**"What I really needed was the truth". Exploring the information needs of people with Complex Regional Pain Syndrome**

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**Abstract**

**Background**

United Kingdom guidelines indicate individuals with Complex Regional Pain Syndrome (CRPS) require information and education to support self management. This qualitative study explored the specific information requirements of patients with CRPS and provides insight into how health professionals can best provide this.

**Methods**

Following informed consent, eight semi-structured telephone interviews were conducted with adults living with CRPS. Participants were asked about their experience of receiving information since diagnosis and what information they would prefer to receive. Interviews were transcribed and data analysed using thematic analysis.

**Results**

Two themes related to the individuals’ experience of receiving information; ‘Facing the unknown’ describes how the participants reported little information was available and the impact of this. ‘The need to be an expert’ describes how they needed to be proactive to seek this information themselves. Three themes related to what information the individual would choose to receive; ‘Seeking the truth’ describes the need for knowledge, in particular accurate, honest information. ‘The shared experience’ describes the positive and negative aspects of sharing information with others experiencing CRPS. ‘Access to expertise’ describes the need for access to reliable information, resources and expertise.

**Conclusion**

The reported lack of information resulted in a struggle for participants to understand their condition, access professional expertise and appropriate treatments. Health professionals require access to accurate information in order to share this with individuals with CRPS in a timely manner. Easily accessible and high quality patient resources to facilitate early referral for expertise are required. A central resource to identify local expertise would be valuable.

**Introduction**

Complex Regional Pain Syndrome (CRPS) is a chronic pain condition affecting a limb and predominantly occurring after injury (Harden et al. 2010). It is characterised by intense pain, disproportionate to the initial trauma. The limb may appear oedematous, the skin shiny and discoloured, with alterations in temperature and limb hair growth. Allodynia is a common feature of CRPS; where a non painful stimulus to the limb evokes a pain response. Women are more likely to be affected (3.4:1), with the peak age of onset being 50-70 years (de Mos et al. 2007). Prospective studies indicate that for many people the symptoms of CRPS can resolve within 6-13 months (Bean et al. 2014) however, for approximately 15-20% un-resolving CRPS, persistent allodynia and reduced motor function may substantially affect their quality of life (Field et al. 1992; Geertzen et al. 1998; Galer et al. 2000).

Despite more than 10,000 people living with CRPS of more than a year's duration in the United Kingdom (Shenker et al. 2014), it is a little known condition of which many health professionals are unfamiliar. This lack of awareness, confounded by symptoms which are common to other conditions, and the lack of a definitive test for CRPS, may result in a delay in diagnosis and the commencement of important rehabilitation strategies (de Mos et al. 2007; Lewis et al. 2007). The opportunity to access information regarding CRPS is crucial to raise awareness of the condition, to facilitate prompt referral to those with expertise in CRPS, to initiate and engage with therapies early in the onset of the condition, and to prevent secondary problems (Harden et al. 2006; Goebel et al. 2012). Recent UK guidelines for the diagnosis and management of CRPS in primary and secondary care, identify the need for appropriate patient information and education to support individuals in managing their CRPS (Goebel et al. 2012). However, there is little evidence exploring the specific information needs of people with CRPS. Brunner et al. (2010) explored patients actual knowledge of CRPS and found it was limited, potentially undermining their ability to successfully self-manage the condition. Another study, with individuals undertaking a specialist CRPS in-patient programme, identified the importance of patients being able to access high quality information to increase their knowledge of their condition , normalise their experience and learn new coping strategies (Rodham et al. 2012b). To the best of the author’s knowledge no study has explored the information needs of a broader patient group, who may or may not have experienced specialist services. A greater understanding of the patients’ perspective will enable health professionals to better meet the needs of the wider patient population, through provision of high quality information and resources. Therefore, this study aimed to provide an insight into what information is most needed by an individual with CRPS and how people with CRPS prefer to access this information.

