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Occupational adaptation and identity reconstruction – a grounded theory synthesis of qualitative studies exploring adults’ experiences of adjustment to chronic disease, major illness or injury

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Abstract

Background Adjustment to occupational disruption and loss following illness or injury is a complex, subjective experience. A number of studies have provided an insight into this process within specific conditions and populations. Some studies reveal a process of adapting to occupational demands (occupational adaptation). Others describe reconstruction of an occupational identity focusing on how one’s identity is both expressed and defined through occupation. Examining these studies collectively can provide a deeper insight into these processes.

Purpose This study involved a synthesis of qualitative studies investigating the lived experience of adjusting to chronic disease or a significant health event. The key research question was how do people adjust to chronic disease, major illness or injury from the perspective of occupational adaptation and occupational identity?

Method A systematic search of four databases identified qualitative studies exploring the personal experience of adjustment in adult populations with a range of significant health issues (excluding mental health and palliative care). Using occupational adaptation and occupational identity as sensitising concepts, findings of eligible studies were re-analysed using a twelve-step grounded theory methodology, identifying central themes, bringing these together collectively to construct a theoretical framework.

Results: 37 papers met inclusion and quality criteria. Analysis revealed a process of adapting how and what occupations were performed, and re-establishing an occupational identity, facilitated by achieving adequate levels of competence, motivation and confidence.

Conclusion: This synthesis provides further evidence to confirm adjustment to chronic disease, major illness or injury as a process of reconstructing an occupational identity and occupational adaptation.

Keywords: occupational well-being, recovery, occupational adaptation, occupational identity, qualitative

Background

There is a significant body of research exploring recovery or adjustment following chronic disease, major illness or injury. Much of this research stems from a biomedical paradigm exploring the efficacy of interventions, often in acute early rehabilitative care with a focus on improving occupational performance. Such performance-based approaches typically address remediation of underlying cognitive, physical and affective skills necessary for the execution of occupations, and/or modification of the task or environment to enable occupational engagement (Townsend & Polatajko, 2013). However, the experience of adjustment and reintegration back into life and occupational roles after illness or injury is complex and multidimensional, involving a number of interrelated processes which extend beyond the achievement of functional outcomes.

Acknowledging the complex and interactional nature of the adjustment process, theorists in the western world have described adjustment from the perspective of various inter-related occupation-based frameworks. One such framework is based on occupational adaptation (Frank, 1996; Kielhofner, 2008, Schkade & Schultz, 1992) which was first described by Schkade and Schultz (1992) and involves achieving or maintaining competence in occupation through adaptation to occupational demands. It is a normal, life-long process experienced by everyone as they interact with their environment (Kielhofner, 2009). However, a significant health event may cause a sudden and significant change in occupational ability which can overwhelm adaptive capacity. Since Schkade and Schultz first identified this concept, it has been further developed and verified by other authors (Bontje, Kinebanian, Josephsson, & Tamura, 2004; George, Schkade, & Ishee, 2004; Kielhofner, 2008; Mansson Lexell, Iwarsson, & Larsson Lund, 2011; Parsons & Stanley, 2008; Wells, 2015; Williams & Murray, 2013b) in specific study populations including older people (Bontje et al., 2004), people with acquired brain injury in rural areas (Parsons & Stanley, 2008), multiple sclerosis (Mansson Lexell et al., 2011), renal disease (Wells, 2015) and stroke (Williams & Murray, 2013b).

Other theorists have viewed the adjustment process through a framework of occupational loss and reconstruction of an occupational identity (Carroll & Coetzer, 2011; Cotton, 2012; Gould, DeSouza, & Rebeiro-Gruhl, 2005; Lalibert Rudman, 2002), highlighting the impact a significant health event can have on an individual's life direction and identity. Individuals shape their identity as their life story unfolds (Clark, 1993) and this identity gives meaning to experiences and life. As Christiansen (1999) described, it is through occupation that individuals primarily express their identity and also how they are typically identified. All too often, the individual's sense of self may shift from a competent occupational being to a "disabled" self when first confronted with illness or injury.

Numerous studies, stemming from various epistemological roots, have explored the individual experience of adjustment from these and other perspectives. Individually, these reports all provide rich standalone descriptions from the context of specific conditions and study samples. However, as Whalley Hammell (2007) highlighted there is a need to accumulate the understandings from the growing body of qualitative studies in the health sciences to achieve a "level of understanding and conceptual development that is greater than the sum of its parts" (p. 125). Now there is a critical mass of adjustment studies, it is timely to examine these collectively to move towards the construction of an overarching theory grounded in a deep understanding of the subjective experience and personal meaning of occupational adaptation and identity. These insights will help inform health service provision, promoting an enriched client focus and enhanced outcomes.

Purpose of Study

This study aimed to synthesise existing qualitative research exploring the process of adjustment in a range of study populations from an occupational perspective. The research question was: how do people adjust to chronic disease, major illness or injury from the perspective of occupational adaptation and occupational identity? Whilst individual adaptation and adjustment experiences are unique, common themes are emerging in the literature and it was hoped common threads related to occupational adaptation and identity reconstruction could be integrated into a higher level theoretical framework which might have broader applicability. Through reviewing and re-analysing existing studies as a collective using a grounded theory methodology (Eaves, 2001), with “occupational adaptation” and “occupational identity” as sensitising concepts (Charmaz, 2003), the authors aimed to inductively construct an overarching framework grounded in occupational science.

Methods

Study Design

Whilst studies exploring adjustment vary in their methodology, presenting a challenge to integration, a majority use grounded theory, or contain theoretical elements describing the process and meaning of adjustment. Therefore, a grounded theory synthesis method was chosen as it allows a consistent approach to data collection and analysis (Kearney,1998). Additionally, the symbolic interactionist underpinnings of grounded theory, with its focus on