



Citation for published version:

Rodham, K, Boxell, E, McCabe, C, Cockburn, M & Waller, E 2012, 'Transitioning from a hospital rehabilitation programme to home: exploring the experiences of people with complex regional pain syndrome', *Psychology and Health*, vol. 27, no. 10, pp. 1150-1165. <https://doi.org/10.1080/08870446.2011.647820>

DOI:

[10.1080/08870446.2011.647820](https://doi.org/10.1080/08870446.2011.647820)

Publication date:

2012

Document Version

Peer reviewed version

[Link to publication](#)

This is an Author's Accepted Manuscript of an article published in Rodham, K., Boxell, E., McCabe, C., Cockburn, M. and Waller, E., 2012. Transitioning from a hospital rehabilitation programme to home: Exploring the experiences of people with Complex Regional Pain Syndrome. *Psychology and Health*, 27 (10), pp. 1150-1165, copyright Taylor & Francis, available online at: <http://dx.doi.org/10.1080/08870446.2011.647820>

University of Bath

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

**Transitioning from a hospital rehabilitation programme to home:
Exploring the experiences of people with Complex Regional Pain Syndrome**

Rodham, K., Boxell, E., McCabe, C., Cockburn, M. and Waller, E

Abstract

Complex Regional Pain Syndrome (CRPS) is difficult to diagnose and is characterised by burning pain in one or more limbs. Treatment is palliative not curative and focuses on improving function. This requires patients to make long term changes to their behaviour. As with all such regimens, adherence is often poor. This study explored the lived experience of ten patients who had returned home after completing a two-week in-patient treatment programme. The interviews focused on how they coped with the transition from hospital to home, and on the things which they considered had facilitated or hindered this transition. *Battling for Control* was an overarching theme that connected the four superordinate themes: “*Gaining Momentum*” which facilitated the implementation of treatment advice, “*Distance from the pool of expertise*” which detailed the barriers to adherence experienced; “*It helped me realise it wasn't all in my head*” which detailed a facilitative process, and the ‘*nag list*’ which was a technique patients’ used to garner support. The paper offers insights into the transition experience. A key outcome is the recognition of the need to better prepare patients for their transition back home.

Key Words: Complex Regional Pain Syndrome; Interpretative Phenomenological Analysis; Coping; Adherence.

**Transitioning from a hospital rehabilitation programme to home:
Exploring the experiences of people with Complex Regional Pain Syndrome
Rodham, K., Boxell, E., McCabe, C., Cockburn, M. and Waller, E**

Introduction

Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy (RSD), usually occurs after a precipitating event or trauma, but may occur spontaneously (Kozin, 2005; McBride & Atkins, 2005; Stanton-Hicks, 2006). Burning pain is the most characteristic symptom of CRPS; other symptoms include swelling, coldness, colour changes, tenderness, hypersensitivity, increased sweat and hair growth, and motor changes (Galer et al., 2000; Kozin, 2005). Commonly affected sites include hands, feet and knees. Symptoms are usually experienced in a single limb, though CRPS may occur in multiple limbs and other body regions (Baron, Fields, Jänig et al., 2002; Stanton-Hicks, Jänig, Hassenbusch et al., 1995; Veldman, Reynen, Arntz & Goris, 1993).

Diagnosing CRPS can be a lengthy process characterised by scepticism on the part of the clinician, and confusion for the patient (McCabe & Blake, 2008). This is due in part to the lack of specific tests or biomarkers to confirm diagnosis of CRPS (Kozin, 2005). It is also difficult to give definite information on a patient's prognosis, resulting in feelings of confusion, uncertainty and a lack of control for some patients (Rodham, McCabe & Blake., 2009).

Treatment for CRPS

Bruehl and Chung (2006) suggest that psychological and behavioural factors can both exacerbate and maintain the pain and dysfunction associated with CRPS. Therefore a combination of physiotherapy (PT), occupational therapy (OT), desensitisation and psychological therapy are recommended by many researchers in the field (e.g. Geertzen, van Wilgen, Schrier & Dijkstra, 2006; Kozin, 2005; Stanton-Hicks, Burton, Bruehl, et al., 2002). Adherence to healthcare professionals' advice is essential in order to lessen the impact that CRPS has on patients' lives.

Adherence to healthcare professionals' advice

Evidence suggests that regimens requiring long-term changes to behaviour tend to have poorer adherence (Lawrence, Graber, Mills, Meissner & Warnecke, 2003). Consequences of non-adherence vary, but include low quality of life, provider and patient frustration, increased hospital admissions and wasted health care resources. Accordingly a growing body of researchers have looked at the facilitators and barriers to treatment adherence in chronic illnesses (including osteoarthritis (OA), rheumatoid arthritis (RA), chronic lower back pain (CLBP) and fibromyalgia (FM)). For example, Petursdottir, Arnadottir and Halldorsdottir (2010) found that exercise adherence in people with OA was influenced by more than twenty different factors. These included poor attitude to exercise, limited past history of successful exercise, low perceived benefits of exercising, low levels of family support, lack of physician encouragement and lack of training partners. Similar factors have been found in studies of patients with RA, FM and CLBP (e.g. Iverson, Fossel, Ayers, Palmsten et al., 2004; Slade, Molloy & Keating, 2009; Sokundi, Cross, Watt & Moore, 2010). Specific barriers to adherence to treatment programmes include an inability to fit recommendations into their routine (Campbell et al., 2001; Hendry et al., 2006), the belief that exercise is too

time consuming and boring (Iversen, Fossel & Daltroy, 1999), tiredness and forgetting (Medina-Mirapoix, Escolar-Reina, Gascon-Canovas, Montilla-Herrador & Collins, 2009).

