Application of a user-centred approach to needs elicitation for chronic pain self-management support

Rachel O'Connor

Project report submitted in part fulfilment of the requirements for the degree of Master of Science (Human-Computer Interaction with Ergonomics) in the Faculty of Life Sciences, University College London, 2008.

<u>NOTE BY THE UNIVERSITY</u>

This project report is submitted as an examination paper. No responsibility can be held by London University for the accuracy or completeness of the material therein.

Acknowledgments

Abstract

The Pain Management Clinic (PMC) at University College London Hospital of Neurology (UCLH) offers a multidisciplinary chronic pain programme. This programme includes training patients to equip them with a combination of physical and psychological self-management skills that enable them to assume responsibility for managing their pain.

This study focuses on identifying obstacles encountered by PMC patients in the application of self-management behaviours and determines patient needs that could be supported technologically. To identify these needs, two studies were undertaken – Study 1 to elicit patient needs through the user-centred research methodology of De Rouck et al.'s, (2008) in telemedicine application development and Study 2 to validate the resulting needs.

Study 1 consisted of interviews with ten PMC patients (two male, eight female) with an average age of 55 and two senior PMC practitioners. The resulting data was quantitatively analysed and grouped into three main themes that moderate patient adoption and adherence – Skill Development, External Support and Encouragement, and Information Seeking and Use – leading to the creation of 31 patient need statements.

Study 2 consisted of interviews with three patients (one male, two female) and one PMC practitioner. These validation sessions identified additions and changes to the need statements, as well as the different emphases of the practitioner and patients for those changes.

Comparison of the needs identifed in our study with those addressed in previous telemedicine research (e.g. Naylor et al., 2002) suggests that adopting a user-centred approach to needs elicitation enables broader understanding of patient requirements. Specifying a tool based on this broader understanding could lead to better support for patients in overcoming the obstacles of chronic pain self-management, unlike the common practice within telemedicine of design only involving patients to evaluate a system designed to address a particular self-management need or needs.

Our findings further suggest that the user-centred approach is more effective in identifying needs because of the complex patient factors found to moderate adoption and adherence of self-management. Furthermore the participative nature of chronic condition self-management requires patients involvement in the care process and therefore their input is as necessary as that of practitioners.

Table of Contents

Tables

Appendices

CHAPTER 1. Introduction

Chronic pain is an "expensive and pervasive" condition to treat and support (Arnstein et al., 2002). It is also a factor in many conditions, so it is difficult to determine the actual number of chronic pain sufferers (Smith, Hopton & Chambers, 1999). Statistics suggest that 10-15% of the British population (majority female) suffer some chronic pain. These statistics, however, fail to account for people not seeking medical treatment – therefore, the problem could be more pervasive (Smith, et al., 1999).

Chronic pain's pervasiveness poses a problem to the medical profession (Smith, et al., 1999; Turk & Okifuji, 2002), as does the influence of physical, psychological and social factors. How these factors influence treatment has prompted the development of multidisciplinary programmes for chronic pain patients who have undergone multiple medical treatments without successful pain eradication (Okifuji, 2003).

Typically, these programmes focus on transferring responsibility for pain control and management to patients through the improvement of physical and psychological functioning (Ashburn & Staats, 1999; C de C Williams et al., 1993). The Pain Management Clinic (PMC), University College London Hospital, offers one such programme to teach patients pain self-management skills as a complement to medical pain treatment, through group-based COPE ("Changing the Outcomes of Pain Experiences") or one-to-one (individual) training.

Patients chosen for COPE are those whose pain affects their whole lifestyle – demonstrated by major loss of fitness, mood changes (depression, anxiety, decrease in confidence and self-esteem) and high medication use. To take part, patients must be comfortable in a group, have time to attend weekly day-long sessions and not be taking soporific or sedative medication. Conversely, those taught self-management individually tend to experience difficulties in only one area, e.g. fitness or psychological function.

The PMC self-management training aims to improve patients' quality of life by equipping them with the knowledge, skills and tools needed to self-manage their condition. To benefit from this training, patients also need to make behavioural and cognitive changes (Kerns & Rosenberg, 2000) through Cognitive Behavioural Therapy (CBT) that challenges patients' beliefs about their inability to either function or improve their current situation (Moore et al., 2000; Turk, Swanson & Tunks, 2008).

Successful pain-management has benefits for the patient – improved quality of life, reduced need for prescription drugs and possible return to work – and for both social and medical services – reduced costs associated with patient disability allowance, medical treatment and prescription drugs (Okifuji, 2003). Although there are clear benefits, only 70% of patients will be using the learned skills at completion of a pain management programme (PMP) (inpatient and outpatient), decreasing to just 30% over time, indicating the majority of patients' longer term inability to self-manage their pain outside the clinical setting (C de C Williams et al., 1996; Kerns & Rosenberg, 2000; Maruta, Swanson & McHardy, 1990). Such failure in self-management adoption and adherence has been attributed in part to the following:

1. Degree of change experienced by a patient during treatment, e.g. if gains are experienced during treatment, post-treatment behavioural change is more likely to continue (C de C Williams et al., 1996);

2. Patients' beliefs of treatment efficacy and their readiness for self-management (Kerns & Rosenburg, 2000; Turk & Okifuji, 2002); and

3. Chronic pain's treatment as an acute condition with treatment ceasing after self-management training, rather than maintaining "regular check-ups and continuing care" consistent with other chronic conditions (Turk & Okifuji, 2002).

Investigations into strategies promoting self-management continuation and reduction in drop-out have been requested (Turk & Okifuji, 2002). Our study responds to that request by identifying PMC patients' needs for support in self-management adoption and adherence that could ultimately be fulfilled by technology, so reducing drop-out. These needs are identified through adapting the user-centred Phase 1 ("Selection of the User Group") and Phase 2 ("Primary Exploration of User Group Needs") of the De Rouck, Jacobs & Leys (2008) user research approach to telemedicine design in the following two studies:

1. Qualitative analysis of PMC patient and practitioner interviews to understand patients' obstacles to pain self-management outside the clinical environment and to determine patient needs; and

2. Validation of the resulting need statements with patients and practitioners.

Chapter 2 of this research reviews the literature on the effectiveness and efficacy of PMPs and how technology has been trialled in the telemedicine domain to enable patients with chronic conditions to self-manage outside the clinical environment. The general methodology applied to both studies is outlined in Chapter 3, while Chapter 4 and Chapter 5 present the methodology and results of "Study 1 – Needs Elicitation". Chapter 6 presents the methodology and results of "Study 2 – Needs Validation". Chapter 7 discusses the results of both studies in the context of previous research and discusses further research possibilities.

CHAPTER 2.   Literature Review

2.1.   Overview

Identifying how technology can support chronic pain self-management adoption and adherence by Pain Management Centre (PMC) patients requires an understanding of the clinical approaches to chronic pain management and of the research into use of technological support for chronic condition self-management. There are, therefore, two main areas in the literature pertinent to review to determine their influence on our research:

1.   Pain Management Programmes (PMP); and

2.   Telemedicine Research.

2.2.   Pain Management Programmes

The demands chronic conditions place on health services have driven changes in patient care models in the UK (Department of Health, 2005b). Furthermore, as the majority of care is being undertaken outside the clinical setting, patients require greater control, information and choice to collaboratively manage their conditions with practitioners (Department of Health, 2005b).

Multidisciplinary inpatient and outpatient PMPs emphasise this collaborative management of chronic pain (Von Korff et al., 1997). The goal of such programmes is to transfer long-term self-management of pain to patients, not only by assisting them in pain control, but also by improving their physical function and psychological coping (C de C Williams et al., 1993; Ashburn & Staats, 1999). Patients referred to such programmes tend to have had a prolonged period of persistent pain (Okifuji, 2003; Ashburn & Staats, 1999) which cannot be cured and which is associated with loss of function, psychological distress, withdrawal and "vocational dysfunction" (Ashburn & Staats, 1999; Moses et al., 1996; Okifuji, 2003).

PMPs have been found to be efficacious and effective methods in treating non-malignant chronic pain (Ashburn & Staat, 1999; Okifuji, 2003; Moore et al., 2000). Turk et al. (2008) attribute this success to PMPs' incorporation of treatment for psychosocial and behavioural factors significant in the maintenance, experience and exacerbation of pain. Investigation into self-management programmes further suggests that they provide both clinical (Turk, 2002; Woby et al., 2003) and cost benefits compared to other pain-interventions, e.g. surgery (Turk, 2002).

Self-management programmes are not uniformly successful, however, and can fail to engage all patients (Kerns & Rosenberg, 2000; Maruta, et al., 1990). Therefore, investigations have sought to identify patient factors influencing PMP success in order to determine improvements. One identified factor is "patient coping style" (assessed through personality profile questionnaires), with negative emotion, hostility to treatment (Cipher, Fernandez & Clifford, 2002) and readiness to change (Kerns & Rosenberg, 2000) highlighted as useful indicators of post-self-management training compliance and particular areas to address in self-management treatment.

PMPs have also been investigated to identify if treatment approach affects programme success and clinical outcome. Comparisons between outpatient-based group and individual programmes find both types to be equally effective (Turner-Stokes et al., 2003). Comparing out- and inpatient programmes (C de C Williams et al., 1996), however, suggests that the intensity, duration and environmental stability of inpatient programmes contribute to their greater effectiveness (C de C Williams et al., 1996). Inpatient success may also be attributable to patients' separation from their habitual environments and the expectations of significant others. However, some patients may experience difficulties applying self-management strategies outside this environment (C de C Williams, 1993).

The multidisciplinary approach to chronic pain treatment is, therefore, supported in the literature as an adjunct to medical pain management. However, PMPs' failure to engage all patients long-term remains a concern as this can lead to deterioration in patient function, e.g. ability to work, medication use and need for continued medical services support (Okifuji, 2003).

2.3. Telemedicine Research

Computer-aided Treatment and Self-management

Von Korff et al., (1997), suggest that self-management of chronic pain shares common elements with management of other chronic conditions. Although there is little chronic pain management-focused research, technology's potential for this domain has been identified through investigations of technological support for self-management of other chronic conditions (e.g. Type II Diabetes). Such studies focus on how technology can facilitate reduction of reliance on healthcare professionals through supporting and empowering patients to manage their symptoms outside the clinical setting (Balas, Boren & Griffing, 1998; Bull, et al., 2005; Kaplan, Farzanfar & Friedman, 1999).

Interventions have also been considered to complement medical (Balas et al., 1998; Kearney et al., 2006) and cognitive behavioural treatment (Naylor et al., 2002), and as support for completed treatment and ongoing self-management (Kaplan, et al., 1999, Lorig et al., 2002; Sorbi et al., 2007; Winzelberg et al., 2003). Other investigations have trialled computer-aided social support, social support communities, online information and outpatient monitoring with a heterogeneous range of chronic patient types and conditions – the frail, elderly, diabetes, coronary disease, HIV/AIDS, breast cancer, mental health and general chronic illness (Balas et al., 1998; Boburg et al., 1995; Coyle et al., 2007; Kaplan, et al., 1999; Kearney et al., 2006; Mooney, et al., 2002; Soar & Croll, 2007). These investigations provide an overview of the types of patient/practitioner support offered:

1. Monitoring and coaching; and

2. Social support and information.

Monitoring and Coaching – Collaborative Two-way Care

Monitoring chronic conditions relies on patient symptom reporting between consultations or trials. This concerns medical practitioners and researchers because of

potential inaccuracies of those reports (Jamison et al., 2001). However, technological interventions have been found to assist when reliability of information is crucial, for example reporting symptoms (Theiler et al., 2007) and trialling new drugs (Celler, Lovell & Basilakis, 2003).

An extension to patient monitoring – the provision of coaching based on patient reports – has been researched by Celler, et al., (2003), who investigated how patient's health could be monitored in partnership with their physician to promote condition management. By periodically connecting to measurement devices via their home computer, patients were able to provide accurate physical data (such as heart rate and blood pressure). This monitoring resulted in reduced re-admissions – and in improvements in treatment compliance and medication management. Celler et al. (2003) relied on static devices, unlike others who piloted mobile devices to collect patient data, and provide coaching and feedback (Kearney et al., 2006; Ma et al., 2006; Sorbi et al., 2007; Tsang et al., 2001)

For example, Kearney et al., (2006) piloted the use of a mobile computer to support chemotherapy patients and also to provide practitioners with accurate and timely patient symptom reports. Kearney et al. (2006) suggest that improving knowledge and enhancing access to information better equips patients to cope with symptoms. Furthermore, in accordance with the findings of Celler et al. (2003), the practitioners gain access to important symptoms potentially missing from patients' reports.

Furthermore, hand-held computers have been identified as useful coaching, monitoring and collaboration tools, as Ma et al., (2006) demonstrated by the use of a PDA to help diabetics manage their diet, check food choices and record intake as an adjunct to review sessions with a nutritionist. Furthermore, Tsang et al., (2001) demonstrated that monitoring diet and blood sugar readings, and subsequent coaching, could be successfully automated through a computerised diabetes system providing immediate dietary feedback via patients' PDAs.