**Methods**

**Study design**

This qualitative research study aimed to explore the participants’ lived experiences of CRPS and gain insight into their world (Parahoo 2006). This approach is appropriate to understand the information needs of people with CRPS from their own perspective. An inductive phenomenological approach allowed the researcher to find meaning from multiple perspectives (Pope & Mays 2006; Weaver & Olson 2006). Thematic analysis was undertaken to establish themes and subordinate themes; defined by Braun and Clarke (2006) as a method of identifying, analysing and reporting patterns in data. Ethical approval was granted by the Research Ethics Committee at the Faculty of Health Sciences, University of Southampton. Written informed consent was provided by all participants.

**Participants**

A convenience sample of eight participants was recruited reflecting the qualitative methodology of a small sample studied in depth (Green & Thorogood 2011). This was realistic and attainable within the constraints of a small discrete homogeneous UK population.

Participants were recruited from three websites directed at those with CRPS or an interest in CRPS, and permissions were obtained from the website owners. Access to the websites was potentially available to any individual with access to the internet. The first eight participants who met the inclusion criteria were recruited into the study. The inclusion criteria comprised adults who were resident in the UK, with a self-reported diagnosis of CRPS. There was no restriction on disease duration as the intention was to capture a wide range of experiences.

**Data collection**

Data were collected using semi-structured telephone interviews in order to recruit a discrete CRPS population over a wide geographic area (Musselwhite et al. 2007; Holt 2010). The researcher (SG) developed an interview guide to ensure that similar data were collected for all participants (Britten 2006). This was reviewed with a Health Psychologist colleague and feedback informed the development of the questions. The interview guide was piloted with a colleague to test face validity and to practice telephone interview technique as recommended in the literature (Green & Thorogood 2011). The interviewer (SG) asked about the individual's experience of CRPS and the information they had received since diagnosis, in relation to the condition and rehabilitation (figure 2). The information they would wish to receive was then explored in terms of what would be most useful and how this should be provided.

**Insert Figure 2**

**Analysis**

The audio recordings of the interview narratives were transcribed verbatim by the researcher (SG) with participant identifiable data removed and pseudonyms allocated to ensure anonymity. A summary of the interview was returned to each participant for respondent validation adding credibility to the data (Green & Thorogood 2011). Each participant had the opportunity to comment on whether this was a true reflection of the interview and make changes if desired. Descriptive coding of the transcript data aimed to keep the codes grounded in the dialogue. The codes were scrutinized and initial themes identified as patterns emerged of words and themes recurring across the data set. The initial themes were reviewed and checked against the context of the data to identify overarching key themes and to ensure they were firmly embedded in the text. To offset researcher bias, one randomly selected transcript was independently coded by a peer researcher (CM). In addition, the research supervisor (JA) checked and agreed a sample of coded data. In order to maintain an inductive approach, there was intentionally no engagement with the literature in the early stages of coding (Braun & Clarke 2006). Data analysis was facilitated using qualitative data analysis management software (NVivo 10).

**Results**

Eight female participants were interviewed, with an age range of 30 years to 59 years (44 : SD 10.7). Six participants had one upper limb affected by CRPS, one participant had CRPS of a lower limb and one participant described CRPS of all four limbs. Seven participants had a disease duration ranging from 2 years to 7 years, with one participant reporting a 15 year duration (mean 5.4 years). The time between onset of CRPS and diagnosis varied from one month to 15 years (mean 37.1 months), with seven of the participants ranging between 1 month and 36 months. Two participants reported attending a specialist CRPS in-patient programme since diagnosis. One participant reported attending a pain management course. The eight interviews took place over 12 weeks (April- July 2013) with each lasting no longer than an hour (range 25 - 51 minutes). Interview summaries were sent to all participants and no changes were requested.

Table 1 presents the demographic data.