Research detailing the lived experience of people with CRPS following in-patient treatment is lacking in the existing literature. One exception to this is a paper by Rodham et al. (2009) which focused on online interactions of people with CRPS, which were analysed to identify participants' support needs. However, the study findings were based on the researchers' interpretation of the interactions, rather than being derived from actual dialogue with people with CRPS. We therefore proposed to engage in an in-depth interactive exploration of the lived experience of people with CRPS who had completed an in-patient rehabilitation programme. The intention was to gain an understanding of how they had experienced the transition from the hospital to the home environment, and in particular what they felt had facilitated or hindered their ability to adhere to the advice given to them by the multidisciplinary healthcare professionals running the programme. This is an important study, for although a number of researchers have written about the experiences of people living with chronic pain (e.g. Gustafsson, Ekholm & Öhman, 2004; Hurley, Walsh, Bhavani, Britten & Stevenson, 2010; Martensson & Dahlin-Ivanoff, 2006), none have explored the experiences of those who are diagnosed with CRPS.

Method

This was a phenomenological study of patients' experience of the transition from an intensive two-week rehabilitation programme to their home environment. In line with the recommendations detailed above, the programme is multi-disciplinary, with a

focus on physical rehabilitation (including PT, OT and hydrotherapy). It also includes sessions with health and clinical psychologists. Since treatment is palliative rather than curative, the main objective is to improve function (Stanton-Hicks, 2006) and to encourage self-management.

Ethical approval for the research was granted by a local National Research Ethics Service (NRES) board and the University of Bath Psychology Department Ethics Committee.

Participants were recruited from the CPRS in-patient programme run at the Royal National Hospital for Rheumatic Diseases (RNHRD). Over a four month period in 2007, all patients who attended the in-patient programme were approached by KR and were given a brief explanation of the research and a written leaflet with further information about the project. Participants were informed that researchers were interested in learning more about their experience of returning home after completing the hospital in-patient programme.

Data Collection

Participants were given a daily diary to complete whilst at the hospital and for one month afterwards at home. They were also given a disposable camera and were asked to take photographs that they thought would help them remember the barriers and facilitators they encountered during their first month home.

Photography has been shown to be a useful method of eliciting patients' experiences, not least because photographs act as triggers for memory (Cronin &

Gale, 1996), and enable participants to show researchers their world. When used in conjunction with interviews, photographs have been found to yield richer, more detailed and precise information than reliance on 'word-only' interviews (Frith & Harcourt, 2007). The diaries and photographs therefore informed the way in which the interview was structured and acted as a useful prompt to help participants remember their experiences (Radley et al., 2005; Radley & Taylor, 2003).

Once participants had returned the diary and the disposable camera, KR arranged a mutually convenient time to conduct the interview. This was typically within three weeks of the completion of the first month back home. Participants were offered face-to-face interviews, but all preferred to be interviewed over the telephone. The interviews lasted between forty-five minutes and an hour and a half, and were recorded using an analogue telephone recorder.

The interview schedule employed non-directive, open-ended questions and was divided into two parts. Firstly participants were invited to reflect on their experience of the in-patient programme itself. Questions included "Was there a typical day on the programme?"; "As the end of the programme approached, how did you feel about your return home?" The second part of the interview focused on the experience of the transition from hospital to home and whether there were things that they felt had facilitated or hindered their transition. In order to aid participants' recall, excerpts from their diaries or mention of their photos were used as reminders to explore each person's unique experiences. Questions included: "Were there any techniques or exercises that you learned that were easy to put into practice when you got home?"; "Did anything or anyone help or hinder you on your return home?"

Photographs were typically referred to towards the end of the interview. The participant and the interviewer each had copies of the photos and the interviewer asked the participant to explain the significance of each photo. The photographs tended to represent mobility obstacles (e.g. stairs) or kitchens that were not easy to manoeuvre in with disability aids. Some photographs featured pet dogs which were seen by participants as being both facilitative (in that they were a source of support) and as a hindrance (in that they were a reminder of mobility problems experienced when participants tried to exercise their pets). One participant (Maria) took a photograph of her husband holding a toilet brush. This was an important occasion to document because she said that it was the first time he had recognised that she needed help with household cleaning chores. Finally, at the end of the interview participants were asked if there was anything else they wanted to add that had not already been covered. This meant that the participants were able to give their views and experiences on any issues important to them that had not been touched upon in the interview.

Analysis

Interviews were recorded and transcribed. All participants were given pseudonyms to ensure anonymity. Interview data were analysed using Interpretative Phenomenological Analysis (IPA). The method of IPA enables the researcher to explore the complex meanings of the participants' views from their own perspective (Smith, Jarman & Osborn, 1999). Researchers' engaged in reflection during the analysis phase and recognition was given to the double hermeneutic: a researcher trying to make sense of the participant trying to make sense of their experience of the transition home (Clarke, 2009).

