

Reflecting the transition from pain management services to chronic pain support group attendance: an interpretative phenomenological analysis

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Abstract

Objectives. Transitioning from clinical care to community-based self-management represents a significant challenge, throughout which social support can facilitate health adjustment and quality of life. However, community-centred, peer-led support structures are often under-used. This study aimed to investigate the decision-making processes involved in the choice to attend a Chronic Pain Support Group (CPSG) following discharge from a Pain Management Programme.

Design. An in-depth, qualitative analysis was undertaken using Interpretative Phenomenological Analysis (IPA), exploring participants' subjective experiences, decisional making, and rationale for initial CPSG attendance.

Methods. Twelve participants (four males, eight females) were recruited from a regional CPSG and completed semi-structured interviews lasting between 45 and 120 minutes. Interviews were transcribed verbatim and analysed idiographically before a cross-case analysis was completed.

Results. Analysis of transcripts resulted in three superordinate themes: (1) The thirst for comparative friendship; (2) Conjecture and the imminent choice; (3) Progressive pain management. These themes reflect a desire for empathic, socially comparative friendships and the search for a forum in which to enhance pain self-management strategies, yet also internal conflict over initial CPSG attendance.

Conclusion. Social support and associated friendships are attractive to prospective CPSG members and are conceptualised as opportunities to engage in social comparison and nurture self-care. The first visit to the support group presents a significant hurdle, but can be facilitated by managing the transition between therapeutic care and CPSG attendance. Clinicians can challenge preconceptions, foster positive viewpoints regarding the group and support collective decision-making to attend. Following initial attendance, psychosocial wellbeing was enhanced.

Statement of contribution

What is already known on this subject?

- Social support functions as a protective buffer against declining health
- Joining a peer-led support group can be initially intimidating and the first visit presents a significant hurdle

What does this study add?

- Participants are predominantly attracted to support groups due to the opportunity to develop new friendships
- Health-related peer groups function as fora for social comparison, enhancing self-esteem and self-efficacy
- Experience of pain management programmes primes willingness to attend support groups
- The initial decision to attend is difficult but facilitated by collective, group decision-making processes
- Health-care professionals dynamically prime the transition towards peer support structures

Introduction

Chronic pain is a significant and widespread issue, causing high levels of distress and disability (Williams, Eccleston, & Morley, 2012). Coping with chronic pain represents a major challenge for the patients who experience this long-term condition and the healthcare professionals (HCPs) who work to support them. Structured interventions for managing chronic pain have become recommended practice across primary and secondary care (British Pain Society, 2013), and treatment guidelines are multidisciplinary, covering a wide-range of educational, medical and psychosocial dimensions within formalised Pain Management Programmes (PMPs).

Challenges to pain management interventions

PMPs incorporating Cognitive Behavioural Therapy generate a moderate impact on measures of disability, mood and pain catastrophizing, and 'third-wave' acceptance-based programmes have engendered positive functional and psychological outcomes (Fedoroff, Blackwell, & Speed, 2014). 'Third-wave' approaches build on older clinical traditions, but prioritise function and flexibility, moving away from trying to alter events or cognitions themselves (Hayes, Levin, Plumb-Villardaga, Villatte, & Pistorello, 2013; Hofmann, Sawyer, & Fang, 2010). However, therapeutic outcomes may diminish with time (Ehde, Dillworth, & Turner, 2014). A recent systematic review concluded that the only persisting outcome at 12-months following PMP completion, when compared with a waiting list control, was mood (Williams et al., 2012). Similarly, when PMPs were compared against active controls, only disability was reduced at 12-month follow-up. With low back pain, pain intensity was reduced immediately after PMP, but quality of life and depression were not improved (Hoffman, Papas, Chatkoff, & Kerns, 2007). To enhance the longevity of PMP outcomes, there is a clear need for additional care beyond the programme end.

It is increasingly evident that the referral of an individual to a standardised care pathway (including both group and individual-based interventions), located within a primary

or secondary care context, is limited and representative of an essentially individualistic treatment focus. Pain is experienced in a social world and coping is often undertaken in the framework of wider familial and community-based support structures (Riekert, Ockene, & Pbert, 2014). Responding to pain is a function of social learning, with pain-related behaviours, beliefs and attitudes formed through childhood and interpersonal modelling (Goubert, Vlaeyen, Crombez, & Craig, 2011). The lived experience of facing a chronic health condition is resolutely social; patients develop an understanding of their condition and expectations for their future through interpersonal exchanges with healthcare professionals (HCPs) and wider social relationships (Davison, Pennebaker, & Dickerson, 2000). Therapeutic interventions isolated from social environments fail to reflect the reality of living with chronic pain in a social world (Sullivan, 2012). Treatment failure or limited outcomes may reflect difficulty in transferring learned skills from a clinical setting to social environments (Linton, Hellsing, & Larsson, 1997), therefore there is a need for research that approaches pain management through the context of social support.

The role of social support

Social support has been conceptualised as emotional, informational and instrumental assistance provided by significant others (House, Kahn, McLeod, & Williams, 1985). It is a multifaceted phenomenon, promoting personal and societal well-being. Social support can be activated through; (i) primary, enduring, informal support structures (e.g. family and close friends), or (ii) secondary, larger, more formalised groups (e.g. hobby groups or work colleagues) (Thoits, 2011). Irrespective of type of social support, outcomes are almost uniformly positive; for example, reduced stress-related reactivity (Lovell, Moss, & Wetherell, 2012), enhanced psychological well-being (Taylor & Stanton, 2007), reduced risk of cardiovascular disease (Compare et al., 2013; Gallagher, Luttik, & Jaarsma, 2011), increased longevity (Uchino, 2009), heightened quality of life, coping and adjustment (Thoits, 2011). Where chronic illness represents a stressor, social support functions as a protective buffer, insulating the individual from decline in physical/mental health (Uchino, Carlisle, Birmingham, & Vaughn, 2011; Uchino, 2009). Such social support structures are potentially invaluable as patients often report a contraction in social opportunities as their condition persists (Rodham, McCabe & Blake, 2009).