Devices delivering feedback have also been used in behavioural training and symptom prevention. For example, Sorbi et al., (2007) used PDAs to deliver coaching to chronic migraine patients, with random prompts delivered to the PDA requesting patients make an entry in an electronic diary. Patients received targeted coaching in response to the contents of this entry. The PDA was found to not only prompt patient reflection and behavioural change, but was also perceived by patients as a personal helper.

Perception of an intervention is important to its effectiveness (Sorbi et al., 2007). Kaplan, et al., (1999) evaluating Telephone Linked Care's automated telephone counselling system, found that some patients perceived they had a relationship with the system's computerised voice, while others found it "condescending and condemning". Furthermore, the inflexibility of the automated branch decision-making system was perceived as preventing patients from explaining why they had not stuck to exercise and diet changes.

Despite patient-system relationships possibly being ambiguous, automation of feedback can be used to reinforce skills learned during self-management programmes.

Naylor et al., (2002) argue that chronic pain patients have learned skills at the end of CBT, but have little experience of using them. During a four-month investigation of an automated telephone system (TIVR) to reinforce CBT techniques taught during a pain management course, Naylor et al. trialled four components:

1. Daily questionnaire – reminded patients of the skills learned during CBT;
2. Didactic skills review – allowed patients to access a short overview of eight different pain management techniques;
3. Skills rehearsal – pre-recorded guides talked patients through particular pain coping techniques; and
4. Monthly therapist feedback – provided access to a monthly personalised message from a patient's therapist.

Naylor et al., (2002) provided access to all components through the telephone keypad. Patients' didactic reviews were performed more regularly during the first month and the fourth month once skill repertoires had reduced. Skills rehearsal and monthly therapist feedback were used regularly. This feedback was important to patients as it demonstrated an ongoing interest in their progress. Overall, Naylor et al. (2002) found that not only did patients show improvements in all measures, they accepted the technology, suggesting TIVR's potential to support self-management training.

All the discussed studies were pilots and further trials are required to evaluate the feasibility, economic, ethical and clinical effectiveness for larger scale use (Kaplan et al., 1999; Ma et al., 2006; Sorbi et al., 2007; Tsang et al, 2001). However, these studies do demonstrate technology's potential to enhance practitioner support and monitoring, and to promote patient self-management in a diverse range of conditions.

Support and Information – Individual Self-Management Tools

The studies above investigate the use of technology to facilitate patient support through recording patient data and providing practitioner/automated feedback. However, technology is also used to encourage self-management by providing information and reducing social isolation.

The complex psychosocial nature of chronic condition management and patient desires to learn more about their condition (Hiesler & Piette, 2005; Loriq et al., 2002; Washington et al., 2008; White & Dorman, 2001) have prompted investigation into information provision and support facilitation. Communication tools have, therefore, been used to address social isolation, based on the premise that patients can benefit from mutual support (Heisler & Piette, 2005) and are sources for expertise on the practicalities of living with a chronic condition (Winkelman & Choo, 2003).

The importance of support from other patients was found in a study of CHESS ("Comprehensive Health Enhancement Support System") which showed that HIV patients used social support services and facilitator-run discussion groups more frequently than information databases (Boburg et al., 1995). Furthermore, the most isolated and under-served in the HIV community (women and cultural minorities) made the most use of these support services. Another benefit suggested for internet-based support groups is their provision of support and information while protecting privacy when patients are most physically self-conscious (Winzelberg et al., 2003).

Reducing isolation is not the only area of patient well-being found to benefit from communication forums and educational facilities. In Lorig et al.'s (2002) study of an email discussion group for back pain patients (in combination with self-management video and handbook), patients' improved in "primary health status variables" as well as in self-care and self-efficacy measures.

While the emphasis has been on the internet to facilitate peer support, alternatives have been investigated which have particular relevance to populations with low computer literacy or access. For example, an interactive voice response (IVR) system delivered over a standard telephone was designed to facilitate male diabetes patients' weekly contact with a "buddy" (Heisler & Piette, 2005). During trials, this contact was found to be a useful adjunct to diabetes care to enhance patients' motivation and self-efficacy. However, patients were concerned about being a good "buddy" (suggesting training was required), while some relationships failed because of differing condition severity and participant motivation (Heisler & Piette, 2005).

As demonstrated by Heisler & Piette (2005), technology can facilitate peer-provided information and support. Furthermore, educational resources are important facilitators of self-care decision-making (Bull et al., 2005) and that importance has led to increased research on the internet of health concerns (Washington et al., 2008). Without moderated content, however, the quality of information found may be unhelpful (Bull et al., 2005; Washington et al., 2008). Practitioner-moderated, internet-based information and education have demonstrated beneficial effects (decreased healthcare visits and painkiller use, increased patient exercise and knowledge) in back pain patients (Schulz, Rubinell & Hartung, 2007).

With such moderation, as well as patient training and healthcare provider-sponsorship, internet-based information can be helpful, readable, valid and sanctioned, while any resulting relationships are respectful and non-abusive (Washington et al., 2008; Winkelman & Choo, 2003). Using expert moderators and content providers, though, has cost and organisational implications (Schulz, et al., 2007). Furthermore, providing such services is perceived by some practitioners to interfere with patient-practitioner relationships by "de-professionalising" contact (Schulz, et al., 2007). Additionally, some patients have concerns about privacy, computer access and the readability of website content (Washington et al., 2008; Winzelberg, et al., 2003). These issues should, therefore, be considered when evaluating the cost and benefits of such interventions.

2.4.   Implications of Research

The literature shows that patient compliance and adherence to the techniques taught in PMPs moderate the programmes' success in reducing pain and improving quality of life through patient adoption of self-management behaviour. When PMPs finish, the onus is on the patient to use the skills taught to manage their condition, however, there is concern about adherence to those teachings longer-term.

The technological approaches explored in the literature seek to facilitate adoption and reduce patient drop-out through development and evaluation of systems to support chronic condition self-management. These systems, as adjuncts to treatment programmes, typically provide monitoring and feedback, or facilitate education and social support post-treatment.

Self-management of chronic pain shares techniques – for example, the use of feedback and monitoring to increase skill learning and patient self-efficacy – with self-management of other chronic conditions (Von Korff et al., 1997). There are also similarities in the moderating factors that affect adoption and adherence, such as social and environmental factors (Von Korff et al., 1997). Management of chronic pain, however, differs from other chronic conditions because of patient perception of the pain, its causes and their control over it, which are as powerful in moderating the pain experience as physiological factors (Loeser & Melzack, 1999; Newman, Steed & Mulligan., 2004).

Therefore, these differences ensure that basing a system on these studies would not fully address patient needs for chronic pain self-management (De Rouck et al., 2008). However, research into other chronic conditions can provide insights into patient acceptance and feasibility of technological interventions, although little focused research has been undertaken in the chronic pain domain

Additionally, medicine's expert-driven nature (De Rouck et al., 2008) means that studies reviewed, except Boburg et al., (1995) and Kearney et al., (2006), were conducted on the basis of practitioner-defined needs (Schulz, et al, 2007; Washington et al., 2008) and not through definition through collaboration with patients (De Rouck, et al., 2008; van't Riet et al., 2001). De Rouck et al., (2008) have responded to this by developing and trialling a methodology that involves users at the beginning of the design process. Our study, therefore, adapts this user-centred approach to identify PMC patient needs for self-management support which could be addressed by technology.

CHAPTER 3.   General Methodology

3.1.   Application of User-Centred Design

This investigation applies a user-centred approach to identifying chronic pain patient self-management needs that could be assisted by technology. Two studies were, therefore, undertaken to establish and validate patient needs:

Study 1 – Needs Elicitation

This study adapted Phase 2 – "Primary Exploration of User Group Needs" – of De Rouck et al.'s (2008) methodology to establish patient needs. The use of Phase 1 – "Selection of the User Group" – will be outlined in "Participant Selection and Contact".

Study 1 included the following steps from De Rouck et al.'s (2008) Phase 2:

1. **"Literature research"**: Review of documentation (COPE Manual and patient statistics) and literature (on pain management programmes) to facilitate domain understanding;

2. **"Exploratory interviews"**: Semi-structured interviews with PMC patients and practitioners; and

3. **"Integration of user research results"**: From the literature research and exploratory interviews.

Study 2 – Needs Validation

Study 2 extended De Rouck et al's methodology by formally validating the patient need statements from Study 1. In De Rouck et al.'s (2008) methodology, these needs would be progressed in the labour intensive Phase 3, "Writing 'social' use cases" (De Rouck et al., 2008).   This progression was not planned for our study, so discussion with patients and a practitioner was included as an additional validation step to ensure needs identified were valid, complete and warranted progression. Furthermore, this study sought to demonstrate the value of adding this additional step to De Rouck et al.'s methodology.

3.2.   Participant Selection and Contact

Unlike the multiple user groups of De Rouck et al. (2008), this study focused on one group – chronic pain patients. Therefore, Phase 1 – "Selection of the User Group" – (De Rouck et al., 2008) of this methodology was adapted accordingly.

One hundred chronic pain patients were selected randomly from patient files at the PMC, UCLH – 50 COPE and 50 individually treated. Patients had to be 18 years old or over, treated between 2006 and 2008, had not been referred to a mental health facility on discharge, had been known at their recorded address and met at least one of the following treatment criteria:

1. Commenced and completed an individual PMP;

2. Commenced and completed COPE;

3. Were currently receiving pain management treatment on an individual basis; or

4. Had commenced but not completed COPE for reasons unrelated to lack of belief in pain self-management (as indicated in discharge letters).

Once selected, patients were contacted by post and invited to participate in the study. Practitioners were selected based on availability and experience of working in the PMC, resulting in two senior practitioners – one Clinical Specialist Physiotherapist (01A) and one Consultant Clinical Psychologist (02A) – participating (See Appendices 1 and 2 for patient and practitioner project information sheets and consent forms).

CHAPTER 4.   Study 1 – Needs Elicitation – Method

4.1.   Patient Selection

Twenty-four patients responded to the invitation to participate. A sample of ten was selected for interview based on the following criteria:

1. Ratio of males to females was 1:4 (in line with COPE patient statistics[1]);

2. Had access to a landline telephone; and

3. Indicated availability for interview between 9th to 15th June, 2008.

The application of the above criteria resulted in the following patient participants:

Patient	Age	Sex	Length of time since intervention	Programme
001	49	F	2.5 months	COPE
002	61	F	Ongoing – nearing end	Individual
003	62	F	4 months – nearing end	Individual
004	58	M	10 months	COPE
005	64	F	18 months - Discharged	COPE
006	63	F	Ongoing – medical focus of treatment	Individual
007	64	F	12 months	COPE/Individual
008	49	F	18 months - Discharged	COPE
009	31	F	Ongoing – medical focus of treatment	Individual
010	58	M	Discharged	Individual

Table 1.   Participant characteristics by selection criteria

Average age of participants' selected was 55 years and none was in full-time employment.

4.2.   Data Analysis Using Grounded Theory

Grounded Theory (Corbin & Strauss, 2008) was chosen as the interview data analysis method to provide an understanding of the challenges that would need addressing to help chronic pain patients transfer self-management fully to their home lives. Corbin & Strauss (2008) see qualitative analysis as reliant on researcher flexibility, creativity, sensitivity and intuition. They, therefore, provide tools through Grounded Theory that assist the researcher with determining the analysis outcome.

---

[1] No corresponding statistics were available for individually treated patients.

Grounded Theory has three main phases: "Description", "Conceptual Ordering" and "Theorizing". "Description" conveys and captures the situation of interest using interviews and observation to form the basis for future analysis. "Conceptual Ordering" takes this descriptive data and reduces it to an abstract form by organising it into categories. Finally, "Theorizing" links these categories and arranges them into a "logical, systematic explanatory scheme" (Corbin & Strauss, p. 53-56, 2008). Corbin & Strauss, (2008) also recommend that the data abstraction is validated, which our study sought in the following ways:

1. Comparison of the developed analysis with the raw data; and

2. Practitioner interviews to validate the researcher's understanding of the self-management techniques taught.

4.3. Procedure

"Description" – Patient and Practitioner Interviews

During a one-week period, telephone interviews of 40-60 minutes were conducted with selected patients. Interviews were based on pre-prepared, semi-structured questions sent to patients by post (on UCLH direction) one week before interview (see Appendix 3 for questions) and recorded for transcription purposes.

Sending pre-prepared questions departs from Corbin & Strauss's suggestion that questioning evolves through subsequent interviews as areas of interest develop. However, patients were informed that questioning could depart from the list provided, in keeping with Grounded Theory. Questions arising from analysis of patient transcripts were used to guide the subsequent face-to-face practitioner interviews to gather their perspective on the difficulties of chronic pain self-management.

