

Decision-making processes for the self management of persistent pain:

A grounded theory study

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Introduction

Persistent pain is a chronic disease significantly impacting on Australian populations and health care (Cousins, 2007), and is more prevalent than asthma and diabetes (Blyth et al., 2001). Within the Australian adult population, 17.1% males and 20% females experience persistent pain (Blyth et al., 2001). Persistent pain is a life-limiting condition fraught with challenging and mostly unpleasant physical, psychological, and social encounters (Gatchel, Peng, Peters, Fuchs, & Turks, 2007; Resnik & Rehm, 2001). These physical, psychological, and social encounters are frequently unpredictable and unwelcome, causing many complex problems for the experiencing individual.

Individuals with chronic illnesses such as persistent pain act as primary care managers, identifying solutions to problems and making necessary adaptations to their life (Funnell, 2000). It is commonly regarded that health professionals have knowledge and will generate a treatment plan, conveying the plan to the individual for approval, modification, or rejection (Thorne, Nyhlin, & Paterson, 2000). However, chronic illnesses are managed by individuals in their own home and any decisions to heed or veto the health professional's recommendations occurs in this nonclinical environment (Edworthy, 2000; Glasgow & Anderson, 1999). Individuals with chronic diseases, such as persistent pain, inadvertently develop expertise about their illness, fostering an elevated interest concerning the decisions made about their health management (Edworthy, 2000; Kenny, 2003; Wilson, 1999).

An increased interest in research into decision-making processes associated with self-management of chronic disease (Pierce & Hicks, 2001; US Department of Health and Human Services, 2006) and cancer pain management (Facione & Facione, 2007; Sainio & Lauri, 2003) has emerged. Other research has explored the information-gathering habits of individuals with persistent pain (McIntosh & Shaw, 2003) and the decision-making processes of individuals managing migraines (Peters, Huijjer Abu-Saad, Vydellingum, Dowson, & Murphy, 2003). Yet, decision-making processes that underpin self-management of persistent pain is a largely unexplored area (Eccleston & Crombez, 2007). Furthermore, general theories on decision-making and self-management have not adequately accounted for the many difficulties faced by individuals enduring persistent pain and the consequences of these experiences for the decision-maker.

Thus, this grounded theory study was undertaken to: 1) explore the meaning decision-making had from the individual's perspective; 2) develop a rich conceptual understanding of the self-management of persistent pain; and 3) understand how this was achieved within a 'real world' environment.

Method

A grounded theory method was suitable for this study as it facilitated theoretical understandings and a creation of explanatory theory through analysis of human responses, interaction, and processes (Charmaz, 2000). The experience of persistent pain influences those social and psychosocial processes of how individuals interact with the self, others, and the environment, and the meanings that are generated from those interactions (McLennan, Ryan, & Spoonley, 2000). Symbolic interactionism was the theoretical perspective taken for this study as it explained the experiences of developing one's self and one's relationships with society (Mead, 1934). Within the paradigm of symbolic interactionism, language, gestures, and expressions, are recognised as symbols (Burns & Grove, 2007). The symbols, language, expression, and gestures related to persistent pain hold symbolic significance to this study, as they provided the context within which decisions were made. This study sought to investigate and clarify the various actions, interactions, and processes that underpinned how individuals made decisions about the management of their condition in the midst of experiencing persistent pain.

Sample

Purposeful and theoretical sampling techniques were used to recruit 13 participants from two Australian pain clinics: a major metropolitan pain clinic servicing the private health sector and a large regional pain clinic servicing the public and private health sector. The first three participants were recruited via purposeful sampling using the following inclusion criteria: aged 18 years and older; able to converse in English; presence of persistent pain; ability to self-care; and currently managed by a clinical pain specialist. The defining criteria for persistent pain used in this study was pain lasting six months or longer; resulting from non-life-threatening causes; was resistant to treatment; and had the potential to continue for the remainder of the individual's life (McCaffery & Pasero, 1999). Selecting participants under the management of a clinical pain specialist ensured that participants had a current diagnosis of persistent pain.

Theoretical sampling is a decisive data sampling technique that stands in reciprocity with the constant comparative analysis approach (Glaser & Holton, 2004; Punch, 2005). Glaser (2002) explained “all is data”, believing there was no such event where data was biased, subjective, objective, or misinterpreted. Hence, Glaser (2002) encouraged that whatever the researcher perceived as a pattern could be interpreted as data. Using Glaser’s approach to theoretical sampling a further 10 participants were recruited to this study. Theoretical sampling occurred as information provided by one participant directed the selection of further participants or data sources, thus, refining or extending data collection and analysis. Data were collected until theoretical saturation occurred as evident by the development of conceptually rich codes, categories and theory about how people made self management choices regarding persistent pain. Ethical approval was sought and obtained from the University Human Research Ethics Committees and the two pain clinic’s Human Research Ethics Committees. Acquisition of ethics approval necessitated the assurance that all participants would have the right to self-determination, privacy and dignity, anonymity or confidentiality, to fair treatment, and protection from discomfort and harm.