Chronic Pain Support Groups (CPSGs)

To counteract social isolation, a wide variety of CPSGs exist, providing predominantly peer-to-peer support structures (Embuldeniya et al., 2013). CPSGs are usually volunteer-led, socially active and well-attended by chronic pain patients from wide-ranging social and cultural backgrounds (Cowan, 2013; Subramaniam, Stewart, & Smith, 1999). CPSGs are ordinarily extra-medical, typically providing peer networking, social events and speakers in an informal meeting structure (Cowan, 2013). Following discharge from PMP, it is recommended that additional support is sought from regional CPSGs (British Pain Society, 2013). However, minimal research has investigated the transition from PMP to CPSG and it is not known why people decide to engage with CPSGs. Joining a CPSG represents a patient-centred, considered decision to seek out social support and engage with self-care (Kitson, Marshall, Bassett, & Zeitz, 2013). Research is needed to investigate the rationale for CPSG

membership, identifying what encourages attendance and which factors consistently influence the decision-making process.

Current study

This study aimed to investigate the lived experience of community-based pain management through the 'life world' of people experiencing chronic, non-malignant pain. In particular, the study explored issues surrounding participants' initial decision to attend a CPSPG after PMP completion through retrospective reflection, providing insight into a small but significant part of the lived experience of community-based pain management. Interpretative Phenomenological Analysis (IPA) was used to explore participant perspectives, decision-making processes (Prochaska et al., 1994), rationales and motivations for CPSPG attendance as it offers opportunity for insight into the self as a sense-making agent (Smith, Flowers & Larkin, 2009). Such an idiographic stance is considered crucial for representing the unique pressures surrounding decision-making processes (Ando et al., 2015).

Method

Participants

Twelve participants (8 females, 4 males) were purposively sampled (following Smith, Flowers, & Larkin, 2009) from a CPSPG in the South-East of England. Potential participants were invited to take part if they suffered from chronic, non-malignant pain, had previously completed a six-week PMP through a hospital in the South-East of England, had attended the CPSPG for two or more years, had attended a minimum of 50% of meetings in the past 12 months and were fluent English speakers. Due to their length of CPSPG membership, participants were familiar with others engaged in the study. All participants were currently retired or unable to work due to their health status. Demographic characteristics are shown in Table 1. All identifying information has been changed.

Procedure

The current study was reviewed and ethical approval granted by the University of Derby, UK, Department of Psychology Research Ethics Committee. Participants were approached, following permission from the CPSPG Committee, via their newsletter and through a presentation at a support group meeting. Prospective participants were given the study information sheet and were asked to contact the researcher if they wished to take part. Written, informed consent was obtained prior to commencement of interviews, which were conducted in participants' homes (N = 11) or at the University of Buckingham, UK (N = 1) and lasted between 45 and 120 minutes. All participants were debriefed, received a £30 gift voucher for their time and travel costs were reimbursed.

Table 1. Participant characteristics and pain history

	Alison	Alex	Charlotte	Jane	Jasmine	Laura	Louise	Nicole	Neil	Stuart	Ron	Rebecca
Gender	Female	Male	Female	Female	Female	Female	Female	Female	Male	Male	Male	Female
Age (years)	48	66		55	61	56	56	45	73	57	58	50
Cause of Pain	Accident	OA	OA, FM	Accident	Accident	Accident	Accident	Accident	OA	Accident	Accident	OA
Pain location(s)	Legs, back, hips, shoulders, right arm	Lower back, knees	Whole body	Spine	Trunk, knees, shoulder, neck, joints	Lower back, knees, right shoulder, elbow & hand	Lower back, hips, legs, hands	Lower back, neck	Knees, neck, shoulders	Lower back	Lower back, legs	Back, neck, knees, elbows
Years with CP	25 years	16 years	20 years	6 years	36 years	8 years	23 years	18 years	4 years	9 years	8 years	13 years
Years since PMP	2 years	3 years	2 years	3 years	11 years	4 years	8 years	3 years	3 years	5 years	6 years	12 years
Length of time at SG	2 years	3 years	2 years	3 years	11 years	4 years	8 years	3 years	3 years	5 years	6 years	12 years
SG Attendance	7 times	12 times	10 times	6 times	12 times	6 times	11 times	12 times	10 times	9 times	6 times	12 times
MPS	9	7	5	5	6	9	7	8	6	6	5	7
MPI	9	6	7	5	8	7	7	8	8	7	6	7

Notes: Pain-related variables are scored using the Brief Pain Inventory (Cleeland, 1992) from 0-10. CP = chronic pain; FM = Fibromyalgia; OA = Osteoarthritis; PMP = Pain Management Programme; SG = Support Group. SG attendance = total number of meetings attended in past 12 months; MPS = Mean Pain Severity (max. 10); MPI = Mean Pain Interference (max. 10). All names are pseudonyms.

