyway.
R: Its interesting isn't it how hot water bottles can help with the pain
J: Yes
R: Okay sometimes people who are close to us may say a few things that make us feel bad even though they are well intentioned, but they might rub us up the wrong way or make us feel frustrated, so is there anything that your partner has done that hasn't been helpful?
J: Oh yes, yes, he gets, the way I see it he gets very frustrated that he can't help me, he cannot take the pain away there's not a lot that he can do bar get me a hot water bottle and he gets so frustrated with me and that kind of turns into anger, sometimes my belly's hurting and he gets quite angry sometimes but its just panic on his part. He wants it away as much as me but he can't handle it
R: Um how does that affect you? Does that make you angry back?
J: Um it makes me feel guilty. You know you see this is your problem and you feel the pain is bothering other people and obviously they're distressed about it because they care about you and you think ooh, its all my fault if I didn't have this, so its just really guilt.
R: So right, what's unhelpful is him getting anxious and angry and then you feeling guilty that he's frustrated with you?
J:yea
R: Is that right?
J: Um, I don't think he's frustrated with me I know that he's frustrated with the situation, same as I am, but its just the fact that its causing arguments
R: Okay, that's very helpful thankyou. Okay anything else about your partner before we move on to what you think other people have done to be helpful or unhelpful?
J: Um, I know that the sex issue is kind of big on his part. I can block off but obviously if there's pain there you can't do it and he gets very frustrated about that, and I feel guilty again, and again there's more arguments, so theres that part. And that does play a very big part in relationships, no escaping that
R: And that makes this sort of pain harder really doesn't it?
J: Yea because you're tummy's getting stressed out and that doesn't make that any better. Um its unfair to tell him to keep silent but to keep silent about it for years, so
R: It sounds very difficult
J: It is really but ah
R: so that's quite fundamental
J: Yea, yea, it's a rather big part of your relationship especially when you're young.
R: Yes, absolutely, so, very difficult. Okay, thank you for that, um, what about other family members?
J: Um my mum, she's fantastic, she helps, she's very much into this alternative therapy, so she's trying to put all these potions down my neck. But she really does, worry about it. My Dad kinda tends to stay a bit silent he's not really one for showing much emotion over anything, so occasionally he'll come out with ideas or support but
R: So your mum's quite helpful?
J: Yea,
R: Have the alternative medicines been useful?
J: No, no. Sometimes she does cause she's a reflexologist, that can help. But those potions no. The most helpful thing is that she obviously cares
R: And is there anything that your family has done which had been unhelpful?
J: Um, they can, well my dad tends to get involved when he has a strong idea about something, he has a strong idea about how I should do something. And that's when he gets involved and he's really quite forceful if he's got an idea and I'm quite stubborn. So he can be quite unhelpful and my mum when they really really do try and push things on me and I just have to say no,
R: I don't want that?
J: Exactly so that's when it doesn't help so much cause I feel like I'm fighting them as well. But it doesn't happen that often.
R: So both things really, they're helpful in that they're trying to help and listen and try things but not so much when they say, you must do this
J: Yes
R: Is that right? (J nodded). Okay good, thank you, alright so we've talked about your partner, family members, what about friends? Have they been helpful at all?
J: Um I don't tend to really talk about it with them, to be truthful. There's gotta be a point when you just, you want to escape it, because it does pretty much consume your entire life and what you do. It does take control and

there's gotta be some point when you just pretend that it doesn't exist, so if I go out with my friends I just put it on the back burner and ignore it so I don't really talk about it with them.
R: Okay so does that mean they've not really been helpful or unhelpful.
J: Yes, I'm sure if I'd talked about it they would be
R: Right okay, but friends don't really come into supporting you with it.
J: No, no, not really no.
R: Is it uh, is it helpful to be distracted by them?
J: Yea, yea
R: I feel like I'm putting words into your mouth there
J: no
R: Please do say no if you disagree with me. So they're not actually supportive or unsupportive but its quite useful to be distracted by them?
J: Yea, um obviously sometimes it will stop me going out, pain will stop me but sometimes I just think right, I'm gonna go out and forget about it and because I don't have that kinda of thing where I'm gonna talk about it all the time, its just, forget about it, pretend, for an evening or whatever. That does help.
R: When you say sometimes you can't go out because of the pain do you tell them why or do you just say you're not coming out?
J: Uh no, I just say I'm not coming out.
R: So its kind of quite hidden really
J: Yea they know I have it but I don't like to make a fuss, no not with them, they've got their own problems.
R: Okay thank you for that, so that's friends, have you encountered anybody else with similar pain?
J: I know a few people who have had IBS, my one friend who I don't really talk to anymore so, we've kind of drifted apart, yea she had IBS and kind of to have a bit of say yea I get that and the kind of pain I get and
R: Okay, so how was that helpful?
J: um it even though you know that there's got to be a 100 people around you that have it, that have pelvic pain, you still do feel like a bit of a freak sometimes. You think, you know, I'm 21 I do feel a bit like a freak and when somebody your age gets the same, similar kind of pain and has similar kinds of restrictions, it is helpful to think that I'm not really that weird.
R: Yes, I can understand that. So you say you haven't really seen this girl much, but has she done anything that's been, or somebody like her, have they done anything that's been unhelpful?
J: Not really, because we started drifting several years ago, it was just when we met up once we started talking about it and I haven't seen her much since so
R: Okay what about doctors?
J: The first doctor I ever saw about my pain was actually my family doctor and he'd been my doctor all my life, and he was really quite dismissive about it. 'They're growing pains, go away,', and a couple of weeks later, 'No I won't go away and I went to see another doctor and changed my G.P to a female doctor and she was marvellous.
R: So you actually had to change, did you have to change the practice?
J: No, no , no it was in the same practice , but I had to re register myself with a new G.P. Yea, I mean you can go and see other doctors if you want to but I just thought if you're going to be that dismissive I'm not going waste my time. And she was, she was fantastic. I do feel because it was going on quite a while she was really really helpful, really concerned every time I saw her but I think she kind of got a bit lost for ideas, and was tearing her hair out at what the hell was wrong with me. So I kind of , I felt after a while I was going round in circles so I started to see another doctor and he's been excellent as well. And he's actually told me about a lot of the new therapies, not new therapies actually, expensive ones that they hadn't told me about because they were too expensive, which kind of frustrated me a bit.
R: So this other one, this other male doctor was he a G.P. as well?
J: Yes, my local G.P. The female doctor, she actually referred me to a gynaecologist who I don't feel helped really at all. I just don't feel like there's any concern and the concern that he does show I feel like its really acted out.
R: So it didn't feel genuine?
J: No not at all. I had, they put a camera, an endoscope or something, he was all really overly concerned, 'We'll combat this I promise you', and all that, and 3 years on it hasn't, and I've only ever seen him, I've been to the gynaecologist many many times with this gynaecologist's name, and I've only ever seen him twice. I keep getting referred round to different consultants and I have to keep telling them the same story and thinking, you know, do you really care?
R: Can you talk about the impact it has, seeing different people? Is that difficult?
J: It is, its actually just exhausting. You do come to expect it and then the last time I was up there I saw Dr X, and I was shocked, oh my God, 'haven't seen you for years.' Um but when you keep seeing other doctors you feel as if you're just being handed around like nobody really wants to take responsibility. When Dr X said we'll combat this I promise you I felt okay if you're taking responsibility that's good. You're doing your job, doing what