Analysis was conducted according to guidelines produced by Smith and Osborn (2003). After reading and re-reading the transcripts, EB noted in the left hand margin of the transcripts anything that was interesting or significant about what the respondent had said. These included summarising statements, paraphrasing, associations or connections, contradictions in what the person is saying, comments on language use etc. The right hand margin was used to document themes. After this process, the themes were listed and connections were looked for between them.

In order to increase the “trustworthiness” of the findings, and minimise the researcher’s role in constructing participant accounts, the transcripts were also coded independently by a member of the research team (KR). In addition, EW and MC independently coded a sample of interview transcripts. No substantial differences were found during the comparison. The themes that were identified were checked with the transcripts to ensure that they were reflected in what the participant had said. The stages were repeated for the remaining transcripts. The final themes were chosen on the basis of the richness, universality and salience of the theme in the transcripts, rather than based on prevalence of the theme alone.

Results

Ten participants took part (9 female, 1 male). Their ages ranged from 22 to 66 years (mean age 42 years) and length of time since diagnosis ranged from 1 to 12 years. The location of participants’ CRPS ranged from a single limb to multiple limbs. Both upper and lower limb CRPS was represented. The younger participants still lived with their parents, one participant lived alone and the remaining 7 participants lived with their partners (see Table 1).

TABLE 1 ABOUT HERE

An overarching theme of “*battling for control*” was evident throughout participants’ accounts. Attending the rehabilitation programme itself was regarded as an empowering experience. Participants reported feeling that they were making progress and ‘*gaining momentum*’. They saw the programme both as a turning point and as a means of recapturing their independence. As their sense of independence grew, so too did the feeling that they (rather than the CRPS) were (re)taking control.

However, difficulties experienced post programme impacted negatively on this increased sense of control. Returning to the ‘real’ world was unpleasant because more barriers than facilitators were encountered. A key issue was ‘*distance from the pool of expertise*’ which meant that participants were reliant on healthcare professionals whom they felt lacked appropriate knowledge and understanding of CRPS. The loss of the close bond and connection that had been built with the in-patient team was then compounded by difficulties encountered when seeking access to local facilities needed to help maintain progress. In addition, the difference between the structured routine of the in-patient programme compared to participants’ less predictable home routine made adhering to the therapists’ advice difficult:

“Umm you know, who’s going to put the rubbish out? You don’t have those things to worry about when you’re in hospital. So you can, you’ve only got to concentrate on improving or making the most of it. Whereas when you come home its different: life gets in the way.” (Justine)

On a more positive note, completion of the programme provided an opportunity for participants to meet healthcare professionals with CRPS expertise, as well as others who were themselves living with CRPS. Contact with these two types of ‘expert’ helped participants to realise that CRPS ‘*wasn’t all in my head*’. It was the acknowledgement that CRPS was ‘real’ which appeared to act as a motivating factor in terms of encouraging loved ones to offer help and support. Such support was sometimes described as a ‘*nag list*’. Each of the themes identified (see Figure 1) are explained in detail below and are presented with supporting quotes.

FIGURE 1 about here

Theme 1: Gaining Momentum: programme as turning point

Participants’ spoke about the importance of gaining momentum which acted as a motivator to give them the strength to recapture their independence and through this process, feel like they were in more control.

“I’d definitely made progress, and feeling conscious that I could keep, keep the progress going, the momentum I gained during that time [time spent on the in-patient programme]” (Susanna)

Participants spoke about how the in-patient programme differed from their experiences outside the hospital environment. The majority noted that prior to the rehabilitation programme, they felt that they had not been offered much help to manage their CRPS and as a consequence many had lost faith in their local healthcare professionals. The in-patient programme in contrast, was viewed as a turning point and seemed to act as a motivating force for participants’ intentions to implement the

healthcare professionals' advice on their return home. In particular, the offer of a place on the programme, and the chance to improve their ability to manage CRPS, gave participants a renewed sense of hope. This sense of hope was the equivalent of a lifeline being thrown to someone who finds themselves out of their depth. This is captured by the quote from Arthur below, who had felt as though he was floundering alone, until the programme gave him something tangible he could cling to:

“So that was the first time I was sort of offered any umm, not just help but skills. Just something to almost grasp hold of that you know I really hadn't been offered anything pretty much at all before.” (Arthur)

Indeed, the sense of desperation in participants' accounts of their 'pre' in-patient experiences was tangible. Metaphors including 'hitting brick walls' and 'being in the wilderness' with 'nothing to hang on to' were commonly employed:

I - “And I just wondered what it was that helps you to keep on trying?”

P – I think it's to be truthful, and it sounds like silly, but it's the support I've got from [rehab hospital]. Umm, especially when my arms first went wrong which was, oh I don't know, about 10/11 years ago. I had no help whatsoever. No support and that's when I first was sent down to [rehab hospital]. And my life has got a lot better since. Where before I felt like I'd hit a brick wall and nobody here was helping me, [rehab hospital] is just...giving me a better quality of life that I just wouldn't have had.” (Caroline)

The philosophy behind the in-patient programme is to teach strategies, skills and techniques that will enable individuals to self-manage their condition rather than becoming reliant on healthcare professionals. Caroline, in the quote above,

demonstrates the importance of feeling supported as a means of helping her work towards a better quality of life. The outcome of CRPS in this case (her arms ‘went wrong’) had considerable impact on her life and her sense of control. With support, her life improved and she was able to adhere to the therapists’ advice (she ‘keeps on trying’). Without exception, all participants noted that they had experienced beneficial outcomes (e.g. increased mobility) as a result of attending the programme. Many moved towards their goals and in doing so reported experiencing renewed hope, a confidence boost and motivation to carry on with the exercises outside of the hospital:

I – “So sort of summing up I suppose; do you think, do you think you’ve benefitted from taking part in the programme?”