Data collection and analysis

To facilitate openness within interviews and encourage participants to discuss issues central to their decisions surrounding joining the CPSG, an open-ended semi-structured interview style was used (Smith et al., 2009). Participants were given freedom to lead the interview and make sense of their experiences through highlighting issues important to them from their own perspectives, whilst still allowing the researcher freedom to probe further on topics related to the aims of the study (Smith, 2011). The interview schedule prioritised exploration of the broad context of participants' experiences with chronic pain and the CPSG, alongside an open-ended, subsidiary probe exploring their decision-making processes. The interview schedule contained five questions: (1) Can you tell me about how you came to experience chronic pain? (2) Remembering back to when you joined the CPSG, can you tell me about that time? (3) How did you decide to join the CPSG? (4) Can you tell me about what it's like to be a member of a CPSG? (5) What does the CPSG mean to you? Interviews were all conducted by the first author, audio-recorded and transcribed verbatim.

A 'bottom-up', idiographic stance was adopted for first-stage analyses, with each transcript analysed independently in full, to reflect the experience of each individual in its own light and allow space for researcher reflection (Smith et al., 2009). Each transcript was analysed recursively, constantly moving between themes and transcript to ensure the analyses were grounded in the data. After an initial reading for familiarity, transcripts were read in-depth for descriptive, linguistic and conceptual content, which collectively formed emergent themes in conjunction with the researcher's reflective notes. A cross-case analysis was then undertaken, abstracting super-ordinate and clustered subordinate themes in order to demonstrate relationships, convergences and divergences, developed and grounded in the data. Quotations presented in results represent key extracts, chosen to best highlight the theme under discussion (Smith et al., 2009).

Quality and rigour

Efforts were made throughout the analyses to maintain a stance of sensitivity, transparency, coherence and rigour through idiographic, iterative practice (Yardley, 2007). An independent auditor with expertise in IPA examined the emergent themes, triangulating clustered themes. The auditor worked closely with transcripts to ensure fidelity to original interviews was maintained. Interpretations of quotations were discussed to ensure themes were an appropriate representation of the data. Due to the interpretative nature of the analysis, it is recognised that the researcher's own views may impact upon the representations of interviewees' thoughts, however efforts were made to 'bracket-off' assumptions and pre-conceptions. A reflective log was kept to allow reflexive engagement and exploration of interpretations (following Smith et al., 2009) and to minimise the influence of the researchers' preconceptions when administering and analysing the research. It is recognised that the 'double-hermeneutic' is part of the active sense-making process by the researcher when conducting IPA; as such, the current interpretation may not be the sole interpretation of accounts. The current research therefore focuses on expression of the experience of participants rather than an application of 'top-down' theory to transcript data (Vangeli & West, 2012).

Results

Analysis of transcripts resulted in three superordinate themes: (1) The thirst for comparative friendship; (2) Conjecture and the imminent choice; (3) Progressive pain management. Super-ordinate and subordinate themes are presented in Table 2.

Table 2. Overview of thematic results

Superordinate themes	Subordinate themes
The thirst for comparative friendship	Catching the lifeline of continued support The friendship agenda The freedom of social referencing
Conjecture and the imminent choice	Now or never Dancing around attendance The confidence continuum
Progressive pain management	The need for continuity Refilling the chronic pain toolkit Living well with pain

The thirst for comparative friendship

The first super-ordinate theme was evident across all participants and represented the powerful role of present and future interpersonal relationships in deciding to invest in CPSG membership.

Catching the lifeline of continued support

During the PMP, participants reported hearing about the CPSG through a presentation by current members. Hearing about the group caused feelings of anxiety and frustration, in particular because it represented discharge from hospital-based pain services and yet seemed a great opportunity, therefore participants felt conflicted between their desire for support yet concern over ‘losing’ their close clinical supervision by pain specialists. This conflict was clearly expressed by Nicole as she felt that the group would have been useful for her before the end of the PMP:

“In my head at that time I was thinking ‘why wasn’t I aware of this before’? Because I would’ve loved to go ‘cause it was an extension of what we were doing.” (Nicole).

For the majority, the conflict was short-lived and the decision to attend was rapid and natural, with their decision-making assisted through the information provided at the PMP: they felt like the CPSG would offer a lifeline, opportunity and a wise choice. Engaging with the group was perceived as a way of ensuring that there was a safety net:

“It is my lifeline. If I didn’t have this, the pain would overtake me.” (Laura).

The majority of participants demonstrated a strong, predominant opinion that joining the group was not optional, but a compulsory and non-negotiable step, a metaphorical safety parachute to ensure adequate support provision in the future:

“And just knowing that support’s there (.) you may never, ever use it, it’s like flying... you have a parachute on, you may never ever use it, but it’s there. It’s compulsory.” (Ron).

The recommendation that PMP completers join the CPSG was not viewed neutrally as an optional decision, but instead, because it had been strongly recommended by HCPs on the PMP, participants felt they needed to adhere to this advice. The need for adherence was not, however, seen as pressure from clinicians, but was a valued recommendation arising from trust built through a successful PMP:

“I was thinking that I’d been told it was a good idea. I trusted what they said because I’d found the actual group, the programme, very useful. I thought ok, they recommend this, I’ll give it a go.” (Jane).

The friendship agenda

All participants expressed sadness, but a sense of inevitability about their contracting social circles since developing chronic pain. They saw chronic pain as the prime reason for losing their so-called ‘normal friends’: they felt they were now perceived to be ‘hard work’ and old friends were not willing to fight to continue with friendships, causing a mutual lack of motivation to maintain such friendships. This was a vicious cycle that Stuart discussed:

“I suppose the best way to put it is that people who were close and regular friends are no longer [...] So from a circle of friends that was yay big, it just goes ‘whoosh’. And it’s very easy to get into a cycle where I’ve got nobody to see so I’m not going to go out.” (Stuart).