you're paid for and then I just kept getting passed around which I thought well, I don't feel like anybody's really concentrating on me, as if its not important enough, and to me it is because its consuming my entire life.
R: Do you think it was unhelpful that he promised that he would combat it?
J: Yes I do, he should have said, 'we'll try our best or whatever'. You can't make that promise and I later found out that there is nothing they can do to absolutely cure it. The first thing he offered me actually when I first went to see him, bearing in mind I was 18 at this time, he said, 'hysterectomy, it's the only real way to get rid of it' And he was quite adamant that that's how it was and I went absolutely mad.
R: It was scary?
J: It was very scary because I thought if that's the only way I can get rid of this pain, I can either not have a womb and not have pain and not have children, or I can have a womb, have pain and probably not get round to having children because its too painful, so what do I do?
R: Sounds very stressful
J: It was yea
R: Because it didn't feel like an option, just no options
J: Exactly and at 18 years old what are you supposed to think? I mean I'm lucky enough, I've been brought up pretty clued up so I just said absolutely no way there is another way. And I did a lot of research myself about it I won't be led on but I know the doctor said the easiest way first.
R: So you didn't feel very trustful?
J: No not really I mean you have to to a certain extent you have to you haven't got their degree, but I just thought, it can't be, that cannot be the only way.
R: So where did you do your research?
J: On the internet really, books, I've got, my mum keeps getting loads of research for me, N (partner) has bought me books on how to deal with pain and my uncle who actually lives in America, phoned me up and sent me books
R: And is that helpful, its another
J: Well yea having everybody pulling together and rooting for you
R: And that's helpful rather than unhelpful?
J: Yea its helpful having books from people and having their support. Yea because you feel like you're going into a doctors surgery with a bit of ammunition , you don't feel totally vulnerable. Like oh God, if they say I have to have a hysterectomy, its what I have to do. And, 'no, I know, I don't believe you there.' Which I think has helped because my saying no to various therapies that I just wouldn't have, like hysterectomy, has finally persuaded them after 3 years to tell me about therapies that were too expensive.
R: Okay, so you felt that you didn't have the whole truth, you didn't have all the information from them?
J: No , it was really unhelpful
R: You would have liked that information earlier?
J: Well yea, I've got a right, I should have all these options and their first option is to say well we'll cut your womb out. That's part of who I am, to me. And at 18 I'm not going to have that taken away from me. That made me feel very angry and it made me feel a little bit alone, and if that's what they think I should do. But of course I haven't so...
R: And you said that the doctor you're seeing now is better?
J: Yea the new male doctor, he's great, I think its just that it's a fresh look on things, a new person to look at it because after 3 years you can get a bit stale. 'Okay what shall we try next?' Because literally hardly anything has helped I'm just on strong pain killers now and its ridiculous.
R: Does that help?
J: Yea, yea you don't really notice how much pain killers help until you don't take them. Now I'm taking hormonal injection which works on your brain that releases the hormones. But yea the new guy is fantastic
R: Yea, so you feel, so exactly why is he fantastic?
J: Because he obviously cares. I think my other doctor did as well but it just got to a point where I felt she had exhausted all of her knowledge really on how to help me and it felt like it was her fault. Yea yea he obviously cares he does get quite passionate about it, and when I tell him about things that the gynaecologist has said and done he gets quite angry. And its nice that I've got somebody with the same views and on the same side as me that can help me so..
R: And that makes you feel less lonely?
J: Yea, yea, just to have somebody on my side that can help, literally can do something. And he's the one that's told me about several other different therapies that they didn't tell me about before because they were too expensive.
R: What are they?
J: They did , simple little things, this injection thing, apparently its really really expensive, um there's an anti-inflammatory I can't take normal anti-inflammatories because it irritates the stomach. So I was just on these poxy little pain killers for years and years and years, until my new doctor finally decided, um told me about these other ones that are about five times more expensive so he's given those to me now.

R: So its better pain management that you feel you've got. Its not that you've got a cure but that people are thinking about how to manage it with you?
J: Yea.
R: Right, that good, you've given me lots of information about what's been helpful and what's been not helpful. What about nurses, have any nurses been helpful or unhelpful?
J: Not really no, the only contact I've had with nurses is with the internal (J shuddered). I got to the stage when I had to have a smear every 3 months or something, and that was horrible.
R: And nurses usually did that?
J: Yea, occasionally my female GP did do it. The internals, the gynaecologist would do as well. (J shuddered again).
R: Okay, so you can't think really, of ways that nurses have been particularly helpful or unhelpful?
J: No apart from the one time that I went into hospital and had it lazered off. Um the nurses on the ward there were lovely. Everybody in the ward were there for pretty much the same thing, everybody was in the same boat and it was a really nice atmosphere there.
R: And how were they lovely, the nurses?
J: Just really understanding , and really caring and not quite as harsh as you can get from hospital when they tell you you're not in pain when you are.
R: And have you had that?
J: I have had that but not with pelvic pain.
R: Because you've had other..
J: I had a knee operation yes.
R: Okay so really the nursing has been quite helpful and gentle, but you haven't had a lot.
J: Yea there's only the one real instance
R: Right, and then, finally, acquaintances or strangers? Have any been helpful or unhelpful
J: Um , I don't really tend to talk about it until I know them, its not something that, 'I'm J I have endometriosis', not something that I really go into
R: So strangers haven't had an opportunity to be helpful or unhelpful?
J: No not really, no I only really tell them if I've known them a while, like my boss if I had time off or whatever, I told her
R: Right, and, how was that?
J: Fine really, she didn't say an awful lot, just asked what it was all about
R: So neutral again
J: Yea sort of in between
R: Not one way or the other? Okay well those are all the questions I want to ask you, is there anything that you think is important to add about support or lack of support that you've had.
J: Um I think the main problem area has, well I've learned how to handle my partner, once it came out why he's doing what he's doing, okay I understand that I'll calm down my end. Um, so I understand that now, its still difficult when he gets a bit angry but its really the professionals
R: So you've put that down to anxiety, you think
J: Yea, I think that's why my Dad distances himself because it's a very male thing to do, is to take on the problems of everybody and try and solve them and when they can't I feel that they panic, and when they panic then the initial reaction is to have a go at the person whose causing the panic.
R: So understanding that process has made it easier for you to cope with it.
J: But there are going to be loads of other women that don't, haven't twigged that yet. You know when it first started to happen, I was, 'God what have I done'. You've already got to cope with this yourself and then you feel like well I'm completely ruining my partners' life, he would be better off with other people. I mean if you've got a strong enough relationship then it will survive it, and if you can talk about it like that its fine. You know , luckily we have that. But it makes me think about other women who aren't as fortunate. It's the professionals really that make the difference. If you feel as if they're not helping you. I mean I can get really quite worked up after seeing Dr X, I can come home in tears because I really just. I wait 3 months for an appointment, I go up there, and 5 minutes I just feel like he's churning me through, you know, come on get them through, um don't feel like he's doing an awful lot. And that's what really makes a difference is, if professionals take you seriously and are genuinely concerned. You know you're not just somebody else moaning about pain. That's generally, with gynaecologists and consultants, not so much with GPs because I've known them so long.
R: So that's the biggest aggravation
J: Yes I would say so, it would probably help more if they did take more notice, I don't think there would be half the aggravation there is at home because we would at least feel like there was something that was being done. After 3 years, I'm not any, in fact my pain's worse.
R: So even if its managing it, not curing it, would that help?
J: Yea, anything just to make the pain a bit better. Even after I take the pain killers, I've taken pain killers this morning, it hurts a lot, but I mean if it could just reduce it to an amount when I can think right I can go for a swim

or check my dogs. I can do that without. I might be able to do that but its taking a risk, what if I get half way and then I can't go any further what do I do? Or have a proper relationship with my boyfriend, if it could just reduce it down to that then I could manage the rest myself. Because you do have to do a certain amount of self pain management don't you?
R: When you say a proper relationship, do you mean a sexual relationship?
J: Yea, yea, that would help an awful lot, because it does cause an awful lot of tension.
R: J thank you so much for agreeing to be interviewed and for being so open. The information you have given has been very helpful.
J: You're welcome.