**Insert Table 1**

Five overarching themes and ten sub themes were identified which clearly addressed two areas (figure 1);

1. The individuals’ experience of receiving information

2. What information would people with CRPS like to receive?

**Insert Figure 1**

**1. The individuals’ experience of receiving information**

This relates to the participants’ experience of receiving information from the time of diagnosis until the time of interview. Two overarching themes emerged from the data; *facing the unknown* and *the need to be an expert.*

**Theme 1: Facing the unknown**

Even after the diagnosis is made, participants expressed feeling uninformed by health professionals and uncertain about the outcome of the condition. This theme comprised three sub themes.

**Access to information about CRPS**

Participants described limited availability of information from health professionals regarding CRPS after the initial diagnosis is made. All recalled being given verbal information at diagnosis although this often comprised the name of the condition only without further elaboration. This left them feeling uncertain of the implications:

"*But they [the health professionals] didn't actually explain what the condition was...... and so it was all kind of unknown*" (Helen).

Post diagnosis, availability of information improved if participants were attending a CRPS specialist centre, however those reporting most satisfaction with the information received had taken part in a CRPS two week intensive programme.

"*I was actually given a big envelope with these sheets in, which was brilliant because it was applicable to me, it was applicable to my condition and all the information in there I could relate to*" (Jane).

 For others, the information given to them by health professionals was mainly verbal and insufficient for their needs. Consequently, some participants struggled to recall what they had been told and did not comprehend the relevance of therapies, initiating the need to independently seek further information.

"*I didn't know why it [mirror visual feedback] was good or why it would work and I have actually looked that up since*" (Anna).

**Impact of the information**

Information was often inconsistent, conflicting and did not address many of the fears associated with the symptoms. In particular there was uncertainty whether using the limb would worsen the condition.

"*The thing is, part of you is, should I be using that arm if it hurts?*" (Vicky).

Information from health professionals that conflicted with the participant’s personal experience left some feeling a sense of mistrust.

"*When I went and saw the um doctor, the consultant in [name of place], he said it would get better in a year and unfortunately it didn't*" (Kate).

The lack of detailed information provided by health professionals left many of the participants feeling isolated after the diagnosis had been made.

"*You feel very isolated with it.......you don't know anybody else with it and nobody has ever heard of it when you talk to people, so you just feel there is nothing out there and nobody around*" (Vicky).

**Difficulty accessing expertise**

Many participants had experienced a delay in diagnosis and described a struggle to convince health professionals of their experience of CRPS.

"*Nobody was believing how much pain I was in ...... so trying to get them to believe, they just thought it's a plaster cast it doesn't hurt*" (Helen).

Frequently health professionals were unfamiliar with the condition, leading to delay in diagnosis and subsequent treatment. This provoked withholding of information due to a fear of being assumed to have a psychological illness, resulting in the individual not accessing the expertise they needed.

"*You are too scared to tell them, actually I'm having these really bizarre feelings in my leg or the pain's really bad I can't sleep and I feel like my life is intolerable. You just don't feel like you can't tell anyone because you think they will say you are a psychiatric patient*" (Helen)

**Theme 2: The need to be an expert**

The experience of encountering health professionals who had little or no knowledge of CRPS, prompted and necessitated the individual to become their own expert*.* This theme comprises two subsidiary themes.

**Actions for seeking information**

Many participants described seeking information following unsatisfactory interactions with health professionals.

"*Yeah, well I decided that, especially as most of the healthcare professionals I have met don't even know about the condition that if I was going to achieve anything then I needed to be the expert*" (Helen).

One participant described a visit to her GP, to seek advice regarding new symptoms, from which she returned without any clarification;

"*I had to go home and type into Google what was happening to me*” (Lisa).

Health professionals often recommended the internet as a resource and, even when not suggested, it remained the primary source of information for all participants. Several people used online patient led forums as an information resource however, they were deliberately avoided by other participants. Some gained support from sharing the experience but others found it exacerbated their fears.

*"I'm very careful yeah because a lot of them they are quite scaremongering*" (Jane).

**Educating health professionals**

Repeated clinical encounters with clinicians who were unfamiliar with CRPS prompted a need for individuals with CRPS to educate the health professionals. Kate recalls a consultation with her GP describing a sense of responsibility that she needed to be the educator:

"*I had to tell* ***him*** *what it was, and explain it to* ***him***" (Kate).