Consequently, all participants expressed a key desire to build friendships and were motivated to see the CPSG as an opportunity to put this into action. For Charlotte, it was the PMP itself that highlighted this need for friends: doing the PMP in small groups fostered close relationships and a sense of openness and emphasised the need for new friendship groups:

“And that [the PMP] I think brought me out of myself quite a bit and made me want to see if I could go and find somewhere that, y’know, some sort of group of people that I could spend time with.” (Charlotte).

Participants all articulated the difference between friends with pain and friends without; friends who understood pain were conceptualised as people enabling you to move forwards and stretch your capacity for coping, therefore promoting greater adjustment to living with chronic pain. The desire to build friendships was expressed cautiously, suggesting a sense of insecurity as a result of pre-CPSG loss of friends but also elements of self-doubt and self-preservation as participants perhaps did not want to invest too much hope in prospective but hypothetical friendships:

“So it was like I’ll be able to find out more information and I’ll be able to hopefully make a few friends, and hopefully then be able to ask things and maybe even feel able to help as well.” (Nicole).

The freedom of social referencing

Having attended the PMP, participants spoke about finally having met people who understood their experience of pain. This translated into a motivation to seek out further empathic understanding at the CPSG, and the mental freedom, respite and psychological bolstering that this offers. The CPSG offered an atypical environment in which participants experienced freedom from being judged 'different', leading participants to perceive the CPSG as a radical change in culture, moving from isolation to integration:

"I dunno, the only way you could describe it really is being a foreigner in a foreign country and suddenly finding somebody who spoke your own language and you could relate." (Ron).

Being surrounded by people who also suffered with pain also facilitated downward social comparison, which elevated the self-esteem of group members. Seeing others suffering helped participants reconceptualise their health status more positively, reviving new depths of coping and interpersonal learning. For many participants, this social referencing was activated through self-talk, seeking to encourage the self to re-evaluate and re-orientate:

"... I looked at some of my other friends in the group and I'm sitting there thinking I'm slightly better and a few of the members are genuinely really, really sick. And I said to myself 'ah get your backside off your chair'". (Alex).

Conjecture and the imminent choice

The second superordinate theme, supported by data from eleven participants, represented internal conflict surrounding making the initial decision to attend. Such conflict was the result of balancing personal anxieties and self-esteem with the need to make a rational and logical decision to attend, either alone or with colleagues from the PMP.

Now or never

On completing the PMP, participants discussed facing the reality that they needed to make an active choice to continue to utilise the techniques and clinical recommendations they had received, and that if time passed, the impetus for change would diminish. Consequently the sense of urgency was palpable for six participants who therefore made a rapid and immediate choice, rationalised as an essential decision in the context of the post-PMP need for dynamic action without delay. Jasmine argued the decision was pre-weighted towards acceptance of CPSG membership:

"If the PMP hadn't been quite so successful, I might have felt 'what's the point because nobody can help me'... it just opened my eyes so much to the fact that there was still life there so I thought 'go for it'." (Jasmine).

Such rapid decision-making clearly demonstrated that half of participants felt the offer of CPSG membership forced a choice on the approach-avoidance coping continuum:

"So it's a case of I won't know until I go. And if I don't like it, I won't go. I've got to give it a try [...] I didn't flinch, I thought 'no, I'm gonna go'." (Neil).

Dancing around attendance

The remaining half of participants discussed wrestling with the decision to join the CPSG and their ambivalence about this choice. Some participants expressed decision-making difficulties related to readiness to change and fledgling acceptance of their pain condition. The rationale for the difficulty of the decision was typically the disruptive nature of chronic pain and the emotional impact of living with long-term pain. Pain caused internal conflict as participants struggled to overcome their pain-related desire to disengage and instead assert authority over pain:

“I was in two minds whether to go, but I ended up, I said ‘och, bite the bullet, just go’. You’re gonna sit here in pain, so you’re as well sitting in the group in pain and chatting.” (Alex).

Not all participants found such self-talk possible, and many reported passive decision-making, choosing to attend only because colleagues from the PMP agreed to attend. However anger and disappointment was evident in all discussions of collective decision-making; frustration that promises to attend together were broken or that colleagues initially came but did not return:

“So we all [PMP group] decided we’d meet up there [the CPSG]. And that’s where we all would have a reunion every month and that’s how we’ll keep together [...]. (.) It’s only me turned up.” (Ron).

Whether the initial decision or motivation to attend was made independently or collectively, five participants reported appreciating that attendance was never pressurised:

“No pressure. The last thing someone needs that’s in pain is pressure. If you’re pressurised, you back away from it 100%.” (Rebecca).

Evident in their discussions surrounding the lack of external pressure, was the increased propensity to attend; reducing pressure precipitated autonomy in decision-making. Without pressure, they were able to take ownership of their choice and continue to go with or without their colleagues, and the sense of an enhanced internal locus of control was apparent across participants.

The confidence continuum

All participants expressed surprise and satisfaction at their first visits to the CPSG, such positive experiences acting as validation of their choice to attend, imbuing attendees with pride. This enhanced self-confidence and self-efficacy, and participants were encouraged by their own ability to succeed in new environments:

“And it were like a relief now because the relief that I’ve got there and I did it by myself y’know, so I were sorta proud of myself.” (Alison)

Crises of confidence before attending were common, but in those participants who decided collectively with colleagues to attend, confidence levels were significantly higher, evident through their use of positive language. Motivation and momentum were enhanced through joint decision-making:

“So there was a gap of a few weeks I think where I sort of plucked up courage and like I said at first, I went with a couple of friends. They decided they wanted to go along and y’know we’d all go and see what it was like and from that it sort of gave me the incentive to go on my own the next time.” (Charlotte).