P– “On a personal note yes. Umm with umm desensitisation which is you know... and the hydro, umm... helped me prove to meself that things can be achieved. That something that you think you’d never do again, umm is achievable and with the right support and that, you can do anything” (Diane)

Participating in the rehabilitation programme gave Diane the confidence to try things out within the context of the supportive environment. She was able to see for herself what she was capable of with support, and this gave her the confidence to continue to try and to view all sorts of things as possible, which in turn gave her an increased sense of control which fed her motivation to continue to strive towards her goals.

It was clear that participants had experienced a pendulum swing in terms of pre and post in-patient programme experiences. They moved from a sense of

hopelessness and helplessness prior to coming to the hospital, towards what can perhaps be described as an overly optimistic state of being at the end of the programme. Although energising and motivating, this optimism created problems for some of the participants on their return home, when ‘real life’ reasserted itself. This is highlighted by Fiona’s quote below, in which she outlines how she was tempted to try to do too much (being ‘superwoman’) as a reaction against the person she felt she had become because of CRPS (‘a sad patient’). Developing a level of acceptance about what *is* and what *is not* realistic was therefore key to a successful transition home:

I – So what was it like when you got home?

P – Umm it was fine. It was good. I was umm... I was quite happy; I got more physio equipment in the house that we did ourselves, and set things up for me to... be more realistic about what I was trying to do in my day-to-day life instead of trying to be superwoman and just failing miserably. And so just more relaxed I think as well. Umm I just wanted to get away from this... and this sad patient who can’t walk and has to rely on everybody. It was like trying to move on from that. [Inaudible] just have to take a bit more control of it which hasn’t been that easy to achieve because it just isn’t, because realistically it isn’t easy, but I wanted to move on and I’ve tried very hard to do that. (Fiona)

The process of reaching acceptance is far from smooth and requires considerable motivation and strength of character to persevere. The journey is characterised by setbacks (‘failing miserably’), but the desire to move forwards,

tempered by the need to have realistic goals is clearly important in terms of facilitating the transition home.

Theme 2: Distance from the pool of expertise

Many participants mentioned the lack of CRPS expertise amongst the healthcare professionals they encountered outside the in-patient programme.

“Well because my own GP has said “I think you’ve got it in your back.” But they actually don’t know the condition. And that to me is worrying. I would like someone to say “this is where you’ve got it, this is what it can do, this is what it can’t do”. Because when you’re sat at home you imagine all sorts.
(Justine)

Returning home was distressing for participants because they had experienced the supportive in-patient environment where they were surrounded by ‘CRPS experts’, only to return to the ‘outside world’ where they felt that the majority of healthcare professionals lacked the (CRPS-related) skills and knowledge to help.

“Umm, just a little bit sort of deflated thinking, ‘well it’s back to two people who don’t actually know what I’m going on about and...don’t actually know how to treat me. It’s a bit of a deflation when you know that you’ve got to go back to being with other people who don’t have the understanding.” (Jane)

Difficulty accessing appropriate local support was discouraging. As a consequence some participants made the decision to muddle through, preferring this to spending time consulting with healthcare professionals whom they felt did not know about CRPS. For example, Fiona tried to adapt her exercises herself rather than

seek advice from her local physiotherapist. She considered that making an appointment would be a “*complete and utter waste of time*”. Similarly, Barbara could not access hydrotherapy (“*I’ve searched everywhere and I just can’t find a Hydro pool*”) and so had attempted to replicate her hydrotherapy walking exercises in her own bath. This meant that the momentum gained whilst on the programme quickly began to stall and reverse.

“I come back home and I haven’t got those facilities here. And very quickly you slip back in to what you were before.” (Justine)

Although the rehabilitation programme has the philosophy of encouraging self-management, this example also highlights the importance of ensuring that patients know when it might be sensible to seek professional advice. Fiona’s confidence in her ability to alter the recommended exercises could have proved detrimental if the changed exercises did not benefit her, or worse, resulted in harm. Similarly, Barbara could slip and injure herself whilst attempting hydrotherapy exercises in a domestic bath. Others, like Justine, felt that their progress was slipping away because although the will to continue with their rehabilitation was present, access to the appropriate facilities was not.

Difficulty in accessing local facilities was not the only issue; the comparatively reduced frequency with which participants had access to their local healthcare professionals was also a concern. Intensive daily contact with the CRPS team increased participants’ confidence that they were carrying out the exercises correctly and had perhaps inadvertently increased reliance on the expert team. Reduced contact on returning home meant that participants became increasingly

worried about whether they were performing their exercises correctly and so were less likely to carry them out:

“And nobody’s saying ‘you’ve got to be in the physio department for 10’ or ‘you’ve got OT at this time.’” (Diane)

This reliance on someone else taking responsibility for ensuring exercises are adhered to, is counter to the philosophy of the programme, which aims to prepare patients for self-management. Indeed, one of the key messages of the programme which seems to have been lost, is that participants should self-manage and take responsibility for building the exercises into their everyday life. The experience of the return home provided a stark contrast to that of the programme: ‘real life’ does not run to timetables as it does in the hospital environment. This was a tension that many participants voiced and for some, rather than being a means of re-engaging with life, the exercises became the focus around which their life was anchored:

“You know, you can probably imagine if you did nothing but for instance gym exercises, you sort of think ‘what’s the point in being fit. If all I ever do is see the inside of a gym?’” (Arthur)

Losing sight of the reason for engaging in the exercises as highlighted by Arthur (above) can mean that the exercises become the focus, rather than the goals that the exercises are designed to help individuals work towards. When this happened, motivation inspired by completing the programme decreased, and in some cases turned to despair and frustration. Moving from a programme which provided patients with access to a rich variety of resources, to a situation where resources were limited,

expensive and, at worst non-existent, led Justine to conclude that on reflection, the programme instilled false hope:

“It’s almost setting people up to fail. And to be sent a step backwards.”

(Justine)

Theme 3: It helped me realise it wasn’t all in my head

In spite of the difficulties encountered on the return home, participants were unanimous in reporting that an overwhelmingly positive element of the in-patient programme concerned access to CRPS experts:

“Umm but medically wise I felt somebody believed me. It helped me realise it wasn’t all in my head.” (Jane)

Finding healthcare professionals with CRPS expertise was a relief and for some, was the first time that their symptoms had been believed. However, perhaps even more importantly, participants were also able to meet other people with CRPS. The sense of relief at finding someone else who was experiencing similar symptoms was unmistakable in the transcripts. The in-patient programme was often the first time that they had had face-to-face contact with another person living with CRPS. Thus, meeting others on the rehabilitation programme provided validation and comfort in knowing that others were having similar experiences and feelings:

“The other good thing I did find that was really helpful was being with other RSD patients. He was using the same sort of words and terminology and I was thinking ‘I’m so pleased he said that.’ And it was just ‘oh thank god for that.’”

(Jane)

Finding out that other people were reporting similar experiences; had the same way of explaining their experiences; and had insight into how other people with CRPS were feeling, was reported as being incredibly beneficial. It was akin to finding someone else who spoke the same language. Although participants mentioned that they had friendships at home which could provide them with emotional support, they all stated that it was most important to have people around them whom they felt understood both their condition and their treatment. For example, in the quote below, Diane spoke about tactile desensitisation.

“And luckily with the friends that I’ve got, they don’t look at you as if you’ve gone mad when you get a scourer out and start rubbing your leg with it.”
(Diane)

CRPS is a difficult condition to understand and the process of desensitisation can be uncomfortable for the person with CRPS, not just physically, but psychologically. The process of touching their affected limb with a variety of tactile stimuli (such as a scouring pad or a piece of silk) in order to build up a tolerance to being touched, can seem strange to an uninformed or unsympathetic onlooker. Thus the support of healthcare professionals and of loved ones, with knowledge and understanding of CRPS, as well as empathy towards the person with CRPS, was important. Such support was vital in helping the person realise that CRPS was not ‘*all in my head*’. Recognising that CRPS is real can play an important role in terms of motivating the individual to take control and make an active decision to engage with the therapists’ advice.

Theme 4: The Nag List

Four of the participants made reference to the importance of allowing loved ones to both monitor their progress and to intervene to ensure they continued to adhere to advice given. This was viewed in a positive fashion and the term ‘nagging’ was employed in a light hearted manner. Nagging is usually considered a negative behaviour involving continued pressure from another person to complete tasks, however in this context it was regarded more positively. This was illustrated by Barbara who instead of becoming defensive at the enquiry from her husband, remained calm and viewed the enquiry positively. Had ‘nagging’ been employed in its true sense, Barbara’s reaction may well have been very different:

“In fact I mean he only did say to me yesterday ‘now you’re still doing your exercises because I’ve not seen you do them this week?’ and I said ‘no I have been doing them love, but I’ve been having to do it when I’ve gone to bed.”
(Barbara)

Thus, having another person monitoring their progress and reminding them of their therapy and rehabilitation exercise goals was considered helpful. For example, Susanna in the extract below finds it useful to have someone else keeping an eye on her posture:

“And she’s very good at noticing “oh, now you’re leaning, you need to be stranding up straight” and that sort of thing” (Susanna)

Whereas for Diane, it was a crucial motivator enabling her to actively engage in her rehabilitation:

“Umm and that I think if it wasn’t for them I would basically just give up and become a recluse and write myself off completely. But with their support and backing, and persistent pushing, umm I’ve been able to continue with things, I would say.” (Diane)

One participant created a “nag list” in collaboration with her physiotherapist whilst on the programme. Other copies were given to her spouse and family in order for them to be able to remind her. The use of a “nag list” may also act to clarify the ways in which a support person can help the patient:

“Umm, you know and I’ve got umm my physio to write up a nag list. Umm for all the things that I shouldn’t do. You know with tilting and umm the way I was walking, and you know the way not to use my crut... my walking sticks and stuff, so umm my mum done another copy up and they took it quite literally. And so umm it was sort of like kind of drummed into my head because... because of doing it for so many years you can quite easily slip back into the same routine. Umm but you know with my mum and my husband and stuff it was kind of hard to slip back, they were constantly ‘you don’t do this and you don’t do that, and walk properly’”. (Sheila)

Having family members and partners ask (‘nag’) about the rehabilitation exercises was therefore generally viewed in a positive light by the participants. It was seen as a sign that their loved ones cared, but was also a means for those with CRPS to take control of their rehabilitation by engaging help. Compiling the nag list with the help of an expert physiotherapist gives credence to the list and adds weight to the importance of adhering to the programme of exercises. In addition, sharing the list

with a loved one, gives that person permission to ‘nag’ in a manner which is considered acceptable.