Data Collection

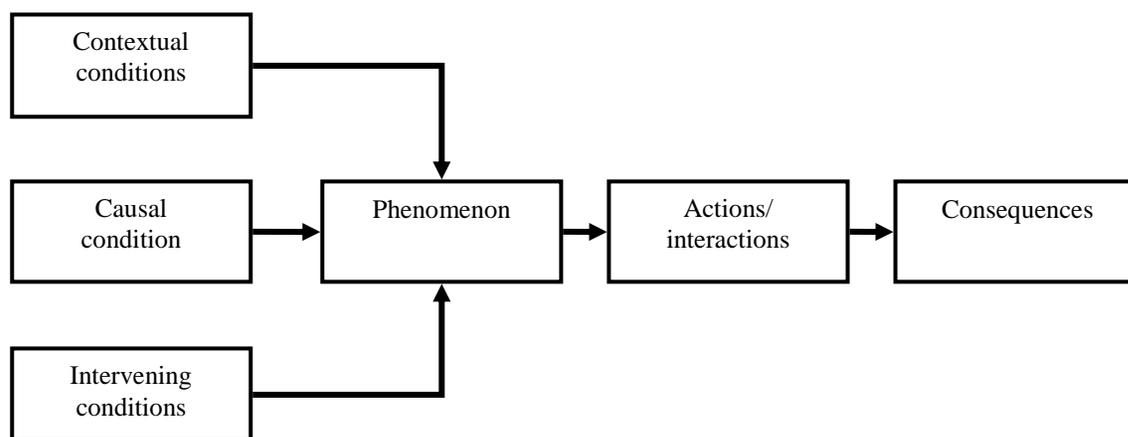
During 2006-2008, the researcher conducted in-depth interviews with each participant either in their home environment or pain clinic consultation room depending on the participant’s preference. A conversational approach to interviewing was used to enable participants to provide rich descriptions of the decision-making processes. Initial interview questions included: a) the types of decisions the participant made regarding the management of the pain condition; b) the level of participation and the importance of making decisions regarding the management of the pain condition; and c) the participant’s perception of the self in the decision-making role. Striving for theoretical saturation interview questions progressively evolved as new areas of interest emerged around decision-making processes of individuals’ self-managing persistent pain. All interviews were audio-taped and transcribed verbatim by a research assistant into a Microsoft Word document. This information was then imported QRS NVivo Version 2.0, which was used for data management.

Data Analysis

Data analysis was conducted using 1) constant comparative analysis and coding and 2) the conditional/consequential matrix (Strauss & Corbin, 1998). Using the constant comparative analysis new data were compared and analyzed

against previously collected data to enable theory development (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Initial data analysis occurred via three levels of coding; open coding, axial coding, and selective coding (Strauss & Corbin, 1998). Open coding produced fragmented data revealing its unique characteristics; whereas axial coding restructured these fragmented pieces back into whole data known as categories and subcategories (Strauss & Corbin, 1998; Charmaz, 2006). For example, open codes *being alone*, *losing hope in self*, *reflecting over losses*, and *talking about suicide* were restructured into the axial code, *struggling for the will to live*. The final level of analysis, selective coding, was a process where axial codes were progressively “selected” or refined in relation to a core category with intricate links binding data together to shape the substantive theory (Strauss & Corbin, 1998). For example, axial codes *fearing alterations to the norm*, *depleting personal energies*, and *struggling for the will to live*, were bound together to form the category, *degenerating self*.

Figure 1 Conditional/Consequential Matrix



Further data analysis occurred as the developing categories and subcategories were examined using the conditional/consequential matrix (Figure 1.). The consequential/conditional matrix is an analytical tool developed by Strauss & Corbin (1998). Using this analytical matrix facilitated the identification of the phenomenon, actions/interactions and consequences and causal, intervening, and contextual conditions to reveal an emergent theory. In this study the phenomenon was the central idea recognized by repeated patterns of actions /interactions that described what people did in response to a problem or situation such as persistent pain (Strauss &Corbin, 1998). The causal, intervening, and contextual conditions were activities or events that shaped problems relating to the

phenomenon. The consequences were the outcomes of the actions/interactions. These elements are detailed more extensively in the findings section.