Participants describe frustration that they felt they had to independently find specialist services and reported the need for personal persistence to be referred onto specialists. There was evidence of increasing confidence during clinical encounters as the participants developed expertise in their condition.

"*You do get to that point and you think well, ask me the question, because I obviously know much more about it than you*" (Vicky).

 Not all participants reported a need to educate all the health professionals they encountered, particularly in relation to rehabilitation. The sense of working together made the experience more positive and supportive:

"*Between us we were quite a team*" (Pamela).

**2. What information would people with CRPS like to receive?**

Three themes emerged when participants reflected on what information they would like to receive; *seeking the truth, the shared experience* and *access to expertise.*

**Theme 3: Seeking the truth**

This theme describes the participants’ desire for honest, accurate information and comprises three subsidiary themes.

**Knowledge of the condition**

The lack of information received from health professionals resulted in self-doubt and self-blame if the CRPS was not improving.

"*What I really needed was the truth because all I believed that was it was only because I hadn't tried hard enough that I hadn't got it sorted and that there was something that I had done wrong*" (Helen).

Some participants, when reflecting retrospectively, wanted an awareness of the possibility CRPS may not quickly resolve, or may indeed worsen. For some, uncertainty added anxiety to an already challenging time.

"*I actually asked a lot of questions cos I'd rather know what I'm facing*" (Pamela).

As the CRPS seemed less likely to resolve some participants reframed their situation and wanted information relating to living with the condition in the longer term. Expectations of rehabilitation were not always realistic but as more information became available expectations were adjusted:

"*I underestimated it...... initially I would have thought getting back to normal... um [laughs] and I think now um two years down the line I think it's getting back to a different sort of normal if that makes sense*" (Jane).

**Information about possible outcomes**

Participants’ described wanting accurate information regarding the possible outcome of CRPS. Several people described how they underestimated CRPS and identified a need for enough information early in the disease course so they would take the condition very seriously from the outset and engage with structured rehabilitation from the start.

“*Saying, look you really* ***have*** *to do this, whereas it was really sort of 'well this will help' but it wasn't made, I don't know, I don't suppose I took it seriously enough and I think somebody should have said to me don't underestimate CRPS*" (Jane).

Initial expectations may reflect the lack information available to the participants. Feedback on progress was considered important especially in relation to realistic expectations from rehabilitation.

"*If people had actually said to me you are doing really well with your rehabilitation, you are in a good place at this point, um but don't expect it to have gone yet then I think I would perhaps mentally prepared for the long haul rather than the short haul* " (Helen).

**Barriers to obtaining information**

Several barriers to obtaining accurate, truthful information were identified. Some participants suggested that the threat of litigation resulting from a precipitating event or subsequent treatment may influence the information made available by health professionals. Others reported how the likely outcome of CRPS only becomes apparent over time.

"*When I was first diagnosed the consultant thought that things might settle down ......... probably a year after the initial diagnosis it was, look things aren't going to change, this is going to be the way it is, if we're lucky*" (Eve).

One participant was discordant with the others need for the truth as she found the possible outcome difficult to cope with and preferred not to confront the reality;

"*It was better not knowing because at least I had hope*" (Kate).

**Theme 4: The shared experience**

The participants had little opportunity to meet others with CRPS and felt very isolated. Contact was mainly via internet sites, such as Facebook, and specialist forums. All participants had access to the internet. The relief of finally meeting someone face to face, experiencing the same condition, was clear.

"*She went 'I know what it's like, I've got this thing called CRPS of my leg' and I went aahhh that's what I've got as well, and she hugged me and it was just like oh my god, because it is, it's so isolating*" (Vicky).

However, the shared experience was not always a positive one. Several participants described the accounts and images of others with CRPS as "scary" and had chosen not to access this information any more.

"*I've scared myself by looking at some of the chat rooms. You know, what some people are describing, you know. It's too scary to look at those anymore*" (Lisa).