However, for carers, it seemed that the distinction between helping loved ones adhere to the programme and providing overzealous support was not always clear. In some cases even when assistance was well intentioned, it was perceived as unhelpful by the recipient. This is shown in the quote below from Sheila who was explaining some of the photographs she had taken:

P- Umm there was a couple of photos of my husband...

I – Were they good photos or... or photos where he’d gotten in the way?

R – Umm kind of gotten in the way.

I – And how would that happen?

R – Umm. Because I mean as any disabled person they want to be as independent as possible. Umm and sometimes he can try and umm help too much. And then I find it difficult then because I’m trying to have to work round him. Even though he’s trying to be helpful.

I – Yeah. Yeah. So is it, is it difficult to try and explain to him?

R – Umm I mean we do, we do talk a lot. You know, he keeps. He says like you know “I’m just trying to help” and I do have to try and push the fact that “you

have to let me try". If I can't do it then I can't do it, but at least I can try.

(Sheila)

It is therefore important that the person with CRPS plays an active role in communicating their support needs clearly in a manner which enables them to work independently towards their goals. The 'rules' around the issue of nagging occasionally need to be revisited and loved ones reminded of what is and is not acceptable. Inviting help from someone else as a means of facilitating one's independence is not always straightforward. The person providing the help can easily begin to overcompensate. In Sheila's example (above), although she speaks of how she and her husband 'talk a lot', it seems that they talk at crossed-purposes. Developing the ability to communicate clearly, as well as listen actively would facilitate the transition home.

Discussion

The aim of this study was to explore the transition from in-patient programme to home experienced by people with CRPS. Specifically we wanted to find out what factors facilitated or obstructed participants ability to adhere to rehabilitation advice once back in their home environment.

The act of completing the in-patient programme was in itself viewed as being a 'turning point' and a motivating factor. It increased participants' positivity, feelings of being understood and also validated their experience. Coming into hospital meant that CRPS was 'real' and was being taken seriously. Perhaps most importantly however, was the issue of battling for control. Participants reported feeling that

completing the programme helped them to feel that they were beginning to take back some control. Researchers focusing on other conditions have also noted that attempts to gain a sense of control over chronic illness and disability can have a positive impact on adherence (Hendry et al., 2006; Schur et al., 1999; Thorstensson et al., 2005).

The transition home was an initially positive experience, whereby participants were buoyed from completing the programme and felt that they were gaining momentum and working towards recapturing their independence. This positive feeling soon reduced as participants realised that they were distanced from the pool of expertise and came to terms with how 'real life got in the way'. Local healthcare professionals were described as lacking in knowledge and participants' experienced difficulty in accessing local facilities. As a consequence, many participants preferred to try to muddle through rather than consult with local healthcare professionals whom they felt lacked expertise. This led to a decline in motivation to continue with the rehabilitation exercises. Other researchers have also noted that without support, the motivation to engage with exercises is likely to wane (e.g. Campbell et al., 2001; Hendry et al., 2006; Marcus et al., 2000). Hurley and colleagues (2010) suggested that group rehabilitation be implemented in order that patients can then provide informal ongoing support after the completion of rehabilitation. In our study, friends, family, health professionals and other patients provided support that helped participants to adhere to their treatment. However it is possible that this is a means by which participants are in some sense handing over responsibility and control to other people for their management, which moves away from the self-management philosophy of the in-patient programme.

Clinical Implications

The participants' accounts highlight the perceived lack of support for people living with a long term chronic condition such as CRPS. First, participants reported that their local healthcare professionals lacked knowledge of CRPS as a condition. This meant that the participants struggled to access information and ongoing support. Second, many participants reported difficulty in accessing facilities. For example, hydrotherapy tends to be offered for a period of weeks, rather than as a longer term therapy. Thus without the personal financial means to access services privately, participants cannot access the facilities they need to maintain and continue progress made on the in-patient programme.

These two issues can impact negatively on the outcome of the rehabilitation programme. Although on completion of the programme participants felt more confident about their ability to cope, this confidence was quickly eroded in the face of what felt like insurmountable barriers. Perhaps one solution is to provide access to specialist outpatient facilities through more frequent follow-up appointments after leaving the programme. This would act as a means of offering further support whilst patients learn to incorporate the MDT advice into their everyday life. This approach may cost more in the short term because out-patient appointments cost money. However, it has the potential to reduce the frequency of visits in the longer term, because such a process would act in the same way that a stabiliser does when a child learns to ride a bicycle: gradually giving patients the confidence and skills they need to take responsibility and control for the self-management of CRPS. Indeed, the MDT team linked to this research have already introduced a form of graded discharge which hands over the management of CRPS to the patient in a graduated fashion.

Finally, involvement of the ‘carers’ is important. Participants noted that both nagging and practical assistance from carers helped them to adhere to the advice offered by the MDT. In contrast, some noted that their support providers could be overzealous with their support. Therefore, the provision of guidelines for carers concerning how best to provide support to the person with CRPS, as well as training in active listening and communication skills would be useful. If resources were available, involvement of the carers in some or all of the in-patient programme would provide the MDT with an opportunity to offer education and guidance about CRPS.