"Conceptual Ordering"

"Microanalysis" (Corbin & Strauss, 2008), was applied to the interview data. Using MAXQDA 2007 software, interview sentences were considered in detail and memos written to guide our interpretation. Memos were associated with lines in the transcripts to determine categories relevant to patient self-management adoption and adherence, and highlight anomalies within and between patient responses. Patient reports of self-management technique use resulted in memos, but no memos were generated if reports were unrelated to self-management.

High-level categories were then assigned to each memo and corresponding text, so that related patient and practitioner responses could be grouped.

"Theorising"

Memos from "Conceptual Ordering" were coded into summary memos which embodied both categories and factors moderating self-management learning and adoption. The relationships between categories and factors were then modelled. From this analysis, patient need statements were identified.

CHAPTER 5.   Study 1 – Needs Elicitation Results

Data analysis revealed that patients faced challenges adopting and adhering to self-management. These challenges were grouped, enabling development of need statements that could be supported by technology. These challenges and need statements are presented in this section:

1. Skill Development;

2. Support and Encouragement; and

3. Information Seeking and Use.

5.1.   Skill Development

Interviews with PMC practitioners highlighted that patients need to be receptive to physical and cognitive behavioural changes emphasised in the self-management approach. Furthermore, patients must be receptive to self-management's applicability to their situation, to understanding what is wrong with them and to accepting that self-management is the correct approach even when presented with conflicting accounts of their pain and its maintenance. While these factors may influence acceptance of the self-management message, analysis of interviews identified other factors that determine the overall success of patient skill development and adoption:

1. Course Materials and Learning Style;

2. Goal-Setting, Progress Tracking and Reinforcement;

3. Routine Development; and

4. Remembering.

Course Materials and Learning Style

According to practitioner 02A, and consistent with Turk & Okifuji (2002), each patient has specific issues and, therefore, a different experience of and response to treatment. Practitioner 02A further indicated that patient-specific issues determine the entry point required for self-management training (e.g. physiological or psychological). Additionally disciplines or skills can influence the learning, adoption or success of another, both positively and negatively,

02A: …the light will go on when someone's explaining to them and they'll say "oh well I can do [that]" and suddenly they walk without a stick or whatever. So, it does mean there are two ways in as well as entanglements that can hold people back.

During the eight COPE sessions, patients must learn technique application and identify how to transfer techniques to their particular situation. COPE applies a generic teaching style to train patients in physiological and psychological self-management skills, with limited time available with practitioners to personalise the materials.

Personalisation and adaptation to different learning styles of training materials was possible in individually taught sessions, but the extent of this personalisation was constrained by the duration and frequency of sessions – with both practitioners highlighting their limited time to adapt materials or provide in-depth feedback. The effect of not receiving personalised feedback is illustrated by patient 005 failure to see the links between topics in the course content. When asked about feedback, 005 indicated,

005:   The trouble is that they've got quite a few people and they can only give everyone two or three minutes at the best and you can only learn so much in that time.

Giving extra time – particularly in COPE – to personalise materials to patients was, however, felt by practitioner 01A to undermine the self-management message, which emphasises the provision of tools so patients can develop the skills to problem-solve in their own situation (Turk, et al., 2008). Despite this view, a lack of understanding of how to apply techniques to specific situations could be the reason why patients encountered issues with certain techniques, e.g. pacing.

Practitioner 01A considers pacing, with its mechanical and cognitive aspects, to be one of the most important skills for chronic pain self-management as it helps patients build fitness and activity over time without increasing pain. Additionally, pacing requires patients to challenge their usual thoughts and motivations about performing activities at the level they used to. Practitioner 01A confirmed that alongside CBT concepts, pacing was hard to grasp as patients needed to not only choose an activity to increase, but also had to calculate how much to increase it by – something patients reported finding tedious or difficult to do.

A problem with the application and understanding of pacing was suggested as each patient interviewed applied pacing differently. For example, patient 004 applies it to building up the duration of sitting to a level that was more functional and comfortable, which is how the technique should be applied as described by practitioner 01A. Patient 007, however, interprets pacing as a planning technique to pace her day's activities around her most mobile times. This variation in use is not solely because of patients' interpretation of the technique, as practitioner 01A acknowledged,

01A: We tried to change it by doing more practical stuff …because we felt that people weren't getting the pacing. But I think there are issues [as to] whether the staff understand pacing because it's not an easy skill.

Even though it is acknowledged that generic tuition could affect correct adoption, patients are unlikely to adopt techniques if they did not have an understanding of their use or applicability. Although COPE sessions do not provide extensive personalisation, practitioners personalise the teachings and their applicability within a discharge letter sent to COPE patients and their GPs;

02A: …Quite a few of the COPE staff worked with me at [another PMP] and what we used to do was a discharge letter to the GP which was more detailed than most GPs will read… a copy went to the patient and the idea was that it was a summing up

for the patient of their achievements, of the way they were going and a reminder of the kind of things that they should look at first if they hit a crisis.

However, the purpose of this discharge letter, as reported by practitioner 02A, could be misinterpreted. For example, patient 005 thought the letter was a kindness rather than a resource for her to reflect on. Furthermore, the effectiveness of the letter depends on whether a patient has fully understood the COPE teachings, as shown by patient 005 who had not recognised the relationship between the psychological and physiological aspects of her pain management,

005: Yes, I think in talking to you it's interesting….and that I've got Dr A's letter set out and everything. I think I need to think more, it's so difficult running around in circles. I don't stop to sort out how I'm going to do it all and possibly the course with telling me to slow down, be honest, say no. it was telling me mental things as well as physical things. And maybe I just wasn't homing in on those sort of things enough. Maybe for me personally I just needed a bit more time with someone lovely like Dr A.

The final difficulty experienced by both COPE and individually taught patients is transferring the provided materials in the way taught in the PMC to the home setting. For example, patients were talked through relaxation in the PMC, but reported being given a paper script which they found difficult to use at home.

007: I would have liked to have said the relaxation was very good, but I really found that without a CD or a tape to follow I've found that quite difficult. I mean if I do do it, I just end up falling asleep.

Practitioners interviewed acknowledged these difficulties. However, time constraints and practitioners' need to encourage independence in patients prevent the further personalisation of teaching and materials required by some patients to support correct learning or adoption of self-management skills.

Patient Needs Identified

1. Self-management information presented in a way that is tailored to a patient's comprehension and style of learning.

2. Skill knowledge and mechanics presented in a way that facilitates correct application outside the clinical setting.

Goal-Setting, Progress Tracking and Reinforcement

Both practitioners highlighted that goal-setting is an important self-management activity, providing patients with meaning and direction for self-management. The PMC teaching curriculum, therefore, includes collaborative goal-setting between patients and practitioners. The practitioners ensure that goals are specific and achievable and that longer-term goals can be broken down into shorter-term physical goals and transferred into a pacing strategy.

Setting, revising and achieving these goals is required beyond the course's duration, because patients' physical improvements may slow down or even cease over

time without further goals to frame and encourage their effort. However, once the course – and by extension collaboration with practitioners – ends, patients generally abandon goal-setting, despite having course materials to refer to. This suggests that collaboration is an important factor in goal-setting – and further suggests that when absent, few, if any goals are set.

For example, 010 has not set goals ("targets") to avoid disappointment if unable to complete them. Only one patient, 004, explicitly mentioned having a goal that guided his self-management activities. Patient 004's specific shorter-term physical goal (increased sitting time) is intended to facilitate a longer-term goal (return to work). However, even though goals and a pacing strategy had been set, this patient's progress has stopped – potentially exacerbated by the difficult of using the provided materials,

004: I don't really find any of it difficult to do except I would say that perhaps I am not being rigorous enough in terms of writing the pacing goals down in terms of trying to build up from 1.5 hours… I suppose because I have not done it, I find that difficult.

The PMC encourages patients to track their progress, both in general and towards goals, to reinforce self-management benefits. The text-based worksheets provided enable patients to plan and record what they have done, but require effort to complete and do not engender an intuitive, graphical view. Practitioner 02A suggests, therefore, that patients need to be motivated and willing to take on the responsibility of setting up such a mechanism. Therefore, additional effort is required if patients want a visual representation of progress, something only patient 001 had done,

001: I just made a little sheet of paper, divided it up… and have one sheet a month. Divide it and write down… …you can see you had other days when you weren't feeling great and that's part and parcel of it, and there are others days when you do well… …it's the whole thing of looking at things in a larger scale, and not saying "I feel crap today and it's all awful". Well, you can say, "yes, I had an awful day last week and the day after that I felt okay". And I find that really positive and helpful.

Patient Needs Identified

1. A way to set goals in the home environment that is similar to that used in the PMC.

2. Help to create meaningful goals outside the clinical domain.

3. Sources of inspiration for goal creation to guide self-management activities in the absence of practitioners.

4. A simple way to break goals down into achievable steps and calculate increments to ensure correct pacing of activities to meet those goals.

5. A simple way to store and review progress towards goals.

6. An indication of when a goal is reached and encouragement to create new ones so that patients can continue to increase fitness and everyday activities.

7. Personalised feedback and encouragement based on progress with goals and self-management activities.

Routine Development

Patients highlighted that the homework and support given by practitioners had assisted them in establishing and adhering to a routine while attending the PMC. By creating and adhering to such a routine as encouraged at the centre, patients are able to practise and habituate self-management skills so that those skills become natural behaviours. But, according to practitioner 01A, if patients do not want to or are unable to stick to a routine, they struggle with self-management of pain. Furthermore, patients who do manage to stick to the routine can experience difficulties continuing it when regular PMC contact ceases. As patient 004 says,

004: You do them religiously. Then, after about the three-month period, you find yourself drifting off the pace and suddenly you are not doing it quite as often and then you have to reinvent yourself.

Both practitioners suggest that environmental factors, such as work and family responsibilities, can also counteract continuation and establishment of self-management routine once visits to the PMC cease. Those factors are seemingly mitigated while patients visit the PMC, particularly on COPE, as patients are removed from other responsibilities and allowances are made by significant others, enabling patients to focus on the training and integration of required activities,

01A: I think for some patients they may compartmentalise COPE… …they think right "I'll give it everything I've got" …in a way, it gives clear communication to others what they're doing so that other people know that they're doing a course depending on how they have communicated it.

After the conclusion of COPE the patients' "real life" responsibilities return and may prevent continuation of the routine established during COPE,

01A: …I think COPE finishes and then the rest of their life events happen …things they might have put off whilst they were in COPE, they may become bigger issues after COPE so they're left with "right I've still got to go to work, I've still got to do the kids, I still feel that things haven't changed …as fast as I'd hoped, my expectations haven't been met". So I think the real life, as some patients talk about, comes in and I think personally it's hard to make changes. I think it's very hard to make changes without good support, good reinforcement from peers or from family or others. …if that's not there then I think people really struggle.

This was demonstrated by Patient 005 who was required to support family members' schedules at the expense of her exercise classes, while patient 010 was not even able to develop a routine as he had been focused on his significant others' serious illnesses for a long time,

010: The whole idea of any timetabling of my life is just not possible.

I: Is that now?

010:   It's been like that for a long time...

Although practitioner 01A acknowledged that routine development is important, the PMC-provided materials do not appear to offer an easy way for patients to integrate the pain management routine established at the centre into their other responsibilities. This is further compounded by the COPE handbook's multiple worksheets that require consolidation to build a schedule (See Appendix 6 for examples of these worksheets).   Therefore, a patient already experiencing time pressures or unwilling to be tied to a routine may perceive setting up a routine as too much of an additional burden.

One patient (001), a recent graduate of COPE, however, has taken on this burden and developed a written routine by integrating the provided worksheets,

001:   You can talk yourself out of things too much so I kind of don't let myself think too much.   I just decide I'm going to do that and I decide normally the day before what I'm going to [do], so in the morning I don't have to think. I just look at my sheet of paper about what I want to try and achieve, unless I'm feeling absolutely awful...

The length of time away from the centre also determines how routine is established and followed. Patients, who are well practised and apply the spectrum of self-management skills regularly, use calendars or normalised activities into their day without a written schedule. Certain patients (004, 006, 007 and 008), for example, perform their exercises, breathing or relaxation first thing in the morning and last thing at night, while exercises are also done during regular activities such as making drinks. These patients identified that skill habituation had occurred so scheduling has become less of an issue as the routine had moved from paper into "the head" and so requires less perceived effort to maintain.

Skill habituation and normalisation acquired through routine development, as discussed above, are difficult for some patients to reach. Moreover, the paper tools provided to patients do not easily tie into reminders of activities (to be discussed in "Remembering"), nor do they have the flexibility to be adjusted. Additionally, once training ends, some patients' home lives prevent self-management activities being incorporated.

Patient Needs Identified

1. Assistance to set up and maintain the routine commenced during training and to transfer this to the home environment.

2. Help to schedule time to support habituation of particular daily pain management activities.

3. Incorporation of self-management activities within a schedule by adding, changing and removing both home events and appointments. This schedule should enable patients to assess chronic pain self-management activities in response to how they are feeling and make adjustments to activities in response to those assessments.