Rigour

Rigour of grounded theory comes from the theory's ability to fit the phenomenon under study; to "grab" or speak to the people hearing the theory; and to "work" by means of explaining, interpreting, and predicating the phenomenon under study (Glaser & Strauss, 1967). If all three principles, credibility, auditability, and fittingness, are present and obvious during theory development then the study is judged to be rigorous. Credibility is demonstrated when participants guide the inquiry process and their understanding of the phenomenon is reflected in the theory (Chiovitti & Piran, 2003). Credibility is evident in this study through the rigorous coding and analysis of participants' unique experiences as decision-makers; the use of theoretical sampling processes to guide data collection; rigorous processes in relation to ethical behaviour; and the researcher working within a pain clinic during the data analysis stage of this study. Auditability occurs when one researcher is able to reproduce a study by following another researcher's method and conclusions (Carpenter, 1995; Chiovitti & Piran, 2003). Auditability of this study was achieved in four different ways: 1) by scrutinizing how the data was analysed throughout the research process; 2) by completing a documentation and decision trail in the form of memoing; 3) by delineating the researcher's thinking about the data to provide a clear rationale and explanation of how the study was constructed; and 4) from producing clear documentation surrounding conceptual comparisons and the use of conceptual diagramming to the data. Fittingness recognises that the research findings should be as meaningful to the participant, as it is to other individuals, in similar situations or environments (Chiovitti & Piran, 2003). This study generated a substantive theory and demonstrated fittingness by ensuring the participants' meanings related to the phenomenon were reflected in the substantive theory, and that communication of the study findings to health professionals and individuals with persistent pain, was completed to ascertain that the findings held resonance.

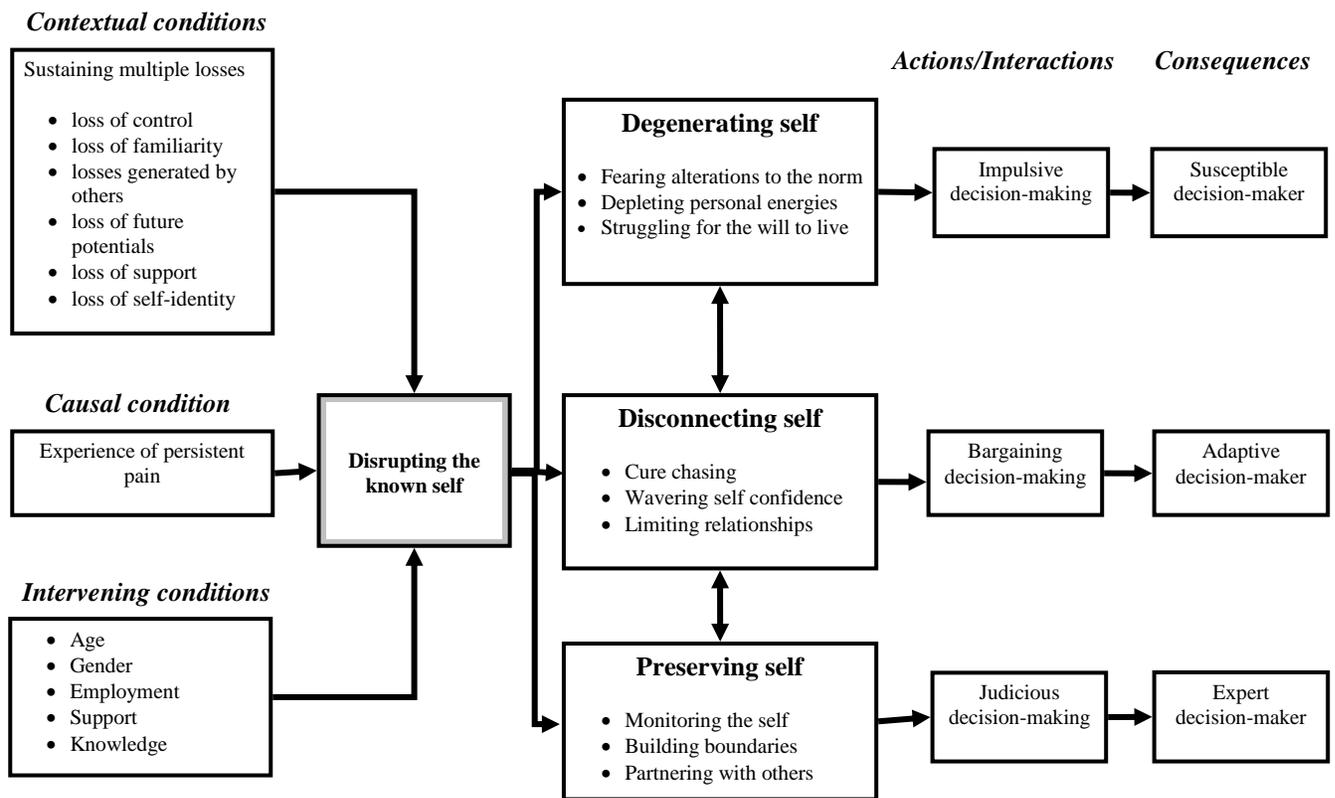
Findings

Participants included females (n=9) and males (n=4). Most female participants were aged between 40 and 65 years (n=8), one female participant was aged 25 years of age. One female participant was employed while the remainder received disability pension (n=8). Comparatively, all male participants were aged between 40 and 65 years (n=4) and