Limitations

There are some limitations to this study which must be highlighted. First, this study explored the experience of the transition home rather than the experience of living with CRPS. As such, it is important to highlight that what we have presented is an evaluation of the intervention process and the support needs of patients rather than exploring the wider issue of the experience of CRPS, which is itself an area requiring further investigation. Second, as noted by Mciver, Jones and Nicol (2010:1280), participants ‘portray a particular version of events, as well as a particular version of themselves’. Whilst this does not mean that the version they offer is untrue, it is well to remember that it is their interpretation of their experience that they are offering. Third, the length of time since diagnosis varied from 1 to 12 years, and as such participants had been living with CRPS for different amounts of time prior to completing the in-patient rehabilitation programme. This may have impacted on their ability to implement behaviour change; the longer a person has lived with a condition and developed ways of coping with it, the harder it is to make changes to these habits and adhere to health advice. This is highlighted by Sokundi et al. (2010) who note that

the greater the degree to which a programme requires a change in lifestyle, the less likely people will adhere. Finally, there are potential disadvantages to the health professional also acting as researcher. In this study, KR was aware of the potential blurring of boundaries around her roles as researcher and CRPS psychologist and therefore engaged in reflective practice throughout the data collection phase to ensure 'Researcher vs Therapist Dilemma' boundaries were not crossed (Alty & Rodham, 1998: p 278). Participants had consented to take part in research, not a therapy session; it was therefore important to be explicit that the aim of asking about their experiences was not to provide psychological support, but to help the CRPS team learn more about the patient experience of the transition home.

Conclusion

With these limitations in mind, this research provides valuable insights into the experience of the transition from hospital to home and of the concomitant obstacles and facilitators that participants face as they try to adhere to health advice offered. The findings highlight the experiences of this group as they negotiate the uncertain transition process. It is clear that the programme has a positive impact on patients' self-confidence, but that the reality of the return home and the stark difference between the support that was provided in-house and that which is available locally, detracts from the progress made. These insights will enable the MDT to better prepare patients for the challenges they potentially face when they leave the in-patient programme.

Acknowledgements

We thank the participants for sharing their time and experiences. We should also like to thank the Royal National Hospital for Rheumatic Diseases Donated Funds Committee for funding this research (project number RB284).

References

Alty, A. & Rodham, K. (1998). The Ouch! Factor: Problems in conducting sensitive research. *Qualitative Health Research*, 8(2), 275-282.

Baron, R., Fields, H.L., Jänig, W., Kitt, C. & Levine, J.D. (2002). National Institutes of Health Workshop: reflex sympathetic dystrophy/complex regional pain syndromes-state-of-the-science. *Anaesthesia and Analgesia*, 95, 1812-1816.

Bruehl, S. & Chung, O.Y. (2006). Psychological and Behavioural Aspects of Complex Regional Pain Syndrome Management. *Clinical Journal of Pain*, 22(5), 430-437.

Campbell, R., Evans, M., Tucker, M., Quilty, B., Dieppe, P. & Donovan, J.L. (2001). Why don't patients do their exercises? Understanding non-compliance with physiotherapy in patients with osteoarthritis of the knee. *Journal of Epidemiology Community Health*, 55, 132-138.

Clarke, C. (2009). An introduction to interpretative phenomenological analysis: A useful approach for occupational therapy research. *British Journal of Occupational Therapy*, 72(1), 37-40.

Cronin, O. and Gale, A. (1996). Photographs and the therapeutic process. *Clinical Psychology Forum*, 89, 24-28.

Frith, H. & Harcourt, D. (2007). Using photographs to capture women's experiences of chemotherapy: Reflecting on the method. *Qualitative Health Research*, 17(10), 1340-1350.

Galer, B.B., Henderson, J., Perander, J. & Jensen, M.P. (2000). Course of symptoms and quality of life measurement in Complex Regional Pain Syndrome: A pilot study. *Journal of pain and symptom management*, 20(4), 286-292.

Geertzen, J.H.B., Van Wilgen, C.P., Schrier, E. & Dijkstra, P.U. (2006). Chronic pain in rehabilitation medicine. *Disability and Rehabilitation*, 28(6), 363-367.

Gustaffson, M., Ekholm, J. & Öhman, A. (2004). From shame to respect: Musculoskeletal pain patients' experience of a rehabilitation programme, a qualitative study. *Journal of Rehabilitative Medicine*, 36, 97-03.

Hendry, M., Williams, N.H. Markland, D., Wilkinson, C & Maddison, P. (2006). Why should we exercise when our knees hurt? A qualitative study of primary care patients with osteoarthritis of the knee. *Family Practice*, 23, 558-567.

Hurley, M.V., Walsh, N., Bhavnani, V., Britten, N. & Stevenson, F. (2010). Health beliefs before and after participation on an exercise-based rehabilitation programme for chronic knee pain: Doing is believing. *BMC Musculoskeletal Disorders*, Volume 11, article 31, DOI: 10.1186/1471-2474-11-31.

Iversen, M.D., Fossel, A.H. & Daltroy, L.H. (1999). Rheumatologist-patient communication about exercise and physical therapy in the management of rheumatoid arthritis. *Arthritis Care and Research*, 12, 180-192.