Social comparison was made by all participants; comparing themselves to others with CRPS. Downward comparison was utilised and enabled them to see their own situation more positively, although this was difficult to admit.

"*In some ways it's helpful to read, and this sounds awful, in some ways it's helpful to read about people that are worse than me and think well at least I'm not there, with maybe a yet question mark*" (Lisa).

The competitive nature of some accounts online frustrated those wishing to stay more positive and participants reported that this could have a negative effect on their own coping mechanisms. As a consequence, several participants chose to avoid these sites altogether.

**Theme 5: Access to expertise**

This theme describes the participants’ struggle to access the information they needed and comprises two subsidiary themes; access to reliable information and access to expertise.

**Access to reliable information**

Participants wanted recommendations of accurate and reliable websites; in particular UK based resources as this seemed more relevant regarding local treatment options. One participant described particular frustration that information usually focused on one affected limb, and little reference was made to CRPS potentially spreading.

"*It's all over my body now. It's going in my neck and my face and I want some information for people like me*" (Lisa).

Specialist advice regarding pregnancy with CRPS was considered very important and two participants described a struggle to access any information addressing this.

 Information directed at employers was also sought as participants identified a lack of understanding of adapting to CRPS in a work environment and it was clear many wished to continue working.

"*The thought of giving up work and sitting back wasn't an option and never had been an option*" (Eve).

**Access to expertise**

Many participants referred to the importance of accessing expertise early in the disease process, to facilitate diagnosis and treatment. Some described requests for referral to specialist centres being declined by clinicians, resulting in frustration and what was described as "a missed opportunity" (Lisa).

"*There was a query ......whether I would benefit from going down to the centre in [name of place] for intervention and it was deemed that they didn't think that I would benefit from that, so that was canc.., that wasn't progressed”* (Eve).

Access to local expertise was considered very important to many participants and availability of resources to enable them to identify this. Anna described with frustration, coming home from a specialist CRPS programme, where she had been surrounded by expertise, and then being unable to find a therapist in her local area with an interest in CRPS:

"*It's the resourcing really, what's available to you in your local area? Who can you turn to? You know, there must be people in [name of place] where I live, there must be people who know about it somewhere but I can't find them and why can't I?*" (Anna).

In summary, the participants described receiving little information from many health professionals at diagnosis and beyond. As a consequence they had to be proactive to seek this information themselves. Accurate, honest information was sought, to understand the potential seriousness of CRPS and enable treatment strategies to be approached accordingly. Participants reported feeling isolated as there was little opportunity to meet others with CRPS.

**Discussion**

This study provides a unique insight, from the perspective of individuals with CRPS, of what information is needed to enable them to engage with the rehabilitation process. The participants’ accounts identified poor availability of information regarding CRPS from the time of diagnosis onwards resulting in unanswered questions and a sense of uncertainty of what CRPS meant for them. This reflects the poor level of disease knowledge of those with CRPS already identified in the literature (Brunner et al. 2010) and suggests this experience may be widespread, as the participants represented different areas of the United Kingdom. Health professionals were often perceived as lacking in knowledge and awareness of CRPS, and consequently information was sought elsewhere. Our participants reported a need to become their own expert, choosing to seek information predominantly from the internet. A study exploring the transition from a CRPS in-patient programme to home, found similar findings, with people preferring not to consult health professionals whom they felt lacked expertise, preferring to try and cope independently (Rodham et al. 2012a). The current study adds additional insight as it encompasses a wider population rather than only those experiencing specialist in-patient care. As a consequence of seeking information independently some participants considered they had a level of expertise greater than the health professionals they encountered. This shift from passive recipient of information to playing a more active role, at times as an educator, may be influenced by both necessity and the availability of the internet to obtain health information (McMullan 2006). However, adopting a level of expertise perceived as greater than the health professional manifested in a complicated relationship at times.