23

4. Reminder facilities associated with their schedule to help with remembering to perform self-management activities.

5. A way to record or mark activities as completed in schedules.

6. A way to review schedules, past and present to be able to see progression with self-management.

Remembering

As highlighted, PMC-taught skills are intended to challenge patients' ways of thinking and so result in behavioural changes. Furthermore, the act of attending the centre reinforces this challenge by prompting patients to develop new routines and daily structures that aid remembering aspects of self-management.

PMC Materials and Remembering

Patients are provided with materials – a manual for COPE patients and leaflets for individually taught patients – which provide a reference for the course content. After training is completed, the onus is then on patients to remember what they have been taught through referring to these materials and practising self-management skills. A letter summarising the patient's specific learning (as referred to in "Course Materials and Learning Style") is also sent to each patient and their GP to remind both about the areas to consider if the patient experiences a crisis. Additionally, the letter is a tool for the GP to remind patients of the triggers that they should monitor and respond to with self-management behaviours.

Some patients find the leaflets, COPE manual and letter to have limitations as a remembering aid in the home environment. For example, environmental factors which interfere with a patient's ability to remember the behaviours self-management requires are not addressed in the materials. Nor do these materials address the reported impact of medication on patients' memory, concentration and thought clarity, or external factors – people and unscheduled events – which can interfere with a patients' ability to remember self-management.

The leaflets, COPE manual, and letter serve, at best, as a way for patients (assuming they remember to refer to them) to 'refresh' their knowledge. However, as Table 2 demonstrates, there are other areas of self-management which the PMC materials cannot support but which require assistance with remembering according to patients:

Aspects patients need to remember:	Applicable Skill	Supported by PMC Materials
1. What the skills are	All skills	Yes
2. How to perform a skill	Exercises, relaxation, breathing, CBT	Yes
3. When to perform a skill	Exercises, relaxation, breathing	No
4. The steps required in skill performance	Exercises, CBT	Yes
5. When to pause during skill performance	Pacing	No
6. To reflect on their personal pain triggers and the pre-emptive action required	Individual to patient	Yes
7. Which skill is applicable during a particular situation	CBT, breathing, relaxation	No
8. To reflect on the success of their self-management activities and make adjustments as required.	All skills	No
9. The longer term benefits of a skill	All skills	Yes
10. To perform postponed activities later	Exercises, relaxation, rehearsal of breathing, CBT	No

Table 2.   Aspects patients require assistance in remembering

Aspects 1 and 6 in Table 2 are supported by the manual and leaflets but some patients report only referring to them when prompted, e.g. by the need to remember how to perform an exercise or during a crisis. And while Aspect 9 is also supported, patients would not refer to the manual without positive prompts to do so.

For example, patient 010 could not see the benefits of performing exercise because of the pain caused. Nor did he remember to refer to the materials to reinforce the benefits of performing exercises as his focus was on avoiding pain, rather than self-management. Therefore, even when information is available, without a positive prompt the materials may not be used.

The practical application of skill information is not addressed by the PMC materials, as seen in Aspects 3, 5, 7, 8 and 10. Without prompts, these aspects can be forgotten either as instructions or as decision-making aids in particular situations. For example, patient 010 understood the benefits of breathing exercises from the training, but found remembering it challenging (Aspect 3),

010:   Again that might be that I need to stick some Post-it®s up around the place to remind me to take a deep breath… The fact that I have just taken a deep breath [means] I feel bit better.

For self-managers who have yet to realise the long-term benefits of self-management activities in physical or psychological improvements, memory of the benefits is solely based on their training (and from reference to the materials – Aspect 9). For some patients, this can be a challenge, as patient 010 demonstrates,

010: I think it would have to be some means of reminding me to do them [the exercises] and then I've got to find some exercises. It's all going to cause me some pain, and then it's the cost-benefit of it. The cost-benefit of it is more difficult for me to appreciate.

Tools, as alluded to by patient 010 above as "means" and as used by five other patients in the study, provide clues as to patients had attempted to resolve difficulties experienced in remembering aspects of the training. No pattern of tool usage is to be found as both inexperienced and experienced self-managers adopted tools, e.g. alarms/bleepers (recommended by the PMC) and lists, as outlined in Table 3.

Reminder	Skill	Use	Patient	Potential problems or Reported problems
List	Routine skills	Patient is groggy from her medication when waking. The list outlines her self-management activities for the day.	001	Patient may forget to refer to list.
Bleeper/ alarm	Pacing	To remind patient that time is up for a particular paced activity.	004, 006	Not always practical in a social situation.
Partner	Triggers	Patient's partner reminds her of what she should not do.	006	Partner may be absent.
Social cues	Pacing	Social timings and prompts act as a reminder when patient cannot use bleeper in a social situation.	004	Periods easily mistimed.
Monthly email	CBT	Patient receives prompt to reflect on new ways of thinking and techniques related to those new ways.	001	Only monthly and not personalised.
Post-it® notes	Exercise	Placed around the house reminders for patient to perform exercises.	004, 010	Can be removed by others or ignored.
Manual/ Leaflets	Exercise	Referred to when how to perform an exercise cannot be recalled.	003, 007	Relies on patient knowing what they are looking for or remembering to look.

Table 3.   Types of reminders patients use and their associated problems

Experience and Remembering

Patients' experience of integrating self-management and their level of skill habituation influence the types of reminders required. Inexperienced self-managers reported struggling with remembering to perform particular self-management activities, e.g. exercises, whereas the more experienced, who have managed to remember and integrate self-management skills, reported that skills were "second nature",

008:   …you know you sit down to watch a programme but [after] 5 minutes I will stand up, just have quick stretch and then sit down…

I: So, how do you remember to get up every 5 minutes?

008:   I don't know, I just do. It's just become sort of like a habit to me now.

Overall, the results suggest that the PMC-supplied materials support some forms of remembering.   However, as patients' adoption of other tools demonstrate, it is necessary for patients to have more than the PMC resources – particularly as patients face challenges outside the clinical setting which can interfere with remembering and, therefore, habituation of behaviours.

Patient Needs Identified

1. Help to remember to perform activities related to chronic pain management.

2. A way to postpone reminders to a more convenient time in response to unforeseen events.

3. Ability to easily refer to instructions for the self-management technique the patient needs to perform if they experience difficulties remembering the specifics of it.

4. Reminders of the benefits of self-management activities for particular skills, particularly when the activities may seem unappealing.

5. Help to remember the steps involved in fulfilling specific self-management activities. Help needs to be presented in such a way that the patient is able to perform each step, so enhancing patient reflection and skill development.

6. Help and encouragement with rehearsal of skills, which are only used in specific situations, such as banishing negative thoughts.

7. A way to identify personal pain triggers in the event of a crisis or flare-up (as identified at the hospital) and the self-management techniques which might assist with pain relief.   Such identification needs to enable effective pre-emptive behaviour to be taken and communications assisted if a GP visit is required.

8. Ability to set alarms for paced activities that prompt patients to stop or take a break from a particular activity that is known to cause discomfort after a period of time.

    If the break has a time limit, patients need to be reminded when to resume the activity.

9. Adaptable alarms and reminders that allow them to be used publicly without drawing unnecessary attention.

5.2.   Support and Encouragement

Other benefits, not discussed so far, patients derive from the clinical setting are social support and encouragement for self-management behaviour development. This section looks at factors inside and outside the clinical setting which affect support and encouragement for patient self-management.

Support from the PMC

Chronic pain patients reported a sense of isolation before attending the PMC, as patient 002 expressed,

002:   I try not to talk a lot about my medical problems to tell you the truth because… I think people get bored with you if you're always going on about your medical problems…

During COPE, patients can meet other pain sufferers which they reported reassured them that they "were not alone" and the pain was not "in their head". Both individual and COPE patients also gain support from practitioners' understanding of the pain experience. When self-management training is completed, patients are able to contact the practitioners at the PMC until they are finally discharged. This further reassures them, despite knowing there could be delays in receiving a response because of the practitioners' workload.

Despite this availability of practitioner contact, practitioner 01A reported that consistently fewer calls are received from patients than expected – only one (009) of the patients interviewed reported calling the centre. Practitioner 01A suspected that patients may feel that they should already know the answers which may discourage them from using this facility, although the patients gave multiple reasons – 1) they did not need help, or 2) they wanted to resolve a question independently, showing that certain patients had fully engaged with self-management. However, some patients require more than *ad hoc* telephone contact to help them overcome the challenges of making the transition to self-management outside the clinical environment. As patient 005 highlights,

005:   I felt slightly frustrated… …once we'd finished that was it sort of thing. But on the other hand… they can't keep babying you… You get to the point where you actually start to rely on them and I think a lot of people get like that because you have someone to talk to. You've got someone to help you about your pills a bit and I think it's quite difficult when you leave.

Practitioners are also mindful of this development of reliance upon them, as this can undermine the patients' ability to take responsibility for their pain self-management.

Support at Home

Patients may experience difficulties without support outside the PMC or may feel guilty when they perform self-management activities if the condition is not acknowledged by family members. A lack of support may also lead to resuming old habits, as patients are unable to integrate the self-management skills learned because of pressure to continue with previous activities, for example in their home life,

005:   I keep running around like a little blue-arsed fly. My husband's in a high-powered job and because he leads an extremely busy life, I have to manage the rest of our lives… I'm quite busy all the time.

Lack of support is recognised by practitioners as detrimental to self-management adoption – and adapting the programme to compensate for this lack of support is not possible because practitioners do not have time to assess the patient's home or personalise activities. However, when present, support can help to reinforce learned skills continuation; for example, patient 006's husband reminds her of her pain triggers and undertakes household chores when she cannot do them.

Peers

Any support perceived to be from other patients during COPE only lasted for the duration of the programme. Patients are used more as reference points to address patients' feelings of isolation and to compare situations. Patient 008 found the group supportive and enabling, while others – 001, 004 and 005 – found the patients not to be on their "wavelength", did not suffer from the same medical conditions or were "too negative" without the moderation of practitioners. Therefore, contact between patients after COPE tends to not last long, despite peer contact being recommended by practitioners.

When asked about other patients as sources of support, COPE patients were less interested than those individually treated, possibly attributable to COPE patients' negative experiences of other patients in their group. However, if contact was moderated by a practitioner, COPE patients regard contact with patients with comparable problems as a good source of information and tips.

GP Support

The patient's GP is the first point of medical contact during a flare-up, but GPs do not tend to collaborate with the PMC in delivering care, according to the practitioners. Even though GPs are informed when patients are discharged, some may have reservations about reinforcing the multidisciplinary self-management message and may even, according to practitioner 02A, negate that message with conflicting advice, e.g. take bed rest rather than stretch to relieve pain.

Furthermore, some GPs are reticent to change the PMC-prescribed polypharmacy as they do not understand its synergy or medication when reviewing its dosage and frequency. This reticence can prevent two successful self-management benefits – lowered reliance on pain control medication and lowered risk of side-effects – as well as excludes the patients from active participation in their care. This lack of collaboration with both the PMC and patients can also interfere with patients moving further with their self-management,

005: ...so I found the staff [at the PMC] very helpful and sympathetic... in fact I would very much like to talk to a couple of staff more because I am getting nowhere with my own doctor and he just pushes everything back to them and everybody just says "oh stay with the COPE you're on".

General Support

Our findings suggest that social support availability varies across patients and, when present, does affect self-management adoption. It is, however, difficult for the PMC practitioners to offer additional support, particularly as time constraints and lack

of understanding of patients' non-clinical environments prevent them addressing problems a patient may have in their support network. However, there are some patients with little support at home who may benefit from additional support from the PMC (or a device attached to the PMC) when they start to integrate self-management into their lives.

Patient Needs Identified

1. A way to contact the PMC and practitioners which supplements email and telephone modes of contact if patients experience difficulties making the transition outside the clinical setting with their self-management.

2. A way to elicit and receive feedback during the initial stages of their transition from guided to solo self-management when experiencing difficulties applying aspects of the training outside the clinical setting.

3. A way to find patients who have the same condition and comparable expectations of the relationship if the patient wishes to seek support from peers.

5.3.   Information Seeking and Use

Patients were motivated to source additional information to that provided by the PMC to help further understand and manage their condition. This information-seeking was found to start before self-management training, while the types of information referenced depended on the patient's diagnosis and treatment stage.

Three particular information seeking stages were, however, identified:

1. Sense-making – during initial stages of diagnosis and medical treatment;

2. Learning Support – during and after self-management training; and

3. Maintenance – long-term self-management.

Sense-making

Most patients interviewed had researched their condition (online, through subscription-based magazines and books) to make sense of their medical diagnosis, and gain understanding of their condition's aetiology and/or treatments available. Research by patients at this stage addresses some of the sense of isolation, as patients read about other patients with comparable problems.