By contrast, those attending alone appeared much more tentative, hesitant and concerned over whether they had made the correct decision:

“The way Ron and this other lady were speaking, it was like it sounds really good. But I was also really hesitant because it would be another lot of strangers that I didn’t know.” (Nicole).

Progressive pain management

The third superordinate theme, representative of the views of all participants, addresses issues raised through a need for continuity in care and the transition from PMP to CPSG membership. There was a clear desire to extend the health provisions that participants had received, to build on the practical knowledge of pain management strategies and enhance quality of life in the future.

The need for continuity

Positive perceptions of the PMP were extremely important to all participants and strong drivers in the decision to attend the CPSG. The PMP primed CPSG attendance on multiple levels; through HCP referrals, the need to continue with learned techniques and the ease of contact with healthcare services. Nine participants saw the CPSG as a simple extension of the PMP. Viewing it so enabled them to reduce worries about attendance as the decision was, to some extent, nullified. They attended because the PMP had finished and they were moving on to whatever came next:

“I’ll be honest with you, I didn’t want the six weeks [PMP] to end. I didn’t, honestly, I loved going to the church and doing all the things we done. And so I went ‘the monthly group’s gonna hopefully be something the same’”. (Alex).

For four participants, this decision was in order to maintain close contact with the clinical staff periodically attending the CPSG. They were motivated by the opportunity to access clinical expertise without a formal appointment, and saw this as an advantage that needed to be maximised and a method of preventing health-related decline. There was a clear sense of self-preservation, ensuring they were mentored and looked after, with informal support structures potentially providing assistance or mitigation in case of a health emergency:

“I thought I’ll go. Just to keep in touch with pain. Because you don’t always get an appointment from them and if they then decide they can’t help you any more then you come away from them. You’re lost in the crack. So I thought, ‘no, I’ll go to this pain group’ and at least I’ll get to see these people. And maybe not all the time, but I’ll get to see them and if I do need help, maybe these people will know how to help me.” (Laura).

Participants seemed keenly aware of their own fallibility in continuing to use what they had learned, therefore had a thirst for active accountability. They expressed their decision to attend as part of a damage-limitation measure, deliberately initiating an accountability strategy, which would ensure their continued self-management:

“But obviously sorta sometimes you sorta go back to your old ways, you need somebody to say ‘get back and do that’. That’s what I need, I need a kick” (Alison)

Refilling the chronic pain toolkit

Joining the CPSG, for ten participants, represented a technique by which they could self-manage their pain. Three participants explicitly re-used the language that they had been taught on the PMP about the need for a pain toolkit, and the CPSG was effectively relocated into the toolkit as a strategy to enhance self-care:

“There are days when you try to go to your toolbox for a distraction and there’s none left in so you have try and find something else. And soon the toolbox gets empty and you’ve got to try and replenish it with other things that work.” (Neil).

Refilling the toolkit was also viewed at a deeper level; the CPSG offered new things to go into the toolkit through peer-to-peer learning and information-exchange. Participants respected that the group offered an opportunity to hear from others who had first-hand experience of comparable conditions, therefore their advice became invaluable:

“It’s like we can have a natter amongst ourselves; ‘have you gone and tried this, have you had a word with that, have you spoken to someone about that?’ Trust me, we’ve tried absolutely everything there is.” (Jane).

Through this, they could retain an internal locus of control, learning vicariously through others on an equal level of social comparison, in order to select what would work for their own pain.

Living well with pain

Joining the CPSG was a decision that was resolutely future-focused, facilitating renewed quality of life and enhanced coping strategies to continue living well with pain. The support group offered a place where pain would not control the sufferer, but where power could be reasserted, enabling participants to maintain a promotion-focus rather than (re)lapse into learned helplessness:

“It’s my way of making myself get up, get going and go out to this group. It’s like having a special room in the house that you go to get your mind back. That’s the only way I can put it ‘coz it’s so close to where I live. It’s ‘I am going to the pain group, I don’t care what’s going on’.” (Laura).

Participants were therefore determined in their desire to live well with pain and attendance was seen as a contract with the self in order to regain a sense of identity. By talking with others they reaffirmed that what they were doing to manage their pain was correct and they could learn to reengage with life positively:

“It wasn’t so much that I was learning how to cope, it was the fact that I was having what I was doing confirmed as being the right thing”. (Ron).

In essence, the decision to join the CPSG allowed participants to live well with pain, in spite of pain. Participants were able to avoid maladaptive coping through a strong network of interpersonal support, which functioned as a protective barrier, insulating them from further pain-related psychosocial decline.

Discussion

This study investigated the rationale surrounding the decision to attend a CPSG following PMP completion. Results demonstrated three superordinate themes: The thirst for comparative friendship; Conjecture and the imminent choice; and Progressive pain management. Collectively, these reflected the challenge of living with pain as an individual within a changing social world, and the desire to engage with social support.