were either actively employed (n=2), retired (n=1) or receiving a disability pension (n=1). All participants were Caucasian. Male participants acquired an education level of year 10 (n=4). Female participants acquired varied education levels including year 8 (n=2), year 10 (n=3), year 12 (n=2), diploma (n=1), and degree (n=1). Relationship status for the participants varied being either married (n=4), divorced (n=7), single (n=1) or widowed (n=1). All participants had experienced persistent pain for between 15-43 years, with the exception of one female participant who had experienced pain for only 5 years. Pseudonyms were used throughout this study to afford anonymity to study participants.

Theory Development: Transforming the Deciding Self (see figure 2.)

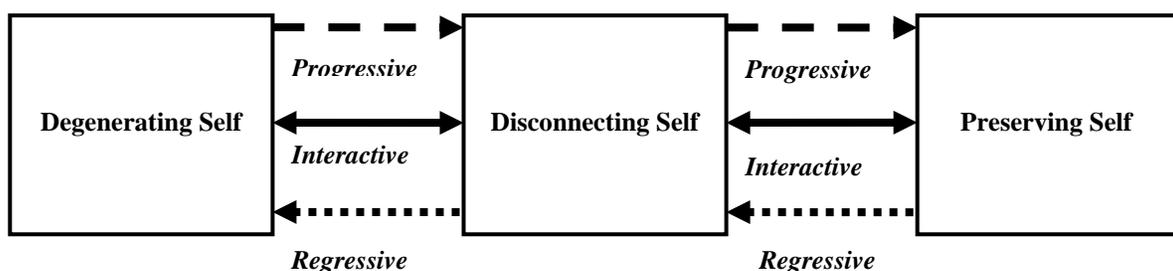
Figure 2 Transforming the deciding self



The phenomenon to emerge from the causal, contextual and intervening conditions that confronted each participant was the disruption of the known self into three distinct self-identities, the degenerating self, disconnecting self, and preserving self. The causal condition, the experience of persistent pain; the contextual condition, the multiple losses

sustained by the participants; and the intervening conditions, the participant's age, gender, employment, support, and knowledge shaped the problems that related to the disruption of the known self. The actions/interactions participants performed in response to the problems generated by the disruption of the known self, was to engage in three different styles of decision-making, impulsive, bargaining and judicious decision-making. The consequences of engaging in these styles of decision-making were the development of three types of decision-makers, susceptible, adaptive and expert decision-makers. The emergent theory, transforming the deciding self, conceptualizes these processes as those that underpin the decision-making of individuals who self-manage persistent pain. The findings reveal that individuals transform into three distinct types of decision-makers, and undertake three styles of decision-making in response to the changes in self-identity caused by the distressing experience of persistent pain and multiple losses.

Figure 3 Movement between self-identities



This study identified that participants moved between various self-identities (see figure 3) dependant on the perceived level of control over the pain and life direction; the degree of loss sustained; the physical and emotional fatigue levels; and the quality of interrelations the participant had with others, such as health professionals, family, and friends. Movement between these identities was never fully completed nor was it linear; rather, the individual oscillates between identities, and at times can retain aspects of two identities. Exploration of the intricacies of these self-identities revealed that these were associated with particular decision-making styles and types.

Degenerating Self, Impulsive Decision-Making and the Susceptible Decision-Maker

The degenerating self was a self-identity where many uncertainties were experienced and the realization of persistent pain and associated losses were actualized. The degenerating self was characterized as being alone; experiencing fear, frustration, and fatigue in body and spirit; losing control and hope of self; and talking about suicide. The degenerating

self engaged in the processes, *fearing alterations to the norm, depleting personal energies, and struggling for the will to live.*

Fearing alterations to the norm. Fearing alterations to the norm is the basic knowledge that you can no longer take comfort in what is familiar, and the experience of persistent pain evoked many unfamiliar responses. The most significant and damaging responses to the experience of persistent pain were fearing the unknown and the unfamiliar. The range of fear extended from the primal fear toward the actual pain sensation to an overwhelming fear that the pain will never stop. Karen was clearly experiencing the latter,

It [pain experience] scared me because the pain's increasing and going into other areas, and I've got a fear in the back of my mind that this could one day take over [my life]. Nothing will ever be the same.

Fearing the unknown potential of the severity and duration of pain precipitated many questions. “When will it end?” “What happens if it doesn’t end?” Fearing the unknown potential of the pain’s duration progressed into fearing a future in constant pain. This ongoing and escalating fear became very tiring for many participants causing a depletion of personal energies.