During and After Training

During instruction, some patients indicated that practitioners had referred them to other sources of information – books and websites – in addition to the PMC-supplied materials. Despite being the most common form of information practitioners recommended, only patient 001 indicated sourcing or reading the suggested books. This may be attributable to the patient preference for the internet as a source of information during the sense-making stage.

Although websites are preferred, only one patient, (009) had been specifically referred to a website by PMC practitioners. This patient was, however, exceptional as she was undergoing medical treatment at the PMC, rather than taking part in a PMP, and she uses the website to help manage her mood and make sense of her treatment in the absence of formal CBT.

Maintenance

Patients who had progressed to habituated self-management found that they referred less to the PMC-provided materials as skills became internalised. Instead, patients require information that supports ongoing self-management and assists with new challenges at this stage.

The information patients seek includes:

1. Pain management in novel situations and events;

2. Medication, treatment, and future operations;

3. Symptoms;

4. Testimonials and tips from other patients;

5. Assistance available - government, occupational health, benefits, etc.;

6. Medical research and studies; and

7. Exercise and support groups.

When assessing sources of information, patients 009, for example, looks for targeted, trusted and regularly updated information on her condition, based on experiences of other patients, free of medical "jargon" and addressing the practical aspects of her treatment,

009: So when you are having a treatment, it is sometimes reassuring that you can read up about it and find out all about it beforehand. The medical literature you get isn't as helpful as it could be. You read through [the website] and somebody has had that operation or that treatment and it's worked for them. You can get some of idea and see what's going on.

Issues with Current Information Availability

The most common sources of information for patients are online or in subscription magazines. One appreciated aspect of the internet, magazines and books is that they enable patients to look for information in their own time. For example, although, patient 009 knows that she can phone a nurse during the day if she has problems, she prefers to use the website because it is there when she needs it.

Quality and relevance

Patients who researched their condition on the internet question the quality of the information available. The perception is that many websites feature non-moderated,

anecdotal evidence and represent commercial interests, encouraging patients to turn to only trusted sources, typically charities, hospitals and well-known clinics (e.g. Mayo Clinic).

Patients felt a lot of the information online and in magazines – even from trusted sources – falls short, however, for their specific issues and offers no personalisation capabilities. Furthermore patients like 007 did not know where to start looking for information that addressed multiple conditions together, while some patients, including 001, 004 and 009, reported accessing non-UK websites to find information on conditions which received little recognition in this country.

Types of Information Wanted

As well as condition-specific information, patients expressed frustration about how difficult it was to find information on non-medical assistance available to them. Practitioner 02A indicated that PMC staff assist patients with more than clinical information, such as disability benefits, work-related issues and occupational health services. And while some patients benefited from this, for example patient 009 who contacted social services for new crutches, not all did. For example, patient 004 was unable to find information either through the PMC or other sources about funding a specialised workstation, which was critical to his return to work.

This difficulty is compounded by patients' changing needs. As their conditions change so do their information requirements for government services and benefits. Patients were not aware of any centralised sources of this information. Even 009 reported that the website targeted to her condition did not have all information she required on assistance available.

Although peers were not regarded as appropriate sources of support, as reported in "Support and Encouragement", their testimonials and tips are viewed as good sources of self-management information, unlike contacts in chat rooms and forums. This reticence could be attributed to the quality of the information posted, as well as the veracity of people participating. Additionally, the PMC uses testimonials to reinforce the success of techniques. This information is not, however, readily available to patients, despite interviews highlighting its desirability because of its provision of practical illustrations of self-management.

Summary

It was found that patients at the maintenance stage require more practical information than during the earlier stages. Such information assists the patient to adapt to new situations and challenges that they face away from the PMC, one of the core skills taught at the PMC.

Patient Needs Identified

1. Ability to source information that is easy to find, up-to-date, uses non-medical language and is relevant to a patient's pain management needs.

2. Valid, trusted and non-commercially motivated information to address specific medical and practical concerns, related to initial diagnosis, prescription

medicines, medical procedures, symptoms, government assistance and benefits, and how to manage pain during major life events or situations.

3. Information should be delivered by a recognisable medical institution or charity that is trusted by patients.

4. Patient testimonials and tips providing ideas for improving self-management skills and knowledge.

CHAPTER 6.   Study 2 – Needs Validation – Method & Results

6.1.   Methodology

Study 2 seeks to validate the user needs identified in Study 1, while extending Phase 2 of De Rouck et al.'s (2008) methodology.

Participant Selection

Two patients were selected from previous interviewees based on:

- Sex;

- Duration away from the centre; and

- Positive self-management experience.

A third patient, 011, was chosen from the 14 respondents not interviewed in Study 1. Like participant 007 in Study 1, patient 011 had experience of both COPE and being treated individually, and – unlike many patients interviewed – was still a regular PMC attendee (see Table 4 for patient breakdown).

Patient	Age	Sex	Length of time since intervention	Programme
001	49	F	3.5 months	COPE
004	58	M	11 months	COPE
011	46	F	Ongoing – medical focus of treatment	COPE/Individual

Table 4.   Participant characteristics by selection criteria

Practitioner 02A was the only practitioner available of the four contacted.

Procedure

Thirty one "Patient Need Statements" generated in Study 1 (See Appendix 4) were sent by email to patients before the interview. Reviews of these statements (each of 90-minutes duration) were conducted in person or by telephone (based on patient preference). The need statements were revised or new ones created based on these interviews.

6.2.   Results

Benefits of Methodology

Study 2 was undertaken to demonstrate the benefits of validation with users as an additional stage in "Primary Exploration of User Group Needs" (De Rouck et al., 2008). Overall, this validation realised several benefits:

1. Targeted review, as an adjunct to the more open interview questions of Study 1, prompted patients to identify and explore further issues, leading to identification of additional needs (See Appendix 5 for changes breakdown).

2. Resulted in six additional needs statements and 11 new need amendments.

3. Provided an early view of possible scenarios of use as patients related needs to their own experiences.

4. Demonstrated different, yet complementary perspectives of patients and practitioner on the user needs, reported in "Patient and Practitioner Perspectives" following.

Summary of Needs Changes

The findings from the validation sessions (see Appendix 5 for full results) indicated that further needs exist for greater personalisation of feedback, facilities to deal with unexpected events and flare-ups, and further information. An example of such personalisation is patients' need to receive feedback on the whole of their self-management progress to allow them to assess their activities. A way of viewing this progress information is also requested to allow collaborative review with their practitioners at the PMC.

Facilities to deal with unexpected events and flare-ups within patients' routines are additional needs identified during validation. Study 1 identified the need to remember flare-up triggers but otherwise did not cover the impact of flare-ups and unexpected events on routines in detail. Study 2, however, enabled identification of the need to record how such events interfere with self-management. Another need identified is the ability to adjust schedules easily to reduce self-management activities to allow recovery following a flare-up without compromising the self-management routine. For example, patient 011 spoke of how she would like the opportunity to 'rewind' her self-management schedule if she has a flare-up of symptoms.

The PMC-provided information did not meet all patients' information needs. Study 1 identified needs for patient information, but did not address those of their families. Despite family members being invited to attend the PMC, Study 2 identified that those who cannot attend require a way to access information explaining the patient's condition and roles family members can fulfil in aiding self-management.

Patient and Practitioner Perspectives

Adopting a user-centred approach to validating needs resulted in views of those needs for goal-setting and progress tracking which were diverse, yet complementary and prompted by the different roles in pain self-management. Patients identified new practical needs (need for flexibility in choosing units for pacing, education for significant others and information on products and services). The practitioner's professional insight, meanwhile, resulted in a focus on supporting tacit skills, patient reflection and decision-making through personalisation of messaging and ensuring correct representation of skill mechanics.

These different perspectives were most apparent in "Goal-Setting and Progress Tracking". Patient 011 identified a need to review their progress with her medical practitioner and a need for greater flexibility with the units used in pacing. When presented with the same needs, the practitioner suggested a need for personalisation of feedback and encouragement based on a patient's progress.

CHAPTER 7.   Discussion

Chapters 4, 5 and 6 present the results of Studies 1 and 2 undertaken to trial a user-centred approach to eliciting user needs for chronic pain self-management that could be supported by technology. These needs demonstrated that patients face a range of challenges maintaining self-management behaviours after regular practitioner supervision ceases.

The telemedicine research, within which our study exists, is more commonly associated with patient evaluations of practitioner-informed systems (De Rouck et al., 2008) than user-centred approaches. The findings of our study will be discussed in light of this existing research and the user-centred design approach, with patient needs identified and validated in our study providing the framework for this discussion.

7.1.   Skill Development

Learning Style

Our findings suggest that self-management training and materials need personalisation and the capability to support different learning styles. It was found, however, that the teaching and materials provided during COPE did not meet these needs owing to practitioner time constraints. Furthermore, and despite having more time *pro rata* with practitioners, even individually treated patients were given generic materials which they may find difficult to use outside the clinical environment.

Generic booklets, however, can be effective in positively enhancing self-management behaviours (Udermann et al., 2004) and can lead to clinical improvements (Coudeyre et al., 2006). Healthcare education material selection and presentation are also important if patients are to be engaged (Burton et al., 1999), while increasing relevance of health materials to a specific patient can further influence comprehension and behavioural change (Kreuter & Holt, 2001). Additionally, materials need to be suitable for patient's health literacy, as this has been found to affect compliance with health management (Bass, 2005).

Certain patients also experience difficulties in the learning and application of self-management skills, because of the lack of applicability of the teachings to them. These findings on personalisation and learning style are supported by Pryor & Jannings's (2004) theory that patients' learning style – either self-directed or dependent – determines the style of instruction they require in a clinical setting.

Making the transition to being self-directed requires patients to understand the relevance of the material to their circumstances (Pryor & Jannings, 2004). This is something that one patient (005) in our study struggled with, and provides explanation as to why her self-management, particularly CBT, had not progressed. Technology can provide the ability to fulfil these personalisation needs, so its ability to deliver this capability should be investigated in the chronic pain domain to enhance patient use and learning.

Goal-Setting, Progress Tracking, Feedback and Reinforcement

Our results suggest patients need assistance setting self-management goals outside the clinical setting. At the PMC, practitioners and patients collaborated on goal identification and fulfilment planning, but when away from the PMC, patients were found to not develop goals to sufficient levels of difficulty and specificity (Playford et al., 2000), or did not set any goals to avoid disappointment caused by non-completion (Guck et al., 2008). Goal-setting was further complicated by the greater administrative effort required of patients if activities to attain the goal required a pacing strategy.

These findings suggest that prompting for creation and inspiration of patient-specific goals and development of existing goals is required – particularly as goals are an important moderator of functional improvement (Tan et al., 1997) and personalisation of goals is crucial to behaviour change (Bandura, 2001). Goals need to be of moderate difficulty to be encouraging (Locke & Latham, 2002), but how specific goals must be to be effective for pain patients requires further investigation as studies in healthy populations do not easily transfer (Gyurcsik, Estabrooks, & Frahm-Templar, 2003).

Technology-assisted collaborative goal-setting has been shown to be a useful supplement to primary care interventions for Type II diabetes patients (Glasgow et al., 2002; Levetan, 2002). The complexity of pain management goals (physical and psychological) may also be more difficult to automate than those of diabetics where specific quantitative goals are plentiful (e.g. reduction in blood glucose level).

Although no such technological assistance has been applied to chronic pain, the PGPQ (Patient Goal Priority Questionnaire) has been used to identify chronic pain patients' physical behavioural goals (Åsenlöf, Denison & Lindberg, 2004). Questionnaires such as this could be trialled in an interactive form to assist patients with goal-setting and potentially remove associated administrative burdens, as demonstrated by "ViTo" in the preventative healthcare domain (Nawyn, Intille & Larson, 2006).

Furthermore, patients were found to need meaningful and encouraging ways to store and review goal progress, as goal-setting and feedback promote motivation and adherence (Earley et al., 1990; Locke & Latham, 2002). Research on goal-setting in primary care focuses on collaborative (patient/practitioner) rather than independent goal-setting and tracking, (Glasgow et al., 2002; Von Korff et al., 1997). However, when patients can independently review progress, health indicator improvements can result, as shown by trials of technological devices for diabetics to receive feedback and monitor their diet and blood glucose readings (Ma et al., 2006; Tsang et al., 2001).

Practitioners provided feedback on patients' personal progress during attendance at the PMC. This positive reinforcement and feedback through "performance achievements" has been shown to increase self-efficacy beliefs in patients and promote continuation of self-management behaviours in the face of obstacles (Elder, Ayala & Harris, 1999; Locke & Latham, 2002; Turk & Okifuji, 2002). A structured way to receive this reinforcement was found, however, to be missing after patients ceased PMC attendance.