The transition into CPSG membership was primed by positive experiences of the PMP and facilitated by peer presentations and self-care recommendations during the PMP. Fostering closer integration between clinical care and support groups therefore enables the PMP to function as a decisional aid, assisting with the decision to attend through peer-to-peer and clinician-initiated information exchange (Edwards & Elwyn, 2009). Clinician recommendation to join the CPSG enabled it to be (re)conceptualised positively, enhancing patient awareness of the benefits of social support (Grande, Arnott, Brundle, & Pilling, 2014). Such decisional-support embodies patient-centred care (NICE, 2012; Stacey et al., 2014) and promoted active decision-making, increasing internal locus of control and agency (Thoits, 2011; Uchino, 2009).

The offer of post-PMP CPSG membership provoked consideration of the choice that needed to be made, the time-line in which the choice had to be made and a critical evaluation of the individual or socially-derived confidence required to act upon a decision to join the CPSG. A divide was evident between making an active choice to engage immediately, or a passive decision to attend as a consequence of a collective PMP peer-group trialling the CPSG together. Those who were less confident in their decision demonstrated choice-related internal conflict and lower self-efficacy. The split between confident attenders and those needing support may represent a continuum on the approach-avoidance coping scale (Roth & Cohen, 1986). Approach-coping in this population consisted of positive self-talk, asserting authority over pain, recognising one's own need for social support as active accountability and choosing to enable their continued use of PMP learned skills; all essentially positive coping strategies (Lazarus, 1993).

The proportional split between patients attending "now or never" and those "dancing around attendance" suggests that the role of the PMP may be in initiating *desire* for change and the CPSG in *maintaining* change. Those who made an active choice to engage with the CPSG demonstrated greater readiness for change, prospectively reflecting a move between the 'action' and 'maintenance' stages in the Transtheoretical Model (TTM) of health behaviour change (Prochaska & Velicer, 1997), with those collectively attending displaying earlier stages of change (e.g. contemplation). In the latter weeks of a PMP, clinicians could deliberately initiate discussion about propensity to attend a CPSG and if

encountering passivity or reticence, could encourage a collective peer-group trial, drawing out debate over the PMP vs. CPSG roles in initiating or maintaining learned skills.

Prospective friendships were a strong attraction: associating with 'pain friends' engendered higher levels of empathic understanding and facilitated social integration (Embuldeniya et al., 2013). This was an outcome of downward social-referencing through Social Comparison Theory; seeing others live with comparable or worse pain enhances self-efficacy and self-acceptance (Davison et al., 2000; Festinger, 1954). Similarly, friendships facilitated feelings of belongingness, a fundamental human need, insulating participants against threats arising from their potential social difference (Baumeister & Leary, 1995). Current findings model those of Embuldeniya et al. (2013) who found peer support reduces social isolation, encourages shared experiential learning and fosters psychosocial well-being. When advertising a CPSG, the friendship agenda should be emphasised as it is an attractive prospect in the context of pain-related reductions in available social support (Cowan, 2013). The existing literature base is very weak regarding the socio-demographic make-up of CPSG participants (see only Subramaniam et al., 1999), recognizing that social support, downward social referencing and friendships were core outcomes in this research; this suggests a need for future research to address those socio-demographic influences which may contribute to support group dynamics. Strong socio-demographic differences may highlight potential inequalities in care, treatment pathways and, ultimately, pain outcomes (van Hecke, Torrance, & Smith, 2013).

Future-oriented, prospective pain management was offered by the support group, reflecting recognition of the continued need to live well with pain in the future, through the application of a toolkit of learned self-management strategies and a renewed desire to manage pain effectively. Joining a CPSG was a function of a desire for continued investment in self-care, maintaining informal contact with support structures and developing a repertoire of self-management approaches. This enabled a promotion-focus, pursuing a positive future, as participants felt the CPSG 'fit' with their goals and future plans and desire for group attendance was intensified in accordance with Regulatory Fit Theory (Cesario, Higgins, & Scholer, 2008; Higgins, 2000). The group offered an opportunity to consolidate pain management skills, minimising risk of their extinction, in congruence with participants' desires to live well with pain (Turk, Rudy, & Sorkin, 1993). Consequently, enhancing patient perception of the CPSG as an opportunity for continuity of care and self-management has the potential to load the decisional balance positively in favour of CPSG membership. Future research could aim to develop interventions which would support the transition from PMP to CPSG, for example decision aids to support individuals with greater choice-related internal conflict or low confidence about deciding whether or not to join the CPSG.

This research offers an insight into the rationale for joining a CPSG, yet it is recognised that the participants in this study represent a self-selected sample, retrospectively recalling their decision-making processes. The sample is effectively a feature of the nature of a support group itself: those who invest in a support group and engage in mutual-support are those who have chosen to do so (Embuldeniya et al., 2013). Consequently, working with this population offers an insight into the perspectives and decision-making processes of those who would choose to engage in social support. Although the gender balance is representative of the chronic pain population as a whole (see van Hecke et al., 2013), the geographical location of the research and the required

fluency in spoken English may have restricted representation of CPSG members nationally for whom English is not a native language. Similarly, there may be differences in the class or education-related structure evident in this south-east UK-based sample, for example, in terms of health literacy (Nutbeam, 2000) or educational status (van Hecke et al., 2013). Future research could aim to consider the perspectives of those who have chosen not to join a CPSG. Due to the nature of the interpretative lens, these analyses are not the only possible interpretation of data (Smith et al., 2009), therefore they are intended as a representation of the dynamic, evolving world expressed by participants at the time of study (Osborn & Smith, 1998), accessed interpretatively and reflexively in conjunction with careful maintenance of a reflective log.