Iversen, M.D., Fossel, A.H., Ayers, K., Palmsten, A., Wei Weng, H. & Daltroy, L.H. (2004). Predictors of exercise behaviour in patients with Rheumatoid Arthritis 6 months following a visit with their Rheumatologist. *Physical therapy*, 84(8), 706-716.

Kozin, F. (2005). Reflex Sympathetic Dystrophy. In Wallace, D.J. & Clauw, D.J. (2005). *Fibromyalgia and other central pain syndromes*. Philadelphia: Lippincott Williams & Wilkins.

Lawrence, D., Graber, J.E., Mills, S.L. Meissner, H.I. & Warnecke, R. (2003). Smoking cessation interventions in U.S. racial/ ethnic minority populations: an assessment of the literature. *Preventative Medicine*, 36(2), 204-216.

McBride, A. & Atkins, B. (2005). Complex Regional Pain Syndrome, *Current Orthopaedics*, 19, 155-165.

McCabe, C.S. & Blake, D.R. (2008). An embarrassment of pain perceptions? Towards an understanding of and explanation for the clinical presentation of CRPS type I. *Rheumatology*, 47, 1612-1616.

Mciver, D., Jones, D. & Nicol, M. (2010). Parents' experiences of caring for a child with chronic pain. *Qualitative Health Research*, 20(9), 1272-1282.

Mårtensson, L. & Dahlin-Ivanhoff, S. (2006). Experiences of a primary health care rehabilitation programme. A focus group study of persons with chronic pain. *Disability and Rehabilitation*, 28(16), 985-995.

Marcus, B.H., Dubbert, P.M., McKenzie, T.L., Blair, S.N., Dunn, A.L. & Stone, E.J. (2000). Physical activity behaviour change: Issues in adoption and maintenance. *Health Psychology*, 19, 32-41.

Medina-Mirapeix, F., Escolar-Reina, P., Gascon-Canovas, J.J., Montilla-Herrador, J. & Collins, S.M. (2009). Personal characteristics influencing patients' adherence to home exercise during chronic pain: A qualitative study. *Journal of Rehabilitation Medicine*, 41, 347-352.

Petursdottir, U., Arnadottir, S.A. & Halldorsdottir, S. (2010). Facilitators and barriers to exercising among people with osteoarthritis: A Phenomenological Study. *Physical Therapy*, 90(7), 1014-1025.

Radley, A., Hodgetts, D. and Cullen, A. (2005). Visualising homelessness: A study in photography and estrangement. *Journal of Community and Applied Psychology* 15, 273-295.

Radley, A. and Taylor, D. (2003). Images of recovery: A photo-elicitation study on the hospital ward. *Qualitative Research*, 13(1), 77-99.

Rodham, K., McCabe, C. & Blake, D. (2009). Seeking support: An interpretative phenomenological analysis of an internet message board for people with Complex Regional Pain Syndrome. *Psychology and Health*, 24(6), 619-634.

Schur, H.V., Gamsu, D.S. & Barley, V.M. (1999). The young person's perspective on living and coping with diabetes. *Journal of Health Psychology*, 4(2), 223-236.

Slade, S.C., Molloy, E. & Keating, J.L. (2009). People with non-specific chronic low back pain who have participated in exercise programs have preferences about exercise: a qualitative study. *Australian Journal of Physiotherapy*, 55(2), 115-121

Smith, J.A. & Osborn, M. (2003). Interpretative Phenomenological Analysis. In Smith, J.A. (Ed) *Qualitative psychology: a practical guide to research methods*. (pp51-80). London: SAGE.

Smith, J.S., Jarman, A. & Osborn, M. (1999). Doing Interpretative Phenomenological Analysis. In Murray, M. & Chamberlain, K. *Qualitative health psychology: theories and methods*: London: SAGE.

Sokundi, O., Cross, V., Watt, P. & Moore, A. (2010). Experiences of individuals with chronic lower back pain during and after their participation in a spinal stabilisation exercise programme- a pilot qualitative study. *Manual Therapy*, 15(2), 170-184.

Stanton-Hicks, M. (2006). Complex Regional Pain Syndrome: Manifestations and the role of neurostimulation in its management. *Journal of Pain and Symptom Management*, 31(4s), s20-24.

Stanton-Hicks, M.D., Burton, A.W., Bruehl, S.P., Carr, D.B., Harden, R.N., Hassenbusch, S.J, Lubenow, T.R., Oakley, J.C., Racz, G.B., Raj, R.P., Rauck, R.L. & Rezaei, A.R. (2002). An updated interdisciplinary clinical pathway for CRPS: report of an expert panel. *Pain Practice*, 2(1), 1-16.

Stanton-Hicks, M., Jänig, W., Hassenbusch, S., Haddos, J.D., Boas, R., Wilson, P. (1995). Reflex Sympathetic Dystrophy: changing concepts and taxonomy. *Pain*, 63, 127-133.

Thorstensson, C.A., Roos, E.M., Petersson, I.F. & Arvidsson, B. (2006). How do middle-aged patients conceive exercise as a form of treatment for knee osteoarthritis? *Disability and Rehabilitation*, 28(1), 51-59.

Veldman, P.J.H.M., Reynen, H.M., Arntz, I.E. & Goris, R.J.A. (1993). Signs and symptoms of reflex sympathetic dystrophy: prospective study of 829 patients. *Lancet*, 342, 1012-1016.