Studies based on electronic data collected from adult diabetes patients leading to personalised feedback from practitioners (Ma et al., 2006) or via an automated system (Tsang et al., 2001) have shown that technological delivery of such feedback can positively affect reinforcement of self-management behaviours. Additionally, ubiquitous computing studies have looked at activity data collection and feedback provision to promote behavioural change (Nawyn, et al., 2006). The only delivery mode found for personalised feedback for chronic pain patients was the telephone, enabling patients to collect monthly reports on CBT progress. Although infrequent, this feedback was well-received by patients and gave them a sense that there was practitioner interest in their progress (Naylor et al., 2002).

Routine Development

This study also identified routine as central to self-management continuation. As some patients struggle to transfer the routine established in the PMC to their everyday lives, patients need support developing a routine during and after training.

Clinical research into PMPs mostly concentrates on measuring treatment efficacy (Newman, et al., 2004), rather than identifying specific practical obstacles faced by patients such as routine development (Turk & Okifuji, 2002). Little is known as to why routine development is so difficult, although this lack of knowledge could be attributable to patients' difficulties in articulating how they develop their routines (Monk, 2000). Our study has identified that lack of routine could result from the additional administrative burden routine development imposes on patients.

Remembering

As well as assistance in developing a routine, patients also were found to require assistance in remembering routine activities, alongside a wide range of other self-management aspects, e.g. technique application and activity benefits. Some patients attributed their inability to remember to medication, although a negative clinical relationship between medication, concentration and memory, (Munõz & Esteve, 2005, Schnurr & MacDonald, 1995; Dick, Eccleston & Crombez, 2002) has not been established.

The relationship between chronic pain and reported memory deficiency is, however, acknowledged (Schnurr & MacDonald, 1995; Dick, et al., 2002). These deficits have been attributed to pain-induced emotional distress (Munõz & Esteve, 2005). The difference between reported memory difficulties and those which consider the effects of medication studied in the laboratory such as Schnurr et al., (1995) may also be contextually derived. For example, memory studies in chronic pain patients focus on performance of administered tests in isolation rather than within the context of their everyday activities. Therefore, tools that can be used in an everyday setting are recommended to aid and assist patients in remembering self-management activities – and inspire confidence in those memories.

Patients use tools to remind them about self-management activities. These tools are most important for inexperienced self-managers whose skills and routines have not reached habituation. Using technology to deliver reminders to mobile phone and PDA and to monitor response to those reminders has been successfully implemented for the elderly and memory impaired – "Memojog" (Morrison, Szymkowiak &

Gregor, 2004) – and for teenage diabetics – "Sweet Talk", which used a database to generate SMS reminders of self-management goals and their benefits (Franklin, et al., 2006).

Remembering benefits of particular activities was found to be a problem for patients in our study and discouraged performance of those activities. Reinforcing the benefits of particular behaviours and their relationship to patient goals is important (Locke & Latham, 2002) to promote continuation. However, technology has yet to be used to reinforce the benefits of self-management activities for chronic pain, unlike diabetes where research has shown reinforcing behaviours through personalisation and association of self-management goals and health benefits encourages short-term improvements (Franklin et al., 2006; Levetan et al., 2002).

Some patients in our study use practice or email prompts to reinforce infrequently used skills, such as CBT, which are difficult to remember unless rehearsed. Using technology this way to rehearse skills has been successfully used as a training adjunct to boost skill development and encourage practice and remembering (Naylor et al., 2002).

Other less frequently used skills, such as pre-empting symptoms to manage and prevent flare-ups, were also found in our study to require attention. Technology can facilitate such pre-emptive behaviour, as demonstrated by the use of random prompts in combination with personalised coaching to encourage reflection (Sorbi et al., 2007). In the short-term, Sorbi et al.'s approach can also be applied to pain patients to habituate attention to pain triggers and remedial action; however, the random prompts could ultimately irritate some patients (Sorbi et al., 2007).

As discussed, aids developed to assist patient recall and prompt actions have focused on a variety of areas – event reminders, associating benefits with actions, skill mechanics and action prompts. Unlike studies targeting specific aspects of skill prompt and recall, our study identifies a broad spectrum of remembering issues affecting skill habituation. It is, therefore, recommended that this spectrum is considered within the resulting support to ensure all patients' practical self-management concerns are addressed.

7.2.   Patient Social Support and Encouragement Needs

Social support is important during establishment and maintenance of self-management (Jamison & Virts, 1990; Holtzman, Newth & Delongis, 2004). As our study shows when support ceases, for example after leaving the PMC, some patients can fail to fully adopt and use self-management techniques. This was found to be the case especially if patients have chaotic home lives or no support from family members, as family members can play a significant role in pain management (Keefe et al., 1999).

Patients identified PMC practitioners as the best source of support, rather than their GPs or peers. PMC practitioners, however, were mindful that providing too much support could undermine patient development of independent self-management. GP support was also perceived to be lacking, which could be attributable to GPs' beliefs about pain, its sources and treatments (Coudeyre et al., 2006; Rainville et al., 2002). And while COPE patients were encouraged to stay in contact with each other

for support, they expressed a preference for practitioner-moderated contacts because of past negative experiences with peers.

Facilitating social support through technology in chronic conditions has concentrated on the use of practitioners (Ma et al., 2006; Naylor et al., 2002; Sorbi et al., 2007), peers (Heisler & Piette, 2005) or a combination of both to promote self-management behaviours and coping via forums, message boards (Boburg et al., 1995; Winzelberg et al., 2003) and email discussion groups (Lorig et al., 2002).

Despite technology and the internet easily facilitating peer contact, unless the match is right across multiple factors, this capability may not result in successful use of peer support (Heisler & Piette, 2005). Patients in our study expressed concerns about the intentions of others and expressed reticence to engage with peers in this way, suggesting further research is required into needs and motives of pain patients who do seek support online (White & Dorman, 2001).

Involving practitioners in patient support is expensive, prompting trials of alternatives, for example practitioner-recorded monthly messages (Naylor et al., 2002) and full automation of reinforcement and feedback (Kaplan et al., 1999; Tsang et al., 2001). Automated system may, however, not meet the expectations of patients (Kaplan et al., 1999).

The results of our study and others suggest that PMC patients may benefit from personalised feedback from PMC practitioners during the initial stages of the transition to solo self-management (e.g. Naylor et al., 2002) or from practitioner-moderated forums (Winkelman & Choo, 2003). Any introduced facility, though, requires care to ensure patients do not become over-reliant on the support provided (Winzelberg, et al., 2003). What's more, such interventions would require economic and organisational feasibility evaluation for the PMC (Schulz et al., 2007).

7.3.   Patient Information Needs

Problem-solving and decision-making required in self-management of chronic conditions require the right information (Lorig & Holman, 2003). Consistent with other studies, our study found that patients have a desire to learn about their condition (Washington et al., 2008) and viewed information as important to self-management. The stage of treatment patients are in determines these information requirements. Three stages were identified – 1) sense-making, 2) during and after the course and 3) maintenance.

Generally, patients use compact, accessible forms of information, e.g. websites and magazines, rather than books recommended by PMC practitioners, to address their medical and practical concerns. Unlike charity-affiliated magazines, which have the support of a organisation perceived to be knowledgeable about the condition they represent, the source and validity of online information are questioned and prompt patients to choose only medical or charity-affiliated websites. These concerns are not unfounded; studies reviewing chronic pain (Washington et al. 2008) and arthritis websites (Ansani et al., 2005; Suarez-Almazor, Kendall & Dorgan, 2001) indicate that websites vary in quality.

Aside from quality concerns, patients experienced difficulties finding information that met their specific needs in magazines, websites and books. This is not specific to chronic pain, though, as reviews of diabetes websites suggest that such websites do not use interactivity to present information specific to particular users (Bull et al., 2005). The multidisciplinary nature of chronic pain and the lack of common chronic pain condition aetiology (Newman et al., 2004) further complicate tailoring of information delivery.

Tailoring websites to meet patients' information needs requires a lot of content which may be perceived as excessively time-consuming by practitioners to create and maintain (Schulz, et al., 2007). However, when websites do have this capability, they can have positive effects on self-management indicators in chronic pain patients – healthcare visits, exercise and painkiller use (Schulz, et al., 2007) – and HIV patients (Boburg et al., 1995).

Although studies have shown patient benefits from self-management adherence, the economic impact of dedicating practitioner time to generating website content versus the economic impact of not providing it has not been investigated. Such investigation will ultimately determine if maintenance of medical websites for patient use is an efficient use of medical funds.

This has prompted suggestions for alternatives to practitioner-managed websites, such as virtual communities (Winkelman & Choo, 2003). Our study identified that patients view peer-provided tips and testimonials as good sources of information. However, it is difficult for patients to find these information types, which could be resolved by virtual communities of practice. Introducing such communities is particularly important as self-management of conditions like chronic pain transforms patients from being healthcare consumers to participants and experts in care (Winkelman & Choo, 2003; Lorig & Holman, 2003). Therefore, the self-management knowledge of such participants could be harnessed to assist others (Winkelman & Choo, 2003).

Study 2 identified that – in addition to patient information – the provision of educational resources was required to assist families to cope and better support patients outside the PMC. Although, patients' families can attend the PMC, attendance was relatively rare as demonstrated by only 27% of patient family members attending (according to COPE statistics).

Providing information which is accessible outside the PMC is, therefore, important because family members play a significant role in patients' pain experience, care and self-management success (Keefe et al., 2001; Snelling, 1993) and also require help coping with the patients' condition (Lim & Zebrack, 2004). The literature suggests, however, that despite this requirement, information provided is generally targeted at patients rather than family members – before such information is readily available, there needs to be an understanding of the information and training needs of patient families (Houts et al., 1996).

7.4. User-centred Approach

Trials of chronic pain self-management support technology, as seen in the studies (Lorig et al., 2002; Naylor et al., 2002; Schulz et al, 2007; Sorbi et al., 2007), were

found to address some but not all the patient needs identified in our study (See Table 5 for how these studies' needs compare with those found in our study). An example of this is Naylor et al.'s (2002) CBT skill development tool (TIVR) which addresses rehearsal, feedback and reinforcement of important, but infrequently used psychological skills.

Naylor et al. (2002) used research literature and training course material to inspire development of the system, rather than taking a user-centred approach. This led to the system addressing specific needs successfully during evaluations with patients, but it would fail to meet the needs of chronic pain patients who had mastered CBT but struggled with other aspects of self-management. For example routine development was not addressed by Naylor et al., yet was found to be important to self-management success in our study.

While studies such as Naylor et al.'s provide insight into self-management and potential modes of support delivery, they do not specifically address all end-user's needs (van't Reit et al., 2001). Furthermore, by basing the technology solely on the literature and course teachings, subtle but important needs can be overlooked because practitioners and patients have different views of self-management (Holman & Lorig, 2000).

The user-centred investigations of Studies 1 and 2 found that patients and practitioners' views of self-management are different, but complementary and what is provided in the clinical setting may not easily transfer to other environments. For example, when suggesting need statement changes, in Study 2, the practitioner's main interest was promoting the self-management ethos – decision-making and reflection. Patient interests were, however, as self-managers and focused on the detailed practicalities of self-management, e.g. specifics of information needed and types of feedback required. Both viewpoints are required, though – the PMC practitioners understand the skills, their effectiveness and the general difficulties patients face, while self-managing patients better know the specifics of obstacles to self-management and work-arounds (Holman & Lorig, 2000; Turk & Okifuji, 2002).

As chronic conditions become more prevalent, focus of treatment has changed from patient as passive consumer (acute conditions) to patient as active participant (chronic conditions) (Holman & Lorig, 2000). The context of treatment in chronic conditions has also changed from the clinical setting as the primary place of care to the patients' home and workplace. Unfortunately, there is some lag in realising this within health services (Holman & Lorig, 2000) and this may explain why telemedicine's focus for self-management support applications has been based so far on practitioner-led needs analysis rather than being patient-centred.

| Chronic Pain Study | Discipline Supported | | General Needs Identified in PMC Patients | | | | | | | | | | | |
| | | | Skill Development | | | | | | External Support | | | Information | | |
	Psychology	Physiology	Learning Style	Routine Development	Goal-Setting	Progress Tracking Review	Feedback	Remembering and Rehearsal	Practitioner Support	Practitioner-moderated Peer Support	Peer Support	Patient-tailored Information	Peer Information	Practitioner-moderated, Peer-provided
OneSelf information website (Schulz, et al., 2007)	o	x	o	o	o	o	x	o	x	x	x	x	x	x
Back Pain Email Discussion Group (Lorig et al., 2002)	x	o	o	o	o	o	o	o	x	x	x	o	x	x
TIVR (Naylor et al., 2002)	x	o	o	o	o	o	x	x	x	o	o	o	o	o
PDA for Chronic Migraine Sufferers (Sorbi et al., 2007)	x	x	x	o	o	o	x	x	x	o	o	x	o	o

Key

o   Need not addressed by study

x   Need addressed by study

Table 5.   Comparison of needs identified in our study and needs addressed by other chronic pain studies

7.5. De Rouck et al.'s Methodology

Our study, as a follow-up to De Rouck et al. (2008), demonstrates that their telemedicine-specific methodology can elicit meaningful needs from patients and practitioners. Furthermore, because patients possess practical knowledge of self-management, such involvement of patients is necessary (van't Reit et al., 2001).