The decision to attend a support group is a significant issue in light of expected costs and benefits of engaging. The decisional balance is positively weighted by the opportunity for continued pain management as an individual surrounded by strong social support structures. CPSG appeal is multifactorial, but is principally influenced through the offer of friendship, representing a collective point of social reference and an opportunity to act on the advice of healthcare professionals. Deciding to attend is enabled through active decision-making processes and can be facilitated through a collective choice to attend, primed during the PMP. Social support is an invaluable resource which promotes healthy outcomes and continued self-care, therefore offering an opportunity for both patients and clinicians alike.

Conflict of interest

The authors declare no conflict of interest.

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References

- Ando, H., Williams, C., Angus, R. M., Thornton, E. W., Chakrabarti, B., Cousins, R., ... Young, C. A. (2015). Why don't they accept non-invasive ventilation?: Insight into the interpersonal perspectives of patients with motor neurone disease. *British Journal of Health Psychology, 20*(2), 341–359. <http://doi.org/10.1111/bjhp.12104>
- Baumeister, R. F., & Leary, M. R. (1995). The need to belong: Desire for interpersonal attachments as a fundamental human motivation. *Psychological Bulletin, 117*(3), 497–529. <http://doi.org/10.1037/0033-2909.117.3.497>
- British Pain Society. (2013). *Guidelines for Pain Management Programmes for Adults*. London: BPS.
- Cesario, J., Higgins, E. T., & Scholer, A. A. (2008). Regulatory Fit and Persuasion: Basic Principles and Remaining Questions. *Social and Personality Psychology Compass, 2*(1), 444–463. <http://doi.org/10.1111/j.1751-9004.2007.00055.x>
- Cleeland, C. S. (1992). Brief Pain Inventory (BPI). In D. C. Turk & R. Melzack (Eds.), *Handbook of Pain Assessment* (pp. 367–370). Guildford Press.
- Compare, A., Zarbo, C., Manzoni, G. M., Castelnuovo, G., Baldassari, E., Bonardi, A., ... Romagnoni, C. (2013). Social support, depression, and heart disease: a ten year literature review. *Frontiers in Psychology, 4*, 384. <http://doi.org/10.3389/fpsyg.2013.00384>
- Cowan, P. (2013). Support Groups for Chronic Pain. In R. Moore (Ed.), *Handbook of Pain and Palliative Care: Biobehavioral Approaches for the Life Course* (pp. 639–648). Rocklin, CA: Springer Science + Business Media.
- Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist, 55*(2), 205–217. doi: 10.1037//0003-066X.55.2.205 205
- Edwards, A., & Elwyn, G. (Eds.). (2009). *Shared decision-making in health care: achieving evidence-based patient choice* (2nd ed). Oxford: Oxford University Press.
- Ehde, D. M., Dillworth, T. M., & Turner, J. A. (2014). Cognitive-behavioral therapy for individuals with chronic pain: Efficacy, innovations, and directions for research. *American Psychologist, 69*(2), 153–166. <http://doi.org/10.1037/a0035747>
- Embuldeniya, G., Veinot, P., Bell, E., Bell, M., Nyhof-Young, J., Sale, J. E. M., & Britten, N. (2013). The experience and impact of chronic disease peer support interventions: A qualitative synthesis. *Patient Education and Counseling, 92*(1), 3–12. <http://doi.org/10.1016/j.pec.2013.02.002>
- Fedoroff, I. C., Blackwell, E., & Speed, B. (2014). Evaluation of group and individual change in a multidisciplinary pain management program. *The Clinical Journal of Pain, 30*(5), 399–408. <http://doi.org/10.1097/AJP.0b013e31829ea1f7>
- Festinger, L. (1954). A Theory of Social Comparison Processes. *Human Relations, 7*(2), 117–140. <http://doi.org/10.1177/001872675400700202>
- Gallagher, R., Luttik, M.-L., & Jaarsma, T. (2011). Social Support and Self-care in Heart Failure. *The Journal of Cardiovascular Nursing, 26*(6), 439–445. <http://doi.org/10.1097/JCN.0b013e31820984e1>
- Goubert, L., Vlaeyen, J. W. S., Crombez, G., & Craig, K. D. (2011). Learning About Pain From Others: An Observational Learning Account. *The Journal of Pain, 12*(2), 167–174. <http://doi.org/10.1016/j.jpain.2010.10.001>