Although the primary source for accessing information, the participants used the internet with caution, actively choosing to avoid certain information, in particular personal accounts of negative experiences. Concerns were expressed regarding identifying reputable sources, which demonstrated an understanding of the inconsistent quality of information available. A cautious approach by patients to the internet is reflected in other studies (Ziebland et al. 2004; Oliver et al. 2008; Rodham et al. 2012b) and, similar to our participants, people with CRPS have previously reported an emphasis on the internet of worst case scenarios (Rodham et al. 2012b).

When the information sought does not meet individuals’ expectations this may inhibit access to, and engagement with, treatment strategies (Hendry et al. 2006; Brand et al. 2010) leading to frustration which can impede engagement with therapy (Dow et al. 2012; Rodham et al. 2013). In this study there was evidence of a gap between what information the individuals reported they need and the information they were able to access. Being provided with accurate information may impact the individuals approach to rehabilitation and balance expectations. Several participants described being unclear if using the affected limb would be detrimental, leading to apprehension and uncertainty. However, even with appropriate advice, pain may have intuitively encouraged disuse. Other factors, such as attitude, social norms and self efficacy can also influence the potential to change behaviour (Bellamy 2004).

There was evidence of a change in information needs as the condition progressed, indicating a possible response shift in the participants’ experience of living with the disease. This is recognised as an adaptive coping mechanism apparent in other chronic conditions (Sinclair & Blackburn 2008). As the chronicity of CRPS became more apparent, the participants reprioritised their information needs with the emphasis being on the information required to adapt to living with CRPS and its limitations. An example of response shift was apparent when one participant described their initial expectation of rehabilitation as to "get back to normal". However, over time the expectation of a complete recovery was reframed and described as “a different sort of normal", suggesting an adjustment to living with a long term condition. Participants' suggested that health professionals should make it clear at the time of diagnosis that CRPS can become a chronic condition so that the important role of rehabilitation is emphasised.

Choosing the appropriate time to discuss the transition of CRPS into chronicity is a challenge for health professionals and is an area which requires further exploration. The interview data were collected retrospectively at a time when the participants had more experience of living with CRPS, and had the opportunity to reflect on their experience, with the potential for recall bias. However, there is evidence from other chronic conditions, that patients want honest disclosure (Fallowfield et al. 2002; Neame et al. 2005) and evading this may delay adjustment to the condition (Fallowfield et al. 2002). Several participants' reported being presented with an optimistic outlook when first diagnosed with CRPS and the current desire for "the truth" early in the condition may reflect this, and underpin the feelings of distrust that were expressed about the information they were given. This presents a challenge for health professionals as currently there are no prognostic markers to help predict an individual’s long term outcome (Marinus et al. 2011). The inability to do so may have been interpreted by the participants as not being given the "truth”. The challenge for health professionals is to provide truthful information which includes sharing the uncertainty of outcome, balanced with reality and hope. These are very high level skills and indicate a need for appropriate training.

Social comparison is evident in all of the interviews; meeting others with CRPS or reading accounts on the internet provided an opportunity to contrast their own situation with others. It was apparent that meeting another person with CRPS face to face validated an individual’s personal experience and reduced their sense of isolation, mirroring work in other conditions (Radford et al. 2008; Kristiansen et al. 2012). Social comparison is a method of self evaluation commonly undertaken at times of uncertainty such as ill health (Dibb & Yardley 2006). Downward comparison is reported as the most common method of comparison for those with a chronic illness and this is reflected by our participants (Buunk et al. 1990). There is clear evidence of downward social comparison providing a means of increasing self esteem by comparing with those considered worse off, consequently enabling them to see their own situation more positively. This reflects the positive affect of downward comparison reported in the literature in others with chronic illness (Wills 1981; Bogart & Helgeson 2000; Hooper et al. 2004). However, for some participant’s, downward comparison provoked an anxiety that their condition may also deteriorate, for example when reading negative accounts on the internet. Research in CRPS supports this finding and similar to the current study, patients’ found it disquieting to admit that it was helpful to compare their own situation to those not doing so well (Rodham et al. 2012b)