Extending De Rouck et al.'s methodology with need statement validation within Phase 2 was found to lead to the identification of further need statements and revisions to existing ones. This may be because patients could review the problems they faced in a structured way that enabled them to articulate the support required. In Study 1's standard interviews, our interviewer needed to identify patient obstacles, rather than the patients articulating them directly, as patients may find it difficult to recognise obstacles requiring assistance that are often habitual and everyday (Beyer & Holtzblatt, 1999). Additional iterations of De Rouck's Phase 2 through the more complex patient needs would also be beneficial to ensure fuller need statement specification, e.g. "Information" and "Learning Style".

Despite achieving successful results through this methodology, the application did not strictly follow De Rouck et al. (2008). Practitioner and PMC access was limited, so validating epidemiology, and organisational and technical feasibility, through initial collaboration with stakeholders (De Rouck et al.'s suggestion for inclusion in Phase 1) did not occur. Therefore, as patients − rather than practitioners − provided the first view of the programme, the researcher's perspective remained initially entirely patient-focused. This lack of access early on to the PMC is not without implications, which will be discussed in "Methodological Concerns & Future Directions".

7.6. Methodological Concerns & Future Directions

By applying a user-centred approach, it was possible to efficiently and effectively realise an understanding of patient needs and practical problems experienced by patients. Despite concerns with De Rouck et al.'s methodology, our study makes three notable contributions to existing telemedicine and HCI research:

1. Identification of complex themes moderating self-management adoption and the gap between what patients need and what time-constrained practitioners can provide.

2. Trialled and demonstrated the applicability of a validation step to extend De Rouck et al.'s, (2008) Phase 2.

3. Demonstrated the validity of user-centred, rather than practitioner-led, approaches to the identification of patient chronic pain self-management needs for technological support.

Despite making these contributions, the approach taken is not without issues, nor does it preclude further research.

Participant involvement

It is unknown if chronic pain condition affects a patient's particular needs for self-management support as our study's overall methodology did not include practitioner validation of respondents. Control over the types of pain conditions represented was, therefore, not enabled and should be investigated to determine if there are specific needs associated with particular pain conditions. However, the results of our study remain valid because a range of conditions and disability levels were presented in the patients interviewed and the goal of the study was to identify generalised needs for tools to support non-condition-specific, multidisciplinary teachings.

Average age of patients interviewed – 55 – differed to the PMC average (44, according to COPE statistics[2]). The literature suggests that while pain management intervention success is not age-dependent (Gagliese & Melzack, 1997), there is no consensus on whether age influences psychological coping (Turk, Okifuji & Scharff, 1995; Herr, Mobily & Smith, 1993), pain experience (Sorkin et al., 1990) or pain perception (Gibson & Farrell, 2004; Gibson et al., 1994). So it is difficult to determine whether age difference between the sample studied and the PMC average affects the validity of this study's results. A wider age sample could substantiate whether age does have an effect and so eliminate doubts about the results' generalisation.

According to COPE statistics[2], 29% of PMC patients are in full-time employment, while 63% are unable to work because of their condition. No patient involved in our study was in full-time employment. Although contextual factors are acknowledged to influence self-management behaviours, the impact of employment as a contextual factor on self-management has not been established (Munir, Leka & Griffiths, 2005). Therefore, it is not possible to determine whether these results can be generalised to include another – and major – moderating context, the workplace. As such, further investigation would determine if non-working patients' needs can be generalised to those in employment and whether employer involvement affects self-management behaviours (as reported by our study's practitioners) beyond a patient's willingness to disclose a chronic condition in the workplace (Munir et al., 2005).

Methodology

Working within a highly regulated environment (with question approval required before they could be posed to patients) precluded full application of Grounded Theory's incremental questioning (Corbin & Strauss, 2008). Not building questioning from patient to patient was, however, mitigated by our methodology's validation step in Study 2. The researcher's experience of Grounded Theory may have also influenced the extent of results reported and needs identified.

Furthermore, strict application of De Rouck et al.'s Phase 1 could have resulted in a more representative selection of chronic pain patients. But it is undefined how necessary this stage is, particularly when access to practitioners is limited – and whether any results would be compromised without it. De Rouck et al. give no

---

[2] Only COPE statistics available from PMC.

indication as to whether the methodology can be adapted to resolve such issues. This contrasts with more mature methodologies, such as Grounded Theory (Corbin & Strauss, 2008), which state the scope for flexibility.

De Rouck et al.'s methodology proposes progressing from Phase 2 to Phase 3 – "Writing Social Use Cases" (in collaboration with stakeholders) – to elaborate patient needs through scenarios of use. Additional validation of our study's results could, however, determine the influence of factors such as age, type of pain condition and employment before elaborating needs in Phase 3. Such validation would need to be undertaken with patients (selected in collaboration with practitioners) and with a practitioner sample.

Other research identified

Our study identified broad and extensive patient needs that could be supported technologically to assist chronic pain self-management. Yet some categories, for example "Information" and "Learning Style" mentioned in "Study 1 – Needs Elicitation Results", were not fully defined. Therefore, further investigation of these categories is warranted through iterations of De Rouck et al.'s Phase 2.

Additionally, our study focused on determining patient needs unconstrained by the feasibility of fulfilment, which could bias the results as medical practitioners can misconstrue the capabilities of – and workload required to maintain – telemedicine tools (Kearney et al., 2006). Therefore, further investigation is required to determine the influence of financial and organisational constraints on the feasibility of supporting specific needs through technology, with initial assessments against each patient need statement determining the extent of any constraint's influence. These initial assessments could then be challenged during and after prototype evaluation.

CHAPTER 8.   Conclusion

Multidisciplinary treatment programmes for chronic pain patients, as offered by the PMC, deliver pain management services to patients with long-standing chronic conditions. Part of this treatment is teaching pain management skills to transfer responsibility of daily pain management to the patient.

By adapting the user-centred methodology of De Rouck et al. (2008), our study results in a fuller understanding of the difficulties experienced (and possible contexts of use) by patients when transitioning from PMC guidance to self-management. The need statements identified can then be used to ensure that any technological support proposed would fully address patients' problems adopting and adhering to self-management.

Furthermore, adding validation to De Rouck et al.'s methodology demonstrates there are different, but complementary views on self-management support needs. By involving patients and practitioners – and validating need statements, our study results in a wider view of needs than those defined through the more common practitioner-led focused studies. Our view of needs should provide the necessary inputs for the design stages and ultimately result in better technological support for self-management (van't Riet et al., 2001).

Comparison of our need statements with those used in previous telemedicine research suggests that our approach creates a richer picture of needs as it includes different, yet complementary patient and practitioner perspectives on self-management support needs. For example, our richer view included needs such as routine development and aspects of remembering (which were practical and not directly related to skill development) which were not addressed in the telemedicine chronic pain studies reviewed.

Our study also identifies that patients experience practical obstacles when integrating self-management into their context which can inhibit their ability to develop and habituate the skills learned in the clinical setting. Addressing the needs associated with resolving these obstacles will further assist patients with the learning and skill development required to be successful pain self-managers.

Furthermore, by uncovering a fuller collection of needs, our study provides a basis for decision-making on how to support and prioritise patients' needs. With a fuller collection results, though, comes a more complex view of patient self-management needs – some of which require further research to elaborate, for example catering to different patient learning styles and information types required by patients. Without further research, though, these needs will not be elaborated to the required level necessary to continue to the next stage of De Rouck et al.'s methodology, creation of "Writing Social Use Cases".

Although our study includes a diverse group of patients, age, chronic pain condition and employment factors are not accounted for and require further investigation to ensure that any ensuing design caters for all patients. Another area which requires further research is the organisational and economic feasibility of such

support provision, as it is acknowledged that this would have an impact on what patient needs to support and how to support them.

The user-centred approach applied makes demands on both organisations and participants – and aspects of De Rouck et al.'s methodology adopted for this study were unsuited to highly regulated and resource-constrained domains. But while chronic pain is treated in such domains, self-management requires greater acknowledgement of the patient as participant and expert (Holman & Lorig, 2000), making a user-centred approach highly suitable to understanding patients' practical application of self-management and how that can be supported effectively.

References

Åsenlöf, P., Denison, E., & Lindberg, P. Behavioral goal assessment in patients with persistent musculoskeletal pain. *Physiotherapy Theory and Practice,* 20(4), 243-254.

Ansani, N. T., Vogt, M., Henderson, B. A., McKaveney, T. P., Weber, R. J., Smith, R. B., et al. (2005). Quality of arthritis information on the Internet. *American Journal of Health-System Pharmacy,* 62(11), 1184-1189.

Arnstein, P., Vidal, M., Wells-Federman, C., Morgan, B., and Caudill, M. (2002). From chronic pain patient to peer: Benefits and risks of volunteering. *Pain Management Nursing*, 3(3):94-103.

Ashburn, M. A., & Staats, P. S. (1999). Management of chronic pain. *Lancet, 353*(9167), 1865-1869.

Balas, E. A., Boren, S. A., & Griffing, G. (1998). Computerized management of diabetes: a synthesis of controlled trials. *In the Proceedings of AMIA Annual Symposium* (pp. 295-299). Bethesda, MD: American Informatics Association.

Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of. Psychology,* 52, 1-26.

Bass, L. (2005). Health literacy: implications for teaching the adult patient. *Journal of Infusion Nursing*, 28(1), 15-22.

Beyer, H. & Holtzblatt, K. (1999). Contextual design. *Interactions*, 6(1), 32-42.

Boberg, E. W., Gustafson, D. H., Hawkins, R. P., Chan, C. L., Bricker, E., Pingree, S., et al. (1995). Development, acceptance, and use patterns of a computer-based education and social support system for people living with AIDS/HIV infection. *Computers in Human Behavior*, 289-311.

Bull, S. S., Gaglio, B., McKay, H. G., & Glasgow, R. E. (2005). Harnessing the potential of the internet to promote chronic illness self-management: diabetes as an example of how well we are doing. *Chronic Illness,* 1(2), 143-155.

Burton, A. K., Waddell, G., Tillotson, K. M., & Summerton, N. (1999). Information and advice to patients with back pain can have a positive effect. A randomized controlled trial of a novel educational booklet in primary care. *Spine,* 24(23), 2484-2491.

Cavanagh, Shapiro, Den Berg, V., Swain, Barkham, & Proudfoot. (2006). The effectiveness of computerized cognitive behavioural therapy in routine care. *British Journal of Clinical Psychology,* 45(4), 499-514.

Celler, B. G., Lovell, N. H., & Basilakis, J. (2003). Using information technology to improve the management of chronic disease. *Medical Journal of Australia, 179*(5), 242-246.

Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory - 3rd ed.* London: Sage Publications.

Coudeyre, E., Givron, P., Vanbiervliet, W., Benaïm, C., Hérisson, C., Pelissier, J., & Poiraudeau, S. (2006). The role of an information booklet or oral information about back pain in reducing disability and fear-avoidance beliefs among patients with subacute and chronic low back pain. a randomized controlled trial in a rehabilitation unit]. *Annales de Réadaptation et de Médecine Physique,* 49(8):600-608.

Coudeyre, E., Rannou, F., Tubach, F., Baron, G., Coriat, F., Brin, S., Revel, M., & Poiraudeau, S. (2006). General practitioners' fear-avoidance beliefs influence their management of patients with low back pain. *Pain*, 124(3):330-337.

Coyle, D., Doherty, G., Matthews, M., & Sharry, J. (2007). Computers in talk-based mental health interventions. *Interacting with Computers, 19*(4), 545-562.

Department of Health (2005b). *Self care - A real choice: Self care support - A practical option*. Retrieved August 5, 2008, from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/Publications PolicyAndGuidance/DH_4100717.

De Rouck, S., Jacobs, A., & Leys, M. (2008). A methodology for shifting the focus of e-health support design onto user needs: A case in the homecare field. *International Journal of Medical Informatics,* 77(9), 589-601.

Dick, B., Eccleston, C., & Crombez, G. (2002). Attentional functioning in fibromyalgia, rheumatoid arthritis, and musculoskeletal pain patients. *Arthritis and Rheumatism,* 47(6), 639-644.

Earley, C., Northcraft, G., Lee, C., & Lituchy, T. (1990). Impact of process and outcome feedback on the relation of goal setting to task performance. *The Academy of Management Journal*, 33(1), 87-105.

Elder, J. P., Ayala, G. X., and Harris, S. (1999). Theories and intervention approaches to health-behavior change in primary care. *American Journal of Preventive Medicine*, 17(4), 275-284.

Franklin, V. L., Waller, A., Pagliari, C., & Greene, S. A. (2006). A randomized controlled trial of Sweet Talk, a text-messaging system to support young people with diabetes. *Diabetic Medicine*, 23(12), 1332-1338.