Depleting personal energies. Depleting personal energies was the overwhelming fatigue of body, mind, and spirit because of the constant effects of persistent pain, multiple losses and living with constant fear. Joyce explained how depleting personal energies resulted in her modified lifestyle,

I just live with it [pain]. It's just always there. You have to learn how to live with it [pain]. What choice do you have? You get so tired that all you can do is make allowances for it [pain]. You can't always fight it and you can't stop living with it.

The depletion of the physical, emotional, and spiritual endurance of many participants were exhibited as a variety of emotions, including depression, aggression, loss of faith, and frustration. All participants at one time or another had depleted their personal energies to such a level that life itself became a struggle.

Struggling for the will to live. Struggling for the will to live manifested as depression, adaptation, suicidal ideation, and the private struggle between *living life* and *leaving life*. The idea of leaving life did not equate only to thoughts of suicide. Many individuals left their life without a physical death. Struggling for the will to live included the degeneration of the self-identity, a failure to connect with others, and eventual surrendering to the pain. Jed, an elderly man who had endured pain for over 30 years, had stopped living life and opted to leave life,

Every single factor of everything day-to-day is difficult to do. No-one knows what I'm supposed to do. What am I supposed to do? I have no-one to get me out of this [pain], so I get more and more depressed... That's the problem with chronic pain it's ongoing; you want to give up all the time.

The processes, fearing alterations to the norm and depleting personal energies were more prevalent in the first few years of experiencing persistent pain coinciding with the time the self was undergoing the most degeneration. Struggling for the will to live was more common after participants had endured obstacles, failures, and disappointments over many months or years of treatment.

Impulsive decision-making and the susceptible decision-maker. The collective processes of fearing, depleting, and struggling evolved from unfamiliar situations and negative experiences related to persistent pain and loss. This caused the individual to respond with reactive and crisis-driven approaches to their problems, resulting in impulsive decision-making. Impulsive decision-making was undertaken by the susceptible decision-maker who was easily influenced and highly impressionable. Jayne's commentary below demonstrates her susceptibility as a decision maker,

It's hard to make decisions because I'm in chronic pain and I'm physically tired. So many things effect my decisions; I don't know who to believe. It's hard to concentrate; it's hard to make decisions.

Risk-taking behavior, impulsive decision-making, and susceptible decision-makers were emerging consequences from the belief that pain controlled the selection of choice. Fearing, depleting, and struggling were processes that supported the belief that pain held control over the participant. Under these circumstances decision outcomes were counterproductive often resulting in erratic and transitory pain relief. Seeking control over the pain and desiring

more successful outcomes necessitated a transition into the bargaining decision-making and adaptive decision-maker.

Disconnecting Self, Bargaining Decision-Making, and the Adaptive Decision-Maker

The disconnection of the self-identify manifested as a result of many failures, including unattained personal goals, unrelieved physical and mental pain, negative perceptions of the self and negative perceptions of the self by others. The disconnecting self was the most common self-identity. This identity was characterized by the disparities existing between what the individual needed and what was provided and the subsequent management of these disparities. As a result of these disparities the disconnecting self often made frantic attempts to control pain and recruit assistance toward the management of pain. These characterizations were conceptualized by the processes *cure chasing*, *wavering self-confidence*, and *limiting relationships*.

Cure chasing. Cure chasing is a process identified by treatment hopping and doctor shopping. Cure chasing explains the assiduous approach taken to find relief from pain with the ultimate, yet remote goal of acquiring cure. Vicky believed cure was matter of recruiting a health professional,

If there is somebody else [health professionals]I haven't tried comes along, I'm willing. You know somebody can always do better, you can get a group of people who do the same job, but some are better at it than others. Sometimes you got to give up one for another. That's why I'm happy to try anything.

Cure became a crucial and intangible aspiration for every participant regardless of their years of experience with persistent pain. Cure chasing was a frustrating process for the individual contributing to a wavering self-confidence within the participant.

Wavering self-confidence. Wavering self-confidence explains the oscillation between self-trust and self-doubt.

Individuals wavered toward self-trust with treatment successes only to swing into self-doubt when treatments failed. Wavering self-confidence was verbally demonstrated in “what if” type of questions participants posed. For example,

“What if I did follow the physiotherapist’s advice would it cure me of my pain?” This self-doubting and subsequent “what-iffing” is clearly demonstrated in Daniela’s oscillation between hope and despair,

I build my hopes up thinking this treatment is a good one, this is gonna work. It doesn't, it really gets you down. I always try [new treatments], just in case, what if this was the one. At the back of my mind a little bit of hope is always there for that small miracle.

Wavering self-confidence resulted not only in doubting the self, but also doubting others. Doubting others resulted in many negative emotions, anger, frustration, and resentment, these in turn resulted in the limiting of relationships.