- Grande, G., Arnott, J., Brundle, C., & Pilling, M. (2014). Predicting cancer patients' participation in support groups: A longitudinal study. *Patient Education and Counseling, 96*(2), 229–236. <http://doi.org/10.1016/j.pec.2014.05.003>
- Hayes, S. C., Levin, M. E., Plumb-Villardaga, J., Villatte, J. L., & Pistorello, J. (2013). Acceptance and Commitment Therapy and Contextual Behavioral Science: Examining the Progress of a Distinctive Model of Behavioral and Cognitive Therapy. *Behavior Therapy, 44*(2), 180–198. <http://doi.org/10.1016/j.beth.2009.08.002>
- Higgins, E. T. (2000). Making a good decision: value from fit. *The American Psychologist, 55*(11), 1217–1230. doi: 10.1037/0003-066X.55.11.1217
- Hoffman, B. M., Papas, R. K., Chatkoff, D. K., & Kerns, R. D. (2007). Meta-analysis of psychological interventions for chronic low back pain. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association, 26*(1), 1–9. <http://doi.org/10.1037/0278-6133.26.1.1>
- Hofmann, S. G., Sawyer, A. T., & Fang, A. (2010). The Empirical Status of the “New Wave” of CBT. *The Psychiatric Clinics of North America, 33*(3), 701–710. <http://doi.org/10.1016/j.psc.2010.04.006>
- House, J. S., Kahn, R. L., McLeod, J. D., & Williams, D. (1985). Measures and concepts of social support. In S. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 83–108). San Diego, CA, US: Academic Press.
- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing, 69*(1), 4–15. <http://doi.org/10.1111/j.1365-2648.2012.06064.x>
- Lazarus, R. S. (1993). Coping theory and research: past, present and future. *Psychosomatic Medicine, 55*(3), 234–247. doi: 0033-31/4/93/5503-0234\$03.00/O
- Linton, S. J., Hellsing, A. L., & Larsson, I. (1997). Bridging the Gap: Support Groups Do Not Enhance Long-Term Outcome in Chronic Back Pain. *The Clinical Journal Of Pain, 13*, 221–228.
- Lovell, B., Moss, M., & Wetherell, M. A. (2012). With a little help from my friends: Psychological, endocrine and health corollaries of social support in parental caregivers of children with autism or ADHD. *Research in Developmental Disabilities, 33*(2), 682–687. <http://doi.org/10.1016/j.ridd.2011.11.014>
- NICE. (2012). *Patient experience in adult NHS services* (Clinical Guidance, Vol. 138). National Institute for Health and Care Excellence. <https://www.nice.org.uk/guidance/cg138> [Last accessed 17th May 2016]
- Osborn, M., & Smith, J. A. (1998). The experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology, 3*, 65–83. doi: 10.1111/j.2044-8287.1998.tb00556.x
- Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion: AJHP, 12*(1), 38–48. doi: 10.4278/0890-1171-12.1.38
- Prochaska, J. O., Velicer, W. F., Rossi, J. S., Goldstein, M. G., Marcus, B. H., Rakowski, W., ... Rossi, S. R. (1994). Stages of change and decisional balance for 12 problem behaviors. *Health Psychology, 13*(1), 39–46. <http://doi.org/10.1037/0278-6133.13.1.39>

- Riekert, K. A., Ockene, J. K., & Pbert, L. (Eds.). (2014). *The handbook of health behavior change* (4th ed.). New York: Springer.
- 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 & Health, 24*, 619–634. doi: 10.1080/08870440802563245
- Roth, S., & Cohen, L. J. (1986). Approach, avoidance, and coping with stress. *American Psychologist, 41*(7), 813–819. <http://doi.org/10.1037/0003-066X.41.7.813>
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9–27. <http://doi.org/10.1080/17437199.2010.510659>
- Smith, J. A., Flower, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Stacey, D., Legare, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., ... Wu, J. H. C. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Of Systematic Reviews (Online)*, 1 (1), 1–265. doi: 10.1002/14651858.CD001431.pub4
- Subramaniam, V., Stewart, M. W., & Smith, J. F. (1999). The Development and Impact of a Chronic Pain Support Group. *Journal of Pain and Symptom Management, 17*(5), 376–383. [http://doi.org/10.1016/S0885-3924\(99\)00012-3](http://doi.org/10.1016/S0885-3924(99)00012-3)
- Sullivan, M. J. L. (2012). The communal coping model of pain catastrophising: Clinical and research implications. *Canadian Psychology/Psychologie Canadienne, 53*(1), 32–41. doi: 10.1037/a0026726
- Taylor, S. E., & Stanton, A. L. (2007). Coping Resources, Coping Processes, and Mental Health. *Annual Review of Clinical Psychology, 3*(1), 377–401. <http://doi.org/10.1146/annurev.clinpsy.3.022806.091520>
- Thoits, P. A. (2011). Mechanisms Linking Social Ties and Support to Physical and Mental Health. *Journal of Health and Social Behavior, 52*(2), 145–161. <http://doi.org/10.1177/0022146510395592>
- Turk, D. C., Rudy, T. E., & Sorkin, B. A. (1993). Neglected topics in chronic pain treatment outcome studies: determination of success. *Pain, 53*(1), 3–16. doi: 10.1016/0304-3959(93)90049-U
- Uchino, B. N. (2009). Understanding the Links Between Social Support and Physical Health: A Life-Span Perspective With Emphasis on the Separability of Perceived and Received Support. *Perspectives on Psychological Science, 4*, 236–255. <http://doi.org/10.1111/j.1745-6924.2009.01122.x>
- Uchino, B. N., Carlisle, M., Birmingham, W., & Vaughn, A. A. (2011). Social Support and the Reactivity Hypothesis: Conceptual Issues in Examining the Efficacy of Received Support During Acute Psychological Stress. *Biological Psychology, 86*(2), 137–142. <http://doi.org/10.1016/j.biopsycho.2010.04.003>
- van Hecke, O., Torrance, N., & Smith, B. H. (2013). Chronic pain epidemiology and its clinical relevance. *British Journal of Anaesthesia, 111*(1), 13–18. doi:10.1093/bja/aet123
- Vangeli, E., & West, R. (2012). Transition towards a “non-smoker” identity following smoking cessation: An interpretative phenomenological analysis: Transition towards a “non-

smoker” identity. *British Journal of Health Psychology*, 17(1), 171–184.

<http://doi.org/10.1111/j.2044-8287.2011.02031.x>

Williams, A. C., Eccleston, C., & Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews*, 11. Article Number CD007407. doi: 10.1002/14651858.CD007407.pub3

Yardley, L. (2007). Demonstrating validity in qualitative psychology. In J. A. Smith (Ed.), *A practical guide to research methods* (pp. 235–251). London: Sage.