APPENDIX 3

EXAMPLE OF FIRST STAGE OF THEMATIC ANALYSIS

Information point	**Page ref.**
Partner helps by getting me a hot water bottle	1.4
Partner helps by giving me a hug	1.4
There is little partner can do to help with the pain	1.5
Partner gets angry with me because he can't take the pain away	1.13
Partner can't cope when I'm in pain	1.14
I feel guilty that my pain distresses my partner	1.18
Partners frustration about pain causes arguments	1.24
I can't have sex when there is pain	1.28
I feel guilty about partner's sexual frustration	1.28
Sex plays a big part in relationships	1.29
Partners sexual frustration causes arguments	1.28
Sexual relationship is particularly important because we are young	1.36
Its unfair to tell partner to put up with sexual frustration long term	1.32
Mum is helpful because she cares	1.45
Dad doesn't show emotion but sometimes makes helpful suggestions	1.40
Dad and sometimes mum hinder by forcefully telling me what to do	1.50/55
Mum and Dad help and hinder at same time	1.54
Mum helps by listening and suggesting I try things	1.54
I don't talk to friends about pain	1.59
When out with friends I pretend pain doesn't exist	2.1
Sometimes pain stops me going out with friends	2.13
Friends have their own problems so I don't make a fuss about mine	2.20
Someone with IBS who was my age made me feel less weird because her experiences were similar to mine	2.27
I changed my GP because he was dismissive	2.35
A female GP was helpful because she seemed to care	2.41
Female GP was at a loss about what was causing pain	2.42
I changed doctor because female GP was at a loss	2.43
Unhelpful when doctors omitted information about expensive treatment options	2.44
Gynaecologist did not show genuine concern	2.48
I was handed round different doctors, no single doctor seemed to take responsibility for me	2.60
The problem didn't seem important to gynaecologists but it was very important to me	3.1
My gynaecologist shouldn't have made cure promises he couldn't keep	3.4
Gynaecologist shocked me by saying hysterectomy was only cure	3.6
It was intolerable to choose between my pain and my womb with little option of having children	3.10
I did not put all of my trust in gynaecologist's judgement	3.20
My partner and family helped me to get more information about the problem	3.22
Information reduced my vulnerability in doctors surgery	3.28
It eventually paid off to be assertive with doctors	3.31
Doctors gave insufficient information about treatment options	3.35
My womb is part of my identity	3.36
I'm angry that doctors threatened to remove my womb when I was so young	3.37
I've got a new doctor because the other ran out of treatment options	3.41
Hardly any treatments have helped	3.42
I don't agree with fact that the only treatment is strong pain killers now	3.42
New doctor is fantastic because he is demonstrative and obviously cares	3.48
My problem exhausted the knowledge of last GP	3.48
New doctor helps by offering all the treatment options	3.54
It was horrible having so many internal examinations	4.6
Nurses in hospital were caring and understanding	4.16
I don't tell people I don't know about the problem	4.26
I can manage my partner now because I understand his anxiety is based on anxiety	4.36
Men tend to try to solve problems when they can't they panic and then blame the person	4.41

causing the panic	
Our relationship has survived because it is strong and we talk	4.47
I worried that I was ruining my partners life and he would be better with someone else	4.46
It's the professionals that make a difference to the problem	4.48
I came home in tears after seeing the gynaecologist	4.50
Gynaecologists didn't take me seriously or care about me	4.52
I want anything that will reduce the pain	5.1
I want to be able to go swimming or walk the dogs again	5.2
I want a normal sexual relationship	5.4
I could manage other aspects of the pain myself	5.5

APPENDIX 4

EXAMPLE OF SECOND STAGE OF THEMATIC ANALYSIS

Information point	**Page ref.**
Helpful from partner	
Instrumental support	
Partner helps by getting me a hot water bottle	1.4
Emotional support	
Partner helps by giving me a hug	1.4
Informational support	
My partner helped me to get more information about the problem	3.22
Not helpful from partner	
Instrumental support	
There is little partner can do to help with the pain	1.5
Partner gets angry with me because he can't take the pain away	1.13
Partner can't cope when I'm in pain	1.14
Partners frustration about pain causes arguments	1.24
Thoughts about relationship	
I feel guilty that my pain distresses my partner	1.18
I can't have sex when there is pain	1.28
I feel guilty about partner's sexual frustration	1.28
Sex plays a big part in relationships	1.29
Partners sexual frustration causes arguments	1.28
Sexual relationship is particularly important because we are young	1.36
Its unfair to tell partner to put up with sexual frustration long term	1.32
I can manage my partner now because I understand his anxiety is based on anxiety	4.36
Men tend to try to solve problems when they can't they panic and then blame the person causing the panic	4.41
Our relationship has survived because it is strong and we talk	4.47
I worried that I was ruining my partners life and he would be better with someone else	4.46
Helpful from family members	
Emotional support	
Mum is helpful because she cares	1.45
Mum helps by listening and suggesting I try things	1.54
Informational support	
Dad doesn't show emotion but sometimes makes helpful suggestions	1.40
My family helped me to get more information about the problem	3.22
Unhelpful from family members	
Dad and sometimes mum hinder by forcefully telling me what to do	1.50/55
Ambivalent support	
Mum and Dad help and hinder at same time	1.54
Unhelpful from friends	
I don't talk to friends about pain	1.59
When out with friends I pretend pain doesn't exist	2.1
Sometimes pain stops me going out with friends	2.13
Friends have their own problems so I don't make a fuss about mine	2.20
Helpful from similar others	
Someone with IBS who was my age made me feel less weird because her experiences were similar to mine	2.27
Unhelpful from doctors	
Dismissive patronising	
I changed my GP because he was dismissive	2.35
The problem didn't seem important to gynaecologists but it was very important to me	3.1
Insufficient emotional support/understanding	
Gynaecologist did not show genuine concern	2.48
Gynaecologist shocked me by saying hysterectomy was only cure	3.6
It was intolerable to choose between my pain and my womb with little option of having children	3.10

My womb is part of my identity	3.36
I'm angry that doctors threatened to remove my womb when I was so young	3.37
I came home in tears after seeing the gynaecologist	4.50
Gynaecologists didn't take me seriously or care about me	4.52
Didn't know what to do	
Female GP was at a loss about what was causing pain	2.42
My problem exhausted the knowledge of last GP	3.48
Inadequate information giving	
Unhelpful when doctors omitted information about expensive treatment options	2.44
Doctors gave insufficient information about treatment options	3.35
Multiple doctors/ lack of continuity	
I was handed round different doctors, no single doctor seemed to take responsibility for me	2.60
Unreliable	
My gynaecologist shouldn't have made cure promises he couldn't keep	3.4
I did not put all of my trust in gynaecologist's judgement	3.20
Ineffective treatment	
Hardly any treatments have helped	3.42
I don't agree with fact that the only treatment is strong pain killers now	3.42
Helpful from doctors	
Emotional support	
A female GP was helpful because she seemed to care	2.41
New doctor is fantastic because he is demonstrative and obviously cares	3.48
Provides wider information and treatment options	
New doctor helps by offering all the treatment options	3.54
Helpful from nurses	
Emotional support	
Nurses in hospital were caring and understanding	4.16
Unhelpful from nurses	
It was horrible having so many internal examinations	4.6
Strangers	
I don't tell people I don't know about the problem	4.26

APPENDIX 5

EXAMPLE OF THIRD STAGE OF THEMATIC ANALYSIS

Information point	**Page ref.**
Instrumental support	
Partner helps by getting me a hot water bottle	1.4
There is little partner can do to help with the pain	1.5
Emotional support	
Caring	
Partner helps by giving me a hug	1.4
Mum is helpful because she cares	1.45
A female GP was helpful because she seemed to care	2.41
New doctor is fantastic because he is demonstrative and obviously cares	3.48
Gynaecologist did not show genuine concern	2.48
Gynaecologists didn't take me seriously or care about me	4.52
Nurses in hospital were caring and understanding	4.16
Listening	
Mum helps by listening and suggesting I try things	1.54
Shared experience	
Someone with IBS who was my age made me feel less weird because her experiences were similar to mine	2.27
Informational support	
Dad doesn't show emotion but sometimes makes helpful suggestions	1.40
Unhelpful when doctors omitted information about expensive treatment options	2.44
My partner and family helped me to get more information about the problem	3.22
Information reduced my vulnerability in doctors surgery	3.28
Doctors gave insufficient information about treatment options	3.35
Mum helps by listening and suggesting I try things	1.54
Taking over	
Dad and sometimes mum hinder by forcefully telling me what to do	1.50/55
Simultaneous help and hindrance	
Mum and Dad help and hinder at same time	1.54
Frustration/ feeling unable to help	
Partner gets angry with me because he can't take the pain away	1.13
Partner can't cope when I'm in pain	1.14
Female GP was at a loss about what was causing pain	2.42
I changed doctor because female GP was at a loss	2.43
Conflict	
Partners frustration about pain causes arguments	1.24
Partners sexual frustration causes arguments	1.28
Guilt	
I feel guilty that my pain distresses my partner	1.18
I feel guilty about partner's sexual frustration	1.28
I worried that I was ruining my partners life and he would be better with someone else	4.46
Impact of pain/disruption	
Sex	
I can't have sex when there is pain	1.28
I feel guilty about partner's sexual frustration	1.28
Sex plays a big part in relationships	1.29
Partners sexual frustration causes arguments	1.28
Sexual relationship is particularly important because we are young	1.36
Its unfair to tell partner to put up with sexual frustration long term	1.32
Restrictions	
Sometimes pain stops me going out with friends	2.13
I want anything that will reduce the pain	5.1
I want to be able to go swimming or walk the dogs again	5.2
I want a normal sexual relationship	5.4
Coping strategies	

It eventually paid off to be assertive with doctors	3.31
Information reduced my vulnerability in doctors surgery	3.28
You have to do a certain amount of self pain management	5.5
Our relationship has survived because it is strong and we talk	4.47
Reframing/constructs	
I can manage my partner now because I understand his anger is based on anxiety	4.36
Men tend to try to solve problems when they can't they panic and then blame the person causing the panic	4.41
Powerful others	
It's the professionals that make a difference to the problem	4.48
Goals/ desires	
I want anything that will reduce the pain	5.1
I want to be able to go swimming or walk the dogs again	5.2
I want a normal sexual relationship	5.4
Putting on front/pretending/not burdening/keeping private	
I don't talk to friends about pain	1.59
When out with friends I pretend pain doesn't exist	2.1
Friends have their own problems so I don't make a fuss about mine	2.20
I don't tell people I don't know about the problem	4.26
Multiple doctors/wearing doctors out	
I changed doctor because female GP was at a loss	2.43
I was handed round different doctors, no single doctor seemed to take responsibility for me	2.60
I've got a new doctor because the other ran out of treatment options	3.41
My problem exhausted the knowledge of last GP	3.48
Level of treatment satisfaction/impact of treatment	
Gynaecologist shocked me by saying hysterectomy was only cure	3.6
It was intolerable to choose between my pain and my womb with little option of having children	3.10
My womb is part of my identity	3.36
I'm angry that doctors threatened to remove my womb when I was so young	3.37
My gynaecologist shouldn't have made cure promises he couldn't keep	3.4
I did not put all of my trust in gynaecologist's judgement	3.20
I came home in tears after seeing the gynaecologist	4.50
Hardly any treatments have helped	3.42
I don't agree with fact that the only treatment is strong pain killers now	3.42
It was horrible having so many internal examinations	4.6
New doctor helps by offering all the treatment options	3.54
Being patronised/not taken seriously	
I changed my GP because he was dismissive	2.35
The problem didn't seem important to gynaecologists but it was very important to me	3.1
Gynaecologists didn't take me seriously or care about me	4.52

APPENDIX 6

MASTER LIST OF THEMES, EXAMPLE PAGE

Theme	Alice	Jackie	Daphne	Marilyn	Sheila	Amy	Deirdre	Anthea
Helpful from a partner								
Tangible support	1.7	1.4	1.12	1.8	1.32, 4.53			
-child care	-	-	1.12					
-relieving of duties	-	-	1.12		1.12			
Emotional support	1.5, 1.10	1.4	1.4,1.38		1.46			
Reassurance					1.4, 1.6			
Sensitivity	-	-	-	-	1.32			
Solution focused/informational support		3.22						
Unhelpful from partner								
Lack of attentiveness	1.13			1.17	1.39	1.9/16		
Anger/frustration		1.13						
Rows/arguments		1.24						
Feeling helpless/anxious in face of pain		1.5, 1.14						
Weakness								2.9
Anxiety translates to anger		4.41, 4.36						
Disbelief/denial of my pain	-	-	1.10,1.24, 1.34			1.4,1.6		2.24
Lack of understanding	-	-	1.38					2.26, 2.29
Misconstruing pain as laziness			1.10/1.20					
Vested interest in pain/self interest						4.62		
Problems of his own								2.45
Relationship with partner difficulties								
My lack of communication about problem	1.20	-	1.29					1.33, 2.8
He, worn down by chronicity of problem	1.20	-	-		1.61			
My guilt about impact of pain on him		1.18, 4.46	-		1.19			
Impact of sexual problems	-	1.28, 1.36, 1.32	-		1.7, 1.26, 3.19			
My irritability/over criticalness	-	-	-	1.19	1.21			
My over-sensitivity	-	-	-		1.36,1.18			
Lack of equity								2.43
Helpful from family members								
Tangible support	1.30							3.32
-relieves, helps with my duties/chores	-	-	-	1.29, 1.32		4.43		3.13, 3.20
-child care						1.30, 1.36		2.56
Emotional support		1.45, 1.54	1.46, 2.15,1.49,	1.42, 1.50	2.10			1.44, 2.61
-regular contact					2.8			

APPENDIX 7

COPIES OF ALL MEASURES USED

THE WEST HAVEN-YALE MULTIDIMENSIONAL PAIN INVENTORY (WHYMPI)

SECTION 1

In the following 20 questions, you will be asked to describe your pain and how it affects your life. Under each question is a scale to record your answer. Read each question carefully and then circle a number on the scale under that question to indicate how that specific question applies to you.

1. Rate the level of your pain at the present moment.

0 1 2 3 4 5 6
No pain Very intense pain

2. In general, how much does your pain problem interfere with your day to day activities?

0 1 2 3 4 5 6
No interference Extreme interference

3. Since the time you developed a pain problem, how much has your pain changed your ability to work?

0 1 2 3 4 5 6
No change Extreme change

__ Check here, if you have retired for reasons other than your pain problem.

4. How much has your pain changed the amount of satisfaction or enjoyment you get from participating in social and recreational activities?

0 1 2 3 4 5 6
No change Extreme change

5. How supportive or helpful is your spouse (significant other) to you in relation to your pain?

0 1 2 3 4 5 6
Not at all supportive Extremely supportive

6. Rate your overall mood during the past week.

0 1 2 3 4 5 6
Extremely low mood Extremely high mood

7. On the average, how severe has your pain been during the last week?

0 1 2 3 4 5 6
Not at all severe Extremelv severe

8. How much has your pain changed your ability to participate in recreational and other social activities?

0 1 2 3 4 5 6
No change — Extreme change

9. How much has your pain changed the amount of satisfaction you get from family-related activities?

0 1 2 3 4 5 6
No change — Extreme change

10. How worried is your spouse (significant other) about you in relation to your pain problem?

0 1 2 3 4 5 6
Not at all worried — Extremely worried

11. During the past week how much control do you feel that you have had over your life?

0 1 2 3 4 5 6
Not at all in control — Extremely in control

12. How much suffering do you experience because of your pain?

0 1 2 3 4 5 6
No suffering — Extreme suffering

13. How much has your pain changed your marriage and other family relationships?

0 1 2 3 4 5 6
No change — Extreme change

14. How much has your pain changed the amount of satisfaction or enjoyment you get from work?

0 1 2 3 4 5 6
No change — Extreme change

__ Check here, if you are not presently working.

15. How attentive is your spouse (significant other) to your pain problem?

0 1 2 3 4 5 6
Not at all attentive — Extremely attentive

16. During the past week how much do you feel that you've been able to deal with your problems?

0 1 2 3 4 5 6
Not at all — Extremely well

17. How much has your pain changed your ability to do household chores?

0 1 2 3 4 5 6
No change — Extreme change

18. During the past week how irritable have you been?

0 1 2 3 4 5 6
Not at all irritable — Extremely irritable

19. How much has your pain changed your friendships with people other than your family?

0 1 2 3 4 5 6
No change — Extreme change

20. During the past week how tense or anxious have you been?

0 1 2 3 4 5 6
Not at all tense or anxious — Extremely tense or anxious

SECTION 2

In this section, we are interested in knowing how your spouse (or significant other) responds to you when he or she knows that you are in pain. On the scale listed below each question, circle a number to indicate how often your spouse (or significant other) generally responds to you in that particular way when you are in pain. Please answer all of the 14 questions. Please identify the relationship between you and the person you are thinking of.____.

1. Ignores me.

0 1 2 3 4 5 6
Never — Very often

2. Asks me what he/she can do to help.

0 1 2 3 4 5 6
Never — Very often

3. Reads to me.

0 1 2 3 4 5 6
Never — Very often

4. Expresses irritation at me.

0 1 2 3 4 5 6
Never — Very often

5. Takes over my jobs or duties.

0 1 2 3 4 5 6
Never — Very often

6. Talks to me about something else to take my mind off the pain.

0 1 2 3 4 5 6
Never Very often

7. Expresses frustration at me.

0 1 2 3 4 5 6
Never Very often

8. Tries to get me to rest.

0 1 2 3 4 5 6
Never Very often

9. Tries to involve me in some activity.

0 1 2 3 4 5 6
Never Very often

10. Expresses anger at me.

0 1 2 3 4 5 6
Never Very often

11. Gets me some pain medications.

0 1 2 3 4 5 6
Never Very often

12. Encourages me to work on a hobby.

0 1 2 3 4 5 6
Never Very often

13. Gets me something to eat or drink.

0 1 2 3 4 5 6
Never Very often

14. Turns on the T.V. to take my mind off my pain.

0 1 2 3 4 5 6
Never Very often

Name or code:.. *Answer date:*..

BARRETT-LENNARD **RELATIONSHIP INVENTORY**: Form **OS–40** (ver. 2)

Below are listed a variety of ways that one person may feel or behave in relation to another person.

Please consider each statement with reference to your present relationship with ________, mentally adding his or her name in the space provided. If, for example, the other person's name was John, you would read the first statement as "John respects me".

Mark each statement in the left margin, according to how strongly you feel that it is true, or not true, in this relationship. Please be sure to mark every one. *Write in a minus number (-3, -2, or -1) when your answer is on the 'no' side', and a plus number (+1, +2, or +3) when your answer is a grade of 'yes'.* Here is the exact meaning of each answer number:–

-3: NO, *I strongly feel that it is* not true.

-2: No, *I feel it is not true.*

-1. (No) *I feel that it is probably untrue, or more untrue than true.*

+1: (Yes) *I feel that it is probably true, or more true than untrue.*

+2: Yes, *I feel it is true.*

+3. YES, *I strongly feel that it* is true.

OS-64

______ 1. ________ respects me. (1

______ 2. ________ usually senses or realizes what I am feeling. (18

______ 3. ________'s interest in me depends on my words and actions (or how I perform). (3

______ 4. I feel that ________ puts on a role or front with me. (8

______ 5. ________ feels a true liking for me. (5

______ 6. ________ reacts to my words but does not see the way I feel. (6

______ 7. Whether I am feeling happy or unhappy with myself makes no real difference to the way ________ feels about me. (7

______ 8. ________ doesn't avoid anything that's important for our relationship. (28

______ 9. ________ is indifferent to me. (17

______ 10. ________ nearly always sees exactly what I mean. (10

______ 11. Depending on my behavior, ________ has a better (or worse) opinion of *me* sometimes than at other times. (11

______ 12. I feel that ________ is genuine with me. (12

______ 13. I feel valued and appreciated by ________. (13&41

______ 14. ________'s own attitude toward things I do or say gets in the way of understanding me. (22

______ 15. No matter what I say about myself, ______ likes (or dislikes) me just the same. (39

______ 16. ________ keeps quiet about his/her real inner impressions and feelings. (-36

______ 17. ________ finds me rather dull and uninteresting. (21

______ 18. ________ realizes what I mean even when I have difficulty in saying it. (30

______ 19. ________ wants me to be a particular kind of person. (19

______ 20. ________ is willing to say whatever is on his/her mind with me, including feelings about either of us or how we are getting along. (44

(Continues... Page 2)

Relationship Inventory—Form **OS–40** (v. 2) *Page 2*

Please continue to write in your answer to every statement, in the left margin. Here, again, are the meanings of each answer number:--

-3: NO, *I strongly feel that it is* not true.
-2: No, *I feel it is not true.*
-1. (No) *I feel that it is probably untrue, or more untrue than true.*
+1: (Yes) *I feel that it is probably true, or more true than untrue.*
+2: Yes, *I feel it is true.*
+3. YES, *I strongly feel that it* is true.

______ 21. ________ cares for me. (25

______ 22. ________ doesn't listen and pick up on what I think and feel. (38

______ 23. ________ likes certain things about me, and there are other things he/she does not like in me. (27

______ 24. ________ is openly himself (herself) in our relationship. (48

______ 25. I feel that ________ disapproves of me. (29

______ 26. ________ usually understands the whole of what I mean. (34

______ 27. Whether thoughts I express are 'good' or 'bad' makes no difference to ________'s feeling toward me. (51

______ 28. Sometimes ________ is not at all comfortable but we go on, outwardly ignoring it. (32

______ 29. ________ is friendly and warm toward me. (37

______ 30. ________ does not understand me. (-54

______ 31. ________ approves of some things about me (or some of my ways), and plainly disapproves of other things (or ways I express myself). (43

______ 32. I think ________ always knows exactly what s/he feels with me: s/he doesn't cover up inside. (56

______ 33. ________ just tolerates me. (33

______ 34. ________ appreciates exactly how the things I experience feel to me. (42

______ 35. Sometimes I am more worthwhile in ________'s eyes than I am at other times. (55

______ 36. At moments I feel that ________'s outward response to me is quite different from the way s/he feels underneath. (52

______ 37. ________ feels affection for me. (61

______ 38. ________'s response to me is so fixed and automatic that I don't get through to him/her. (58

______ 39. I don't think that anything I say or do really changes the way ________ feels toward me. (59

______ 40. I believe that ________ has feelings s/he does not tell me about that affect our relationship. (64

Have you answered every item? Please double check and make sure there are no gaps.

Please note the other person's relation to you, e.g., a personal friend, spouse or partner, mother or other family member, teacher or supervisor, counselor, etc...

HAD Scale

Name:

Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.
This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':
- Most of the time ☐
- A lot of the time ☐
- Time to time, Occasionally ☐
- Not at all ☐

[redacted]

I still enjoy the things I used to enjoy:
- Definitely as much ☐
- Not quite so much ☐
- Only a little ☐
- Hardly at all ☐

[redacted]

I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

[redacted]

I can laugh and see the funny side of things:
- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

[redacted]

Worrying thoughts go through my mind:
- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

[redacted]

I feel cheerful:
- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

[redacted]

I can sit at ease and feel relaxed:
- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

[redacted]

I feel as if I am slowed down:
- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

[redacted]

I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

[redacted]

I have lost interest in my appearance:
- Definitely ☐
- I don't take so much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

[redacted]

I feel restless as if I have to be on the move:
- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

[redacted]

I look forward with enjoyment to things:
- As much as ever I did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

[redacted]

I get sudden feelings of panic:
- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

[redacted]

I can enjoy a good book or radio or TV programme:
- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

[redacted]

Do not write below this line

APPENDIX 8

EVIDENCE OF RESEARCH ETHICS COMMITTEE APPROVAL

University Hospitals of Leicester NHS
NHS Trust

DIRECTORATE OF RESEARCH AND DEVELOPMENT

Leicester General Hospital
Gwendolen Road
Leicester
LE5 4PW

Tel: 0116 2490490
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24 April 2001

Mrs Ruth Warwick
Trainee Clinical Psychologist
London Road
Fairford
Gloucester
GL7 4AR

Dear Mrs Warwick

RE: Project Number: 6960 *[Please quote this number in all correspondence]*
Social support for women with chronic pelvic pain: What is helpful and from whom?