Gagliese, L., & Melzack, R. (1997). Chronic pain in elderly people. *Pain*, 70(1), 3-14.

Gibson, S. J., & Farrell, M. (2004). A review of age differences in the neurophysiology of nociception and the perceptual experience of pain. *The Clinical Journal of Pain*, 20(4), 227-239.

Gibson, S. J., Katz, B., Corran, T. M., Farrell, M. J., & Helme, R. D. (1994). Pain in older persons. *Disability and Rehabilitation,* 16(3), 127-139.

Glasgow, R., Toobert, D., Hampson, S., & Strycker, L. (2002). Implementation, generalization and long-term results of the "choosing well" diabetes self-management intervention. *Patient Education and Counselling,* 48(2), 115-122.

Guck, T., Willcockson, J., Schmidt, R., & Criscuolo, C. Attributions Regarding Unmet Treatment Goals After Interdisciplinary Chronic Pain Rehabilitation. *The Clinical Journal of Pain*, 24(5), 415-420.

Gyurcsik, N. C., Estabrooks, P. A., & Frahm-Templar, M. J. (2003). Exercise-related goals and self-efficacy as correlates of aquatic exercise in individuals with arthritis. *Arthritis and Rheumatism*, 49(3), 306-313.

Heisler, M., & Piette, J. D. (2005). "I help you, and you help me": facilitated telephone peer support among patients with diabetes. *The Diabetes Educator*, 31(6), 869-879.

Herr, K. A., Mobily, P. R., & Smith, C. (1993). Depression and the experience of chronic back pain: a study of related variables and age differences. *The Clinical Journal of Pain*, 9(2), 104-114.

Holtzman, S., Newth, S., & Delongis, A. (2004). The role of social support in coping with daily pain among patients with rheumatoid arthritis. *Journal of Health Psychology*, 9(5), 677-695.

Houts, P. S., Nezu, A. M., Nezu, C. M., and Bucher, J. A. (1996). The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Education and Counseling*, 27(1):63-73.

Jamison, R., Raymond, S., Levine, J., Slawsby, E., Nedeljkovic, S., & Katz, N. (2001). Electronic diaries for monitoring chronic pain: 1-year validation study. *Pain*, 91(3), 277-285.

Jamison, R., & Virts, K. (1990). The influence of family support on chronic pain. *Behaviour Research and Therapy*, 28(4), 283-287.

Kaplan, B., Farzanfar, R., & Friedman, R. H. (1999). Ethnographic interviews to elicit patients' reactions to an intelligent interactive telephone health behavior advisor system. *In the Proceedings of AMIA Annual Symposium* (pp. 555-559). Bethesda, MD: American Informatics Association.

Kearney, N., Kidd, L., Miller, M., Sage, M., Khorrami, J., McGee, M., et al. (2006). Utilising handheld computers to monitor and support patients receiving chemotherapy: results of a UK-based feasibility study. *Supportive Care in Cancer*, 14(7), 742-752.

Keefe, F. J., Caldwell, D. S., Baucom, D., Salley, A., Robinson, E., Timmons, K., Beaupre, P., Weisberg, J., and Helms, M. (1999). Spouse-assisted coping skills training in the management of knee pain in osteoarthritis: Long-term follow-up results. *Arthritis Care & Research*, 12(2):101-111.

Kerns, R. D., & Rosenberg, R. (2000). Predicting responses to self-management treatments for chronic pain: application of the pain stages of change model. *Pain*, 84(1), 49-55.

Kreuter, M., & Holt, C. (2001). How do people process health information? Applications in an age of individualized communication. *Current Directions in Psychological Science*, 10(6), 206-209.

Levetan, C. S., Dawn, K. R., Robbins, D. C., & Ratner, R. E. (2002). Impact of computer-generated personalized goals on HbA(1c). *Diabetes Care,* 25(1), 2-8.

Lim, J-W., & Zebrack, B. (2004). Caring for family members with chronic physical illness: A critical review of caregiver literature. *Health and Quality of Life Outcomes*, 2. Retrieved August 27, 2008, from http://www.hqlo.com/content/2/1/50

Locke, E. A. and Latham, G. P. (2002). Building a practically useful theory of goal setting and task motivation. a 35-year odyssey. *The American Psychologist*, 57(9), 705-717.

Loeser, J. D., & Melzack, R. (1999). Pain: an overview. *Lancet*, 353(9164), 1607-1609.

Lorig, K. R., & Holman, H. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1-7.

Lorig, K. R., Laurent, D. D., Deyo, R. A., Marnell, M. E., Minor, M. A., & Ritter, P. L. (2002). Can a Back Pain E-mail Discussion Group improve health status and lower health care costs?: A randomized study. *Archives of Internal Medicine*, 162(7), 792-796.

Ma, Y., Olendzki, B. C., Chiriboga, D., Rosal, M., Sinagra, E., Crawford, S., et al. (2006). PDA-assisted low glycemic index dietary intervention for type II diabetes: a pilot study. *European Journal of Clinical Nutrition*, 60(10), 9.

Maruta, T., Swanson, D. W., & McHardy, M. J. (1990). Three year follow-up of patients with chronic pain who were treated in a multidisciplinary pain management center. *Pain*, 41(1), 47-53.

Mooney, K. H., Beck, S. L., Friedman, R. H., & Farzanfar, R. (2002). Telephone-linked care for cancer symptom monitoring: a pilot study. *Cancer Practice*, 10(3), 147-154.

Moore, J. E., Von Korff, M., Cherkin, D., Saunders, K., & Lorig, K. (2000). A randomized trial of a cognitive-behavioral program for enhancing back pain self care in a primary care setting. *Pain*, 88(2), 145-153.

Morrison, K., Szymkowiak, A., & Gregor, P. (2004). Memojog - an interactive memory aid incorporating mobile based technologies. *Lecture Notes in Computer Science*, (3160):481-485.

Munir, F., Leka, S., & Griffiths, A. (2005). Dealing with self-management of chronic illness at work: predictors for self-disclosure. *Social Science & Medicine*, 60(6), 1397-1407.

Munoz, M., & Esteve, R. (2005). Reports of memory functioning by patients with chronic pain. *Clinical Journal of Pain.*, 21(4), 287-291.

Nawyn, J., Intille, S., & Larson, K. (2006). Embedding behavior modification strategies into a consumer electronic device: a case study. *In the Proceedings of the 8th International Conference on Ubiquitous Computing* (pp. 297-314). Heildelberg, Berlin: Springer.

Naylor, M., Helzer, J., Naud, S., & Keefe, F. (2002). Automated telephone as an adjunct for the treatment of chronic pain: a pilot study. *The Journal of Pain*, 3(6), 429-438.

Newman, S., Steed, L., & Mulligan, K. (2004). Self-management interventions for chronic illness. *Lancet*, 364(9444), 1523-1537.

Okifuji, A. (2003). Interdisciplinary pain management with pain patients: evidence for its effectiveness. *Seminars in Pain Medicine*, 1(2), 110-119.

Playford, E. D., Dawson, L., Limbert, V., Smith, M., Ward, C. D., & Wells, R. (2000). Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting. *Clinical Rehabilitation*, 14(5), 491-496.

Pryor, J., & Jannings, W. (2004). Preparing patients to self-manage faecal continence following spinal cord injury. *International Journal of Therapy and Rehabilitation*, 11(2), 79-82.

Rainville, J., Carlson, N., Polatin, P., Gatchel, R. J., & Indahl, A. (2000). Exploration of physicians' recommendations for activities in chronic low back pain. *Spine*, 25(17), 2210-2220.

Schnurr, R. F., & Macdonald, M. R. (1995). Memory Complaints in Chronic Pain. *Clinical Journal of Pain*, 11(2), 103-111.

Schulz, P. J., Rubinell, S., & Hartung, U. (2007). An internet-based approach to enhance self-managementof chronic low back pain in the Italian-speaking population of Switzerland: results from a pilot study. *International Journal of Public Health*, 52(5), 286-294.

Smith, B., Hopton, J., & Chambers, A. (1999). Chronic pain in primary care. *Family Practice*, 16(5), 475-482.

Snelling J. (1994). The effect of chronic pain on the family unit. *Journal of Advanced Nursing* 19, 543-551

Soar, J., & Croll, P. (2007). Assistive technologies for the frail elderly, chronic illness sufferers and people with disabilities – a case study of the development of a Smart Home. *In the Proceedings of the18th Australasian Conference on Information Systems* (pp. 1-8). Toowoomba, Queensland: The University of Southern Queensland.

Sorbi, M. J., Mak, S. B., Houtveen, J. H., Kleiboer, A. M., & van Doornen, L. J. (2007). Mobile Web-based monitoring and coaching: feasibility in chronic migraine. *Journal of Medical Internet Research*, 9(5).

Sorkin, B. A., Rudy, T. E., Hanlon, R. B., Turk, D. C., & Stieg, R. L. (1990). Chronic pain in old and young patients: differences appear less important than similarities. *Journal of Gerontology*, 45(2).

Suarez-Almazor, M. E., Kendall, C. J., & Dorgan, M. (2001). Surfing the Net--information on the World Wide Web for persons with arthritis: patient empowerment or patient deceit? *The Journal of Rheumatology*, 28(1), 185-191.

Tan, V., Cheatle, M. D., Mackin, S., Moberg, P. J., & Esterhai, J. L. (1997). Goal setting as a predictor of return to work in a population of chronic musculoskeletal pain patients. *The International Journal of Neuroscience*, 92(3-4), 161-170.

Theiler, R., Alon, E., Brugger, S., Ljutow, A., Mietzsch, T., Müller, D., et al. (2007). Evaluation of a standardized internet-based and telephone-based patient monitoring system for pain therapy with transdermal fentanyl. *The Clinical Journal of Pain*, 23(9), 804-811.

Tsang, M. W., Mok, M., Kam, G., Jung, M., Tang, A., Chan, U., et al. (2001). Improvement in diabetes control with a monitoring system based on a hand-held, touch-screen electronic diary. *Journal of Telemedicine and Telecare*, 7(1), 47-50.

Turk, D. C. (2002). Clinical effectiveness and cost-effectiveness of treatments for patients with chronic pain. *The Clinical Journal of Pain*, 18(6), 355-365.

Turk, D. C., & Okifuji, A. (2002). Psychological factors in chronic pain: evolution and revolution. *Journal of Consulting and Clinical Psychology*, 70(3), 678-690.

Turk, D. C., Okifuji, A., & Scharff, L. (1995). Chronic pain and depression: role of perceived impact and perceived control in different age cohorts. *Pain*, 61(1), 93-101.

Turk, D. C., Swanson, K. S., & Tunks, E. R. (2008). Psychological approaches in the treatment of chronic pain patients – when pills, scalpels, and needles are not enough. *Canadian Journal of Psychiatry*, 53(4), 213-223.

Udermann, B., Spratt, K., Donelson, R., Mayer, J., Graves, J., & Tillotson, J. (2004). Can a patient educational book change behavior and reduce pain in chronic low back pain patients? *The Spine Journal*, 4(4), 425-435.

van't Riet, A., Berg, M., Hiddema, F., & Sol, K. (2001). Meeting patients' needs with patient information systems: potential benefits of qualitative research methods. *International Journal of Medical Informatics*, 64(1), 1-14.

Von Korff, M., Gruman, J., Schaefer, J., Curry, S. J., & Wagner, E. H. (1997). Collaborative Management of Chronic Illness. *Annals of Internal Medicine*, 127(12), 1097-1102.

Washington, T. A., Fanciullo, G. J., Sorensen, J. A., & Baird, J. C. (2008). Quality of Chronic Pain Websites. *Pain Medicine*, (March 2008), 1-7.

White, M. (2001). Receiving social support online: implications for health education. *Health Education Research*, (December 2001), 693-707.

Williams, Richardson, P. H., Nicholas, M. K., Pither, C. E., Harding, V. R., Ridout, K. L., et al. (1996). Inpatient vs. outpatient pain management: results of a randomised controlled trial. *Pain*, 66(1), 13-22.

Williams, A. C., Nicholas, M. K., Richardson, P. H., Pither, C. E., Justins, D. M., Chamberlain, J. H., et al. (1993). Evaluation of a cognitive behavioural programme for rehabilitating patients with chronic pain. *The British Journal of General Practice*, 43(377), 513-518.

Winkelman, W. J., & Choo, C. W. (2003). Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management. *Health Expect*, 6(4), 352-358.

Winzelberg, A. J., Classen, C., Alpers, G. W., Roberts, H., Koopman, C., Adams, R. E., et al. (2003). Evaluation of an internet support group for women with primary breast cancer. *Cancer*, 97(5), 1164-1173.

Woby, S. R., Watson, P. J., Roach, N. K., & Urmston, M. (2004). Are changes in fear-avoidance beliefs, catastrophizing, and appraisals of control, predictive of changes in chronic low back pain and disability? *European Journal of Pain*. 8(3), 201-210.