**Limitations**

This study is not without limitations; firstly participants were self-selected by responding to the study advertisement on the websites which resulted in a female only study population. While this reflected the epidemiology of CRPS, representation from male participants may have added additional insight. Data were not collected on our participants’ education status however many appeared to be highly literate. Knowledge levels have been shown to be higher in those with a higher educational background (Brunner et al. 2010; Daraz et al. 2011) and it may be that the issues reported by this study’s population could be different to those from other socio-economic backgrounds. If our participants, with higher literacy and educational levels were frustrated by a lack of knowledge and awareness and have to rely on their own research then this may represent the “best case scenario” for people using the NHS. People with lower literacy levels are known to do less well when using the NHS for long-term conditions (Lowe et al. 2013). There was the potential for the researcher to be known to the participants through her role at a CRPS specialist centre; however this was only the case for one participant. It was recognised that this prior relationship may impact on the data collected and therefore it was explicitly stated at the start of the interviews that they were conducted in a research capacity. Reflective practice was undertaken throughout the study to address the influence of the researcher in shaping the data collection and ensuring a distinction between the two roles (Pope & Mays 2006; Holloway & Wheeler 2010). Finally, it is recognised that involvement of a patient in the design of the interview guide would have been best practice and is a limitation of the study.

**Conclusion**

The lack of appropriate and timely information available for those with CRPS is apparent from this qualitative study. There appears to be a gap between the information people need to manage their condition and the information they are able to access.The CRPS UK guidelines clearly state the role of the practitioner is to support patients through provision of information (Goebel et al. 2012) and the evidence suggests this has not been the case for our cohort. The challenge for the health professionals is in providing this information at a time appropriate to meet the individuals’ needs; when they are ready to receive it but also to ensure patients do not underestimate the potential for chronicity of this so they engage with treatment early on. There is a need for health professionals caring for those with CRPS to have high level communication skills and knowledge of the condition in order to benefit the individual with CRPS. Clinicians should be aware of the need for early referral and be familiar with referral pathways. The development of a resource or database to identify local health professionals with expertise or an interest in CRPS would be valuable.

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**Sharon Grieve**

**Figure 1. Themes**

**Facing the unknown**

*Access to information about CRPS*

*Impact of the information*

*Difficulty accessing expertise*

**The shared experience**

*With others who have CRPS*

**Seeking the truth**

*Knowledge of the condition*

*Information about possible outcomes*

*Barriers to obtaining this*

 **Access to expertise**

*Access to reliable information*

 *Access to expertise*

**The need to be an expert**

*Actions for seeking information*

*Educating the health professionals*

**Individuals experience of receiving information**

**What information would they like to receive?**

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**Figure 2. Example of questions from interview guide**

Can you tell me a bit about your CRPS?

I would like you to think back to the time of diagnosis and also think about the time since....can you tell me about the different types of information you have received throughout this time?

In general, was this information given in a way that made sense to you? Can you give me any examples?

What different ways have you accessed further information about any aspect of CRPS?

What prompted you to seek more information?

Can you tell me about any information you would consider to be extremely important to know when embarking on rehabilitation?

**Sharon Grieve**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Pseudonym** | **Gender** | **Age (at interview)** | **Limb affected** | **Disease duration****(years)** | **Time from onset until diagnosis****(months)** |
| **Jane** | **F** | **59** | **Left arm** | **2** | **8** |
| **Helen** | **F** | **46** | **Right leg** | **3** | **2** |
| **Vicky** | **F** | **38** | **Right arm** | **5** | **24** |
| **Pamela** | **F** | **55** | **Right arm** | **2** | **1** |
| **Eve** | **F** | **30** | **Right arm** | **7** | **17** |
| **Kate** | **F** | **30** | **Left arm** | **4** | **36** |
| **Anna** | **F** | **49** | **Right arm and upper right quadrant**  | **15** | **185** |
| **Lisa** | **F** | **44** | **Four limbs and face** | **5** | **24** |

**Table 1: Characteristics of participants**