Thank you for the patient information sheet for the above study that was amended in response to the Leicestershire Research Ethics Committee's comments. We confirm that a copy of this has been forwarded to the Committee for their information.

Since all other aspects of your UHL R+D notification are complete, I now have pleasure in confirming full approval of the project on behalf of University Hospitals of Leicester NHS Trust.

This approval means that you are fully authorised to proceed with the project, using all the resources which you have declared in your notification form.

The project is also now covered by Trust Indemnity, except for those aspects already covered by external indemnity (e.g. ABPI in the case of most drug studies).

We will be requesting annual and final reports on the progress of this project, both on behalf of the Trust and on behalf of the Ethical Committee.

In the meantime, in order to keep our records up to date, could you please notify the Research Office if there are any significant changes to the start or end dates, protocol, funding or costs of the project.

I look forward to the opportunity of reading the published results of your study in due course.

Yours sincerely

Dr Nichola Seare PhD
<u>Research and Development Business Manager</u>

APPENDIX 9

LETTER OF INVITATION

Gloucestershire Royal NHS
NHS Trust

Gloucestershire Royal Hospital
Great Western Road
Gloucester
GL1 3NN

Tel: 01452 528555

LETTER OF INVITATION

Social support for women with chronic pelvic pain: What is helpful and from whom?

I wonder if you would be prepared to assist in a study that is being conducted into women with long-term pelvic pain.

Participation will involve you being asked to fill out a questionnaire. You may also be asked for an interview at a time and place convenient to yourself. The information sheet with this letter will explain more about the study. If you would like to discuss the study in more detail you can contact the Principal Investigator, Ms Ruth Warwick, on the number at the bottom of the information sheet.

Any information you provide will be strictly confidential and anonymous and will be used for research purposes only. If you do not wish to take part in the study you may do so without justifying your decision.

I hope that you will feel able to participate.

APPENDIX 10

RESEARCH INFORMATION FOR PARTICIPANTS

Gloucestershire Royal NHS
NHS Trust

Gloucestershire Royal Hospital
Great Western Road
Gloucester
GL1 3NN

Tel: 01452 528555

PATIENT INFORMATION SHEET

Social support for women with chronic pelvic pain: What is helpful and from whom?

1. **What is the purpose of this study?**

Research has shown that social support can be helpful to people who suffer with long-term pain. However, little is known about what forms of social support are helpful to women with long-term pelvic pain. We would therefore like to ask women with this type of pain problem how helpful or unhelpful the efforts of partners, family members, friends, nurses and doctors have seemed to them. This information about social support will improve knowledge about how best to support women like you who are faced with this distressing pain problem.

2. **What will be involved if I take part in the study?**

You will be asked to fill in a questionnaire about the pain, how you are feeling emotionally, your views about your relationship with your partner and about the social support available to you. This should take 30-40 minutes of your time. You may also be asked for an interview by a female researcher in your home or at hospital whichever is most convenient to you. If you agree, this interview will last for approximately an hour.

3. **Will information in the study be confidential?**

All information provided by you will be confidential and will be used for research purposes only. Data will be made anonymous and protected under the guidelines of the Data Protection Act (1998).

4. **What if I am harmed by the study?**

This study aims to get your views and opinions, it is not designed in any way to interfere with your physical or psychological well being or medical care. However, if you find yourself troubled by any aspect of the project you will be given the name of the principal investigator to contact so you can discuss it with her.

5. **What happens at the end of the study?**

After taking part in the study, or if you decide not to take part, the researcher will not contact you again. If you would like information about the findings of the study, please ask the researcher.

6. **What happens if I do not wish to take part in the study or wish to withdraw from the study?**

If you do not wish to take part in this study, or if you wish to withdraw from the study, you may do so at any point and your future treatment will not be affected.

CONTACT NAMES AND NUMBERS

APPENDIX 11

LETTER OF CONSENT

Centre Number:
Study Number:
Patient Information Number:

PATIENT CONSENT FORM

Social support for women with chronic pelvic pain: What is helpful and from whom?

Principal Investigator: Ms. Ruth Warwick

Please initial box

1. I confirm that I have read and understand the Patient Information Sheet ☐
2. I understand that my participation is voluntary and I can withdraw at any time without my medical care or legal rights being affected ☐
3. I will allow the audiotape recording of my interview provided that the recording will be kept confidential, will be used solely for this study and will be destroyed at the end of the study ☐
4. I agree to take part in the above study ☐

....	....	....
Name of participant	Date	Signature
....	....	....
Name of person taking consent if different from researcher	Date	Signature
....	....	....
Researcher	Date	Signature

1 copy for patient; 1 copy for researcher; 1 copy to be kept with hospital notes

APPENDIX 12

COPY OF QUESTIONNAIRE

Social Support
For Women With Chronic Pelvic Pain

CONFIDENTIAL QUESTIONNAIRE

Please would you help with this study by filling out this questionnaire. The information you give will help to improve knowledge about how best to support women who are faced with the problem of long-term pelvic pain. All your answers will remain entirely confidential.

The questionnaire is divided into 6 sections. There are questions about your pain and how you are feeling emotionally. There are also questions to get your views about your relationship with your partner and about the social support available to you. We ask for quite a lot of information so that we can get a detailed picture of your views and experiences.

The questionnaire will take 30-40 minutes to complete. We hope you will find it interesting and easy to fill in. However, if there is anything you are not sure about please don't hesitate to contact Ruth Warwick (the principal investigator) on 07773 389369, or Christine Cordle (local supervisor) on 0116 258 4958

YOUR CONSENT

I confirm that I have read and understand the patient information sheet for this study. I agree to complete this questionnaire and I give permission for this information to be used solely for this study and in an anonymous form.

Signature……………………………………………………………………………………

Name in BLOCK LETTERS……………………………………………………………………

We would also like the opportunity to talk to you face to face. Please fill in your details below if you would be happy for us to contact you to ask you for an interview.

Address:……………………………………………………………………

……………………………………………………………………………

Telephone Number:…………………………………………………………

Preferred time for receiving calls:…………………………………………

Please turn over →

ABOUT YOURSELF

1. Please state today's date: ………./…………/……….
Day Month Year

2. Please state your date of birth: ………/………/……….
Day Month Year

3. Please state your **present** marital status: *(please tick one box)*

Single and living with a partner		Single, not living with a partner		Married	
Divorced/separated		Widowed		Other	

4. How many children have you given birth to? ……….children
(Write 0 if you have never given birth)

5. What is your **current** employment status? *(please tick one box)*

Working full-time (30 hours or more per week)		Working part-time (less than 30 hours per week)	
Caring for home or family (not seeking paid work)		Unemployed and looking for work	
Unable to look for work due to illness or disability		Student	
Other			

6. What is **your** present or most recent occupation?

…………………………………………………………………………………………
(Please write name of job)

7. What is your **partner's** present or most recent occupation?

…………………………………………………………………………………………
(Please write name of job. If you do not have a partner continue with the next question.)

8. How would you describe your ethnic origin? *(Please tick one box)*

Bangladeshi		Indian		Pakistani	
Other Asian		Black African		Black Caribbean	
Black Other		White		Chinese	
Mixed Race		Other			

PELVIC PAIN

In this section we ask you about your diagnosis and treatment. By 'pelvic pain' we mean any type of pain (cramping, shooting, stabbing etc) in the lower part of your belly (the area from your navel down).

1. In which year did you first experience pelvic pain? ....

2. In the last 12 months, have you had: *(please tick No or Yes to each question)*

	No	Yes
pelvic pain with your periods?	☐	☐
pelvic pain during or in the 24 hours after sexual intercourse?	☐	☐
pelvic pain which is there all the time or just sometimes but which isn't related to your periods or sexual intercourse?	☐	☐

3. Has a doctor given you any of the following reasons for your pain? *(Please tick one or more of the following options)*

Endometriosis	☐	Pelvic infection	☐	Adhesions	☐
Uterine fibroids	☐	Ovarian cysts	☐	Uterine/vaginal prolapse	☐
Pelvic congestion	☐	Cystitis	☐	Stress	☐
Appendicitis	☐	Constipation	☐	Irritable bowel syndrome	☐
Back pain/problems	☐	Bowel disease	☐	Can't remember	☐
No reason given	☐	Other reason	☐		

4. What tests have you had for your pain? *(Please tick one or more of the following options)*

Surgery in which a camera was inserted into your belly button (laparoscopy)	☐	Insertion of a camera to look inside your back passage (colonoscopy)	☐
An ultrasound scan	☐	An x-ray	☐
Other	☐	No tests	☐
Don't remember	☐		

5. At what stage of treatment are you? (*Please tick one of the following options)*

Currently having treatment	☐	have had no treatment yet	☐	not having treatment at the moment	☐

6. Have you had tablets or medicines for the problem? (*Please tick one of the following options)*

In the last 12 months?	☐	More than a year ago?	☐

7. Have you had surgery for the problem? (*Please tick one of the following options)*

In the last 12 months?	☐	More than a year ago?	☐	Surgery is planned	☐

8. In the last 12 months, have you suffered any serious or long-standing illnesses or disabilities apart from pelvic pain? *(If so please describe)*

YOUR PAIN AND HOW IT AFFECTS YOU

In this section we ask about how your pain affects your life. Beside each question is a scale to record your answer. Please read each question carefully and then circle a number on the scale beside that question to indicate how that specific question applies to you.

1. Rate the level of your pain at the present moment.	0 No pain	1	2	3	4	5	6 Very intense pain
2. In general, how much does your pain problem interfere with your day to day activities?	0 No interference	1	2	3	4	5	6 Extreme interference
3. Since the time you developed a pain problem, how much has your pain changed your ability to work?	0 No change	1	2	3	4	5	6 Extreme change
4. How much has your pain changed the amount of satisfaction or enjoyment you get from participating in social and recreational activities?	0 No change	1	2	3	4	5	6 Extreme change
5. How supportive or helpful is your partner? (Miss this question if you do not have a partner)	0 Not at all supportive	1	2	3	4	5	6 Extremely supportive
6. Rate your overall mood during the <u>past week</u>.	0 Extremely low mood	1	2	3	4	5	6 Extremely high mood
7. On the average, how severe has your pain been during the <u>last week</u>?	0 Not at all severe	1	2	3	4	5	6 Extremely severe
8. How much has your pain changed your ability to participate in recreational and other social activities?	0 No change	1	2	3	4	5	6 Extreme change
9. How much has your pain changed the amount of satisfaction you get from family-related activities?	0 No change	1	2	3	4	5	6 Extreme change
10. How worried is your partner about you in relation to your pain problem? (Miss this question if you do not have a partner)	0 Not at all worried	1	2	3	4	5	6 Extremely worried
11. During the <u>past week</u> how much control do you feel that you have had over your life?	0 Not at all in control	1	2	3	4	5	6 Extremely in control
12. How much <u>suffering</u> do you experience because of your pain?	0 No suffering	1	2	3	4	5	6 Extreme suffering
13. How much has your pain changed your main relationship and other family relationships? (Miss this question if you do not have a partner)	0 No change	1	2	3	4	5	6 Extreme change
14. How much has your pain changed the amount of satisfaction or enjoyment you get from work?	0 No change	1	2	3	4	5	6 Extreme change
15. How attentive is your partner to your pain problem? (Miss this question if you do not have a partner)	0 Not at all attentive	1	2	3	4	5	6 Extremely attentive

16. During the past week how much do you feel that you've been able to deal with your problems?	0	1	2	3	4	5	6
	Not at all						Extremely well
17. How much has your pain changed your ability to do household chores?	0	1	2	3	4	5	6
	No change						Extreme change
18. During the past week how irritable have you been?	0	1	2	3	4	5	6
	Not at all irritable						Extremely irritable
19. How much has your pain changed your friendships with people other than your family?	0	1	2	3	4	5	6
	No change						Extreme change
20. During the past week how tense and anxious have you been?	0	1	2	3	4	5	6
	Not at all tense or anxious						Extremely tense or anxious

YOUR MAIN RELATIONSHIP

Please miss this section if you do not have a partner at present. We are interested in knowing how your partner (or significant other) responds to you when he knows that you are in pain. If your partner is female please substitute 'she' for 'he'. We are also interested in your views about your relationship with your partner. On the scale listed beside each question, circle a number to indicate how often your partner generally responds to you in that particular way when you are in pain.

	Never						Very often
1. Ignores me.	0	1	2	3	4	5	6
2. Asks me what he can do to help.	0	1	2	3	4	5	6
3. Reads to me.	0	1	2	3	4	5	6
4. Expresses irritation at me.	0	1	2	3	4	5	6
5. Takes over my jobs and duties	0	1	2	3	4	5	6
6. Talks to me about something else to take my mind off the pain.	0	1	2	3	4	5	6
7. Expresses frustration at me.	0	1	2	3	4	5	6
8. Tries to get me to rest.	0	1	2	3	4	5	6
9. Tries to involve me in some activity.	0	1	2	3	4	5	6
10. Expresses anger at me.	0	1	2	3	4	5	6
11. Gets me some pain medications	0	1	2	3	4	5	6
12. Encourages me to work on a hobby.	0	1	2	3	4	5	6
13. Gets me something to eat or drink.	0	1	2	3	4	5	6
14. Turns on the T.V. to take my mind off my pain.	0	1	2	3	4	5	6

On the scale listed beside each statement, circle a number to indicate how much you feel each statement is true about your partner.

No, I strongly feel it is not true	No, I feel it is not true	No, I feel it is probably untrue	Yes, I feel that it is probably true	Yes, I feel it is true	Yes, I strongly feel it is true
1	**2**	**3**	**4**	**5**	**6**

1. He respects me.	1	2	3	4	5	6
2. He usually senses or realises what I am feeling.	1	2	3	4	5	6
3. His interest in me depends on my words and actions (or how I perform).	1	2	3	4	5	6
4. I feel that he puts on a role or front with me.	1	2	3	4	5	6
5. He feels a true liking for me.	1	2	3	4	5	6
6. He reacts to my words but doesn't see the way I feel.	1	2	3	4	5	6
7. Whether I am feeling happy or unhappy with myself makes no real difference to the way he feels about me.	1	2	3	4	5	6
8. He doesn't avoid anything that's important for our relationship.	1	2	3	4	5	6
9. He is indifferent to me.	1	2	3	4	5	6
10. He nearly always sees exactly what I mean.	1	2	3	4	5	6
11. Depending on my behaviour, he has a better (or worse) opinion of me sometimes than at other times.	1	2	3	4	5	6
12. I feel that he is genuine with me	1	2	3	4	5	6
13. I feel valued and appreciated by him.	1	2	3	4	5	6
14. His own attitude toward things I do or say gets in the way of understanding me.	1	2	3	4	5	6
15. No matter what I say about myself, he likes (or dislikes) me just the same.	1	2	3	4	5	6
16. He keeps quiet about his real inner impressions and feelings.	1	2	3	4	5	6
17. He finds me rather dull and uninteresting.	1	2	3	4	5	6
18. He realises what I mean even when I have difficulty in saying it.	1	2	3	4	5	6
19. He wants me to be a particular kind of person.	1	2	3	4	5	6
20. He is willing to say whatever is on his mind with me, including feelings about either of us or how we are getting along.	1	2	3	4	5	6
21. He cares for me.	1	2	3	4	5	6
22. He doesn't listen or pick up on what I think and feel.	1	2	3	4	5	6

No, I strongly feel it is not true	No, I feel it is not true	No, I feel it is probably untrue	Yes, I feel that it is probably true	Yes, I feel it is true	Yes, I strongly feel it is true
1	2	3	4	5	6

23. He likes certain things about me, and there are other things he does not like in me.	1	2	3	4	5	6
24. He is openly himself in our relationship.	1	2	3	4	5	6
25. I feel that he disapproves of me.	1	2	3	4	5	6
26. He usually understands the whole of what I mean.	1	2	3	4	5	6
27. Whether thoughts I express are good or bad makes no difference to his feeling towards me.	1	2	3	4	5	6
28. Sometimes he is not at all comfortable but we go on, outwardly ignoring it.	1	2	3	4	5	6
29. He is friendly and warm towards me	1	2	3	4	5	6
30. He does not understand me.	1	2	3	4	5	6
31. He approves of some things about me (or some of my ways), and plainly disapproves of other things (or ways I express myself).	1	2	3	4	5	6
32. I think he always knows exactly what he feels with me: he doesn't cover up inside.	1	2	3	4	5	6
33. He just tolerates me.	1	2	3	4	5	6
34. He appreciates exactly how the things I experience feel to me.	1	2	3	4	5	6
35. Sometimes I am more worthwhile in his eyes than at other times.	1	2	3	4	5	6
36. At moments I feel that his outward response to me is quite different from the way he feels underneath.	1	2	3	4	5	6
37. He feels affection for me.	1	2	3	4	5	6
39. His response to me is so fixed and automatic that I don't get through to him.	1	2	3	4	5	6
39. I don't think anything I say or do really changes the way he feels about me.	1	2	3	4	5	6
40. I believe that he has feelings he does not tell me about that affect our relationship.	1	2	3	4	5	6

PEOPLE WHO GIVE YOU HELP AND SUPPORT

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give each person's initials and their relationship to you (see example). List only one person next to each of the numbers beneath each question. Do not list more than nine people per question, although you can list less. For the second part, using the scale below, circle how satisfied you are with the overall support you have.

1	2	3	4	5	6
Very dissatisfied	Fairly dissatisfied	A little dissatisfied	A little satisfied	Fairly satisfied	Very satisfied

If you have no support for a question, tick the words 'No one', but still rate your level of satisfaction. The example below has been completed to help you.

Example

Who do you know whom you can trust with information that could get you into trouble?

(a)

No one

1) TN (Brother)

2) LM (Friend)

3) AK (Friend)

4) PN (Father)

5) LD (Employer)

6)

7)

8)

9)

b)

How satisfied? 1 2 3 [✓ 4] 5 6

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1. Who can you really count on to distract you from your worries when you feel under stress?

(a)

No one

1).........................

2).........................

3).........................

4).........................

5).........................

6).........................

7).........................

8).........................

9).........................

b)

How satisfied? 1 2 3 4 5 6

2. Who can you really count on to help you feel more relaxed when you are under pressure or tense?

(a)

No one

1).........................

2).........................

3).........................

4).........................

5).........................

6).........................

7).........................

8).........................

9).........................

(b)

How satisfied? 1 2 3 4 5 6

3. Who accepts you totally, including both your worst and best points?

(a)
No one 3)……………………… 6)……………………… 9)………………………

1)……………………… 4)……………………… 7)………………………

2)……………………… 5)……………………… 8)………………………

(b)
How satisfied? 1 2 3 4 5 6

4. Whom can you really count on to care about you, regardless of what is happening to you?
(a)
No one 3)……………………… 6)……………………… 9)………………………

1)……………………… 4)……………………… 7)………………………

2)……………………… 5)……………………… 8)………………………

(b)
How satisfied? 1 2 3 4 5 6

5. Who can you really count on to help you feel better when you are feeling generally down in the dumps?
(a)
No one 3)……………………… 6)……………………… 9)………………………

1)……………………… 4)……………………… 7)………………………

2)……………………… 5)……………………… 8)………………………

(b)
How satisfied? 1 2 3 4 5 6

6. Who can you count on to console you when you are very upset?
(a)
No one 3)……………………… 6)……………………… 9)………………………

1)……………………… 4)……………………… 7)………………………

2)……………………… 5)……………………… 8)………………………

(b)
How satisfied? 1 2 3 4 5 6

YOUR FEELINGS OVER THE PAST WEEK

In this final section, please read each item and place a tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

Tick only one box in each section

I feel tense or 'wound up':
Most of the time ☐
A lot of the time ☐
Time to time, Occasionally ☐
Not at all ☐

I still enjoy the things I used to enjoy:
Definitely as much ☐
Not quite so much ☐
Only a little ☐
Hardly at all ☐

I get a sort of frightened feeling as if something awful is about to happen:
Very definitely and quite badly ☐
Yes, but not too badly ☐
A little, but it doesn't worry me ☐
Not at all ☐

I can laugh and see the funny side of things:
As much as I always could ☐
Not quite so much now ☐
Definitely not so much now ☐
Not at all ☐

Worrying thoughts go through my mind:
A great deal of the time ☐
A lot of the time ☐
From time to time but not too often ☐
Only occasionally ☐

I feel cheerful:
Not at all ☐
Not often ☐
Sometimes ☐
Most of the time ☐

I can sit at ease and feel relaxed:
Definitely ☐
Usually ☐
Not often ☐
Not at all ☐

Tick only one box in each section

I feel as if I am slowed down:
Nearly all the time ☐
Very often ☐
Sometimes ☐
Not at all ☐

I get a sort of frightened feeling like 'butterflies' in the stomach:
Not at all ☐
Occasionally ☐
Quite often ☐
Very often ☐

I have lost interest in my appearance:
Definitely ☐
I don't take as much care as I should ☐
I may not take quite as much care ☐
I take just as much care as ever ☐

I feel restless as if I have to be on the move:
Very much indeed ☐
Quite a lot ☐
Not very much ☐
Not at all ☐

I look forward with enjoyment to things:
As much as ever I did ☐
Rather less than I used to ☐
Definitely less than I used to ☐
Hardly at all ☐

I get sudden feelings of panic:
Very often indeed ☐
Quite often ☐
Not very often ☐
Not at all ☐

I can enjoy a good book or radio or TV programme:
Often ☐
Sometimes ☐
Not often ☐
Very seldom ☐

THANK YOU VERY MUCH FOR YOUR HELP.

Please return this questionnaire in the envelope provided. No stamp is needed.

APPENDIX 13

WEB SITE NOTICE FOR PARTICIPANTS

Research into chronic pelvic pain

[Follow Ups] [Post Follow Up] [Endo Message Board] [FAQ]

Posted by Ruth Warwick on March 04, 2002 at 14:54:11:

Do you suffer from pain in the pelvic area that has lasted for 6 months or more? It can be pain that is continuous or intermittent and although it might be related to periods or sexual intercourse it happens at other times too. If so please can you help? I am conducting a research project looking at what has been helpful and unhelpful in terms of social support to women who have chronic pelvic pain. This project is part of my doctorate at Warwick University and has full ethical approval from Leicestershire and Gloucestershire Health Authority Ethics Committees. I do not have enough participants. I would be very grateful for your help. If you are interested I can send you more information about the study. If you chose to take part you would be asked to fill in a questionnaire about the pain, how you are feeling emotionally, your views about your relationship with your partner and about the social support available to you. This should take 30-40 minutes of your time. Please get in touch if you are at all able to help. With thanks, Ruth