Limiting relationships. Limiting relationships involved the generation of, and participation in, relationships that had predominately negative or limited outcomes. Most individuals had strained relationships with family members and health professionals. Participants believed support was withdrawn by family members because they grew weary of them. However, it was the perceived withdrawal of support from health professionals that had the greatest effect. Participants believed health professionals withdrew their support for a variety of reasons including exhausting treatment options, differences between potential and actual treatment outcomes, and intolerance toward the participant. Participants believed the health professional’s intolerance of them not only caused retraction of support but involved the passing of judgment. Judgment by health professionals was brought about when labels, such as malingerer or hypochondriac, were bestowed on the participant. Denise recalled an event when the label hypochondriac was used. She discussed the consequences that resulted from being labeled,

I was labeled a hypochondriac by my old GP. He accused me of faking the pain. I couldn't go back. I changed clinics, went to a new doctor, he said, what's the problem. I told him I had pain. He said, where have you been. I lied, told him I was from Western Australia. No way could I say I was at that [other] clinic. He would have believed the other doctor and I would never get help.

The concern of being labeled or judged caused defensive behavior by the participants toward others when they discussed their pain experiences. This defensive behavior distanced the participants from others, further limiting relationships.

Bargaining decision-making and the adaptive decision maker. These processes, chasing, wavering, and limiting resulted from the attempts to control pain and recruit assistance to achieve treatment expectations. Many problems emerged as treatment expectations were unmet and confidence in achieving them faltered. The failure to establish treatment parameters and the ineffective evaluation of treatment outcomes provoked bargaining decision-making. Anthony comments below demonstrate how he has had to balance his sister's approval against his own comfort,

I've tried to get off all tablets, my sister worries about me being on Morphine, she disapproves. The pain gets so severe there's no way in the world that I can get off the tablets. Without the tablets I am a cripple and lie up in bed, get very depressed and just cry. I can't live without the tablets but I don't like upsetting my sister.

Many participants would indiscriminately select therapies thus exhausting their treatment options as they searched for optimal outcomes. They had become adaptive decision-makers modify their choices to suit the situation, with not always the best outcomes. Adaptive decision-makers were the most common typology of decision-maker in this study. However, for some participants the search for permanent pain relief activated a different type of decision-making, judicious decision-making.

Preserving Self, Judicious Decision-Making, and the Expert Decision-Maker

The preserving self is a self-identity that recalls the past experiences of the degenerating and disconnecting selves to evaluate the successes and failure of past treatments so that new management plans can be generated. The gathering and assimilation of information enables development of an effective self-manager of persistent pain. Preservation of the self-identity was least common and was characterized by self-regulatory traits and the ability to undertake compensatory self-growth as a way of managing persistent pain. The preserving self engaged in the processes *monitoring the self, building boundaries, and partnering with others.*

Monitoring the self. Monitoring the self occurred as the individual examined their actions and interactions to ascertain the most appropriate approach to obtain control over pain. Acknowledgment that control over pain was unpredictable and that the individual needed to adapt to this situation was significant in allowing the individual to

maintain current function as a self-manager. Vicky discussed how she would monitor her response to an invitation to visit with friends,

When someone asks me out which involves physical activity the first thing that comes to my mind is, if I stay at home I can control my pain better, if I'm tired I can go to bed, if I wear those shoes I'm going to hurt, if I have to carry anything heavy I'm going to hurt.

Acknowledgment that control was unpredictable and that the individual needed to adapt to this situation was a significant event in relation to self-preservation. By monitoring the self, awareness developed regarding the pain's potential and the participant's management abilities a stark comparison from being overwhelmed by pain, expending precious energy fighting the pain, running from it, and fearing it.

Building boundaries. Building boundaries resulted as individuals' filtered information received from others, thus, effectively buffering themselves from negative influences as protective personal boundaries were built. Filtering, buffering, and boundary building was developed throughout the years of self-managing persistent pain. In the early years of experiencing pain and multiple losses, participants willingly listened to the health professionals' advice and often accepted advice unconditionally. After years of suffering persistent pain and multiple losses individuals developed insight in to what advice was valuable and what advice could be ignored. As individuals gathered more information and endured many treatment disappointments, they became selective about accepting advice from others. Jed recalled a conversation he had with his local GP regarding a change in medication. He stated,

If you can give me a 100% guarantee that these drugs are going to cure me and I'll only be on them [drugs] for six months or twelve months at the most, then yeah, I might swap them with these tablets.

Jed had suffered many years of frustration in relation to unsuccessful treatments and treatment guarantees that had not eventuated. His comment clearly demonstrated boundary building in the form of a trade-off. Jed had defined the boundary as "give me a 100% guarantee" in relation to a timeframe "six months or twelve months at the most" with the trade-off "I might swap them with these tablets." The expression "might" informed the health professional that Jed held control of this decision.

Partnering with others. Partnering with others occurred as the individual acquired support, allocated and accepted various roles. Support is the assistance provided by health professionals and family members. Allocation and acceptance of various roles was the understanding that others fulfill various supportive functions including confidante, advocate, and resource person. The participant usually perceived family members as taking positions of confidante and advocate, while resource positions were filled by health professionals.

Support offered by health professionals and being believed was perceived as being the most influential. This level of support was associated with increased self-worth and improved treatment outcomes for the participant. The narration below explained how important being believed by health professionals at the pain clinic was to Isaac. He commented,

I'm really left in their hands at the moment; they seem to be very interested and caring towards me.

Makes me feel comfortable being here. Having somebody who wants to listen to you is the right step in the right direction.

Recognizing that health professionals were empathetic towards the difficulties of managing persistent pain strengthened partnerships and generated empowerment. Empowerment enhanced the feeling of control over the pain experience. Partnering with health professionals was not always positive particularly when the participant believed they were being misinformed, labeled by others or when support was withdrawn. All participants revealed situations when support was withdrawn and all had expressed distress when recalling how alone they had felt without this support.

Judicious decision-making and the expert decision-maker. Adaptation and modification of past management approaches and relationships with others underpinned the processes of monitoring, building, and partnering. The preserving self scrutinized and interpreted the various management approaches undertaken by past self-identities in relation to pain and loss. These examinations revealed many past treatment failures substantiating the need to develop more effective approaches to pain management. Self-change and self-protective behaviors emerged through prudent self-judgments resulting in improved relationships with health professionals.

Judicious decision-making was the focused, practical, and informed manner in which problems were approached by the individual. Judicious decision-making was influenced by the need for recognition as an expert of pain management and the desire to preserve functionality and performance as a self-manager. The expert decision-maker was characterized by determination and purpose, with rational and prudent judgments. Most participants had limited experiences as the expert decision-maker, as many were unable to maintain the preserving self. Joyce explained what qualified her to be the expert of pain. She revealed,

What makes me an expert in understanding my own pain? Physically experiencing it, no-one else knows what it is like unless they physically experience it. This qualifies me as an expert.

Generally, participants agreed that judicious decision-making was more likely when health professionals provided unbiased and full explanations of the treatment, negotiated outcomes with the participant, and unquestionably accepted the participant's right to make the final decision. Conducting judicious decision-making and partnering with the expert decision-maker improved the self-management of persistent pain.

Discussion

Problems encountered in relation to pain and losses were instrumental in disrupting the known self into three distinct self-identities, degenerating self, disconnecting self, and preserving self. The concept of identity challenges and changes are not new concepts and have been previously explored by Charmaz (1983, 1991, 1994, 1995, 1999); Telford, Kralik & Koch, (2006); and Kralik, Koch, Price, & Howard (2004). Charmaz (1995) recognised that chronic illness forces identity changes. While Kralik et al., (2004) and Telford et al., (2006) identified chronic illnesses as perpetuating shifts in self-identities. Thus, it can be said that humans can and will redefine the self. During interviews and analysis of data it was evident that participants did redefine the self in response to the experience of persistent pain and multiple losses. Each self-identity encountered many divergent and complex problems that collectively emerged as specific processes.

The complex problems associated with pain and loss and these distinct processes generated changes in the self-identities resulting in the manifestation of various styles of decision-making and types of decision-makers. Impulsive decision-making was made in response to fear, depletion, and struggle; generating negative experiences for

individuals, and as a result individuals became highly susceptible as decision-makers. Charmaz (1983) proposed that people experiencing chronic illness experienced a “crumbling away” of self-images and fail to create or maintain a preferred identity. Certainly, the degenerating self exhibited similar crumbling qualities. Charmaz (1995) later expanded on this notion claiming that fear of failure or further illness initiates a slow change in establishing a preferred identity or identity goal. Charmaz’s work revealed that some participants become frightened of taking any risks for fear of losing what has previously been gained. In contrast, this study revealed that the presence of fear initiated a rapid, almost chaotic, response to self-change as the participant made impulsive decisions as the susceptible decision-maker in an attempt to distance themselves for the pain and uncertainty. Many participants recounted broken spirits and abandoned hopes as they questioned whether they would survive this ordeal. Some participants had seriously considered or acted on leaving life. Leaving life ranged from surrendering to the pain experience to the calculated decision to end their life. This finding is consistent with the growing area of research linking suicidal ideation and suicide with experiencing persistent pain (Fishbain, 1999; Fisher, Haythornthwaite, Heinberg, Clark, & Reed, 2001; Smith, Perlis, & Haythornthwaite, 2004; Tang & Crane, 2006). Some literature revealed that 50% of all individuals with persistent pain consider suicide as a viable option for cure (MacDonald, 2000; Thomas & Johnson, 2000). The findings in this study suggest that suicidal ideation may be more prevalent than we suspect, as all study participants had considered suicide at some point during the years they had endured pain.

Bargaining decision-making was characteristic of the disconnecting self and was underpinned by the many conflicts associated with the imbalances generated by cure chasing, wavering self-confidence, and limiting relationships. These conflicts and imbalances resulted in individuals becoming adaptive decision-makers. In a study by De Vlieger, Crombez, & Eccleston (2006) it was identified that individuals experiencing pain for 12 years or more would still persisted in problem-solving without any reduction in their self confidence as decision-makers. Comparatively, findings of this study identified that inconsistencies between the participant’s treatment expectations and the actual treatment outcomes caused a wavering self-confidence within the participant. This wavering of self confidence manifested as bargaining decision-making as individuals posed what-if questions to the self. For example, “what if I took twice as much pain relief before I went to bed, would I sleep better?” The idea of bargaining with the self for a better solution inevitably resulted in adaptation to the individual’s behavior. As individuals realize that losses will be

suffered due to the experiences of pain (Charon, 2006), modification and adaptation to persistent pain eventuates (Tang & Crane, 2006). Turk, Okifuji & Scharff (1995) claim an individual's psychological and emotional state is directly affected by the level of control that individual obtains over these modification and adaptations. The adaptive decision-maker was the most common type of decision-maker identified in this study. It was noted that only some participants would progressed on to becoming the expert decision-maker driven by judicious decision-making.

In comparison to the other self-identities, the preserving self was an identity that demonstrated confidence and motivation as a decision-maker and self-manager of pain. Becoming the preserving self meant the participant had survived degeneration and disconnection and, in doing so, had undergone major transformations in the self-identity. Charmaz also identified the 'preserving self' in her research on the self and identity (Charmaz, 1983, 1991, 1994, 1995, 1999). Charmaz (1994) described the preserving self as maintaining those qualities and attributes of a previously known self to facilitate redefining the new self. Furthermore, the preserving self was a process where past identity dilemmas are reconciled. In this study, the meaning of the preserving self differed and the self-identity did not retain many of the original qualities and attributes of the known self. Instead, the known self was disrupted and through the changes of degeneration and disconnection all that was previously familiar was now unknown. This process precipitated a redefinition of self. In contrast this study identified the preserving self as the identity of reconciliation and quiet confidence as the expert of pain who made judicious decisions. This finding adds to other studies that identified that individuals who experience chronic illnesses often regard themselves as an expert of that condition (Turk et al., 1995; Kelley-Powell, 1997; McGregor, 2006; Paterson, 2001; Paterson, Russell & Thorne, 2001). Redman (2004) believed that, the more expert one is at problem-solving, the more capable one is in predicting future events, thus, arriving at optimal actions more quickly. Bodenheimer, Lorig, Holman, & Grumbach (2002) believed clients were experts, not of their condition, but experts of their own lives.

Self-recognition as the most credible source for understanding and explaining the experiences of pain facilitated the idea that one is an expert of pain. In this study distinct differences between being the expert in managing pain and being an expert decision-maker existed. Understanding and explaining the experiences of pain contributes, but does not exclusively constitute, the expert decision-maker. Expertise in decision-making was demonstrated by those participants who had established adequate self-insight to place protective boundaries against others' negativity. The

findings from this study revealed that self-determination, internal control, and elevated self-awareness enabled the participant to evaluate past experiences and modify decisions in to meet their unique needs. To achieve this level of insight, participants became reflective and analytical regarding the impact pain had on their body and mind.

Participants used reflection to monitor their progress as a self-manager and make judicious decisions. This finding is consistent with other studies that have identified that individuals with chronic illnesses will monitor their symptoms, treatment outcomes, and disease progression (Ivers, McGrath, Purdy, Hennigar, & Campbell 2000; Koch, Jenkin, Kralik, 2004; Zelman et al., 2004).

Conclusion

Findings from this study identified that self-management decisions were made under extraordinary conditions, which included diminished physical capacity, altered psychological reactions, and social isolation. As individuals responded to the emerging problems associated with each distinct self-identity they transformed as decision-makers. The findings from this study provide much more than a beginning to our understanding of what underpins the decision-making of individuals' self-managing persistent pain. This study adds to this knowledge about self-identity changes in response to chronic illness by informing how disrupting the known self impacts upon decision-making during self-management of persistent pain.

Relevance to Clinical Practice

Development of collaborative and productive relationships between the individual experiencing persistent pain and the nurse guiding the self-management of this condition is fundamental to successful health outcomes. This study provides nurses with important information regarding the trajectory of pain and loss, the negative effects that pain and loss has upon the individual, the challenges individuals encounter during decision-making, and the unavoidable changes to the individual's self-identity. Informing nurses about these unique elements of self-management of persistent pain generates a more responsive workforce. We need a nursing workforce that can readily assist individuals with persistent pain to navigate complex decision-making and unique changes in their self identity. We need champions of persistent pain management, not just concerned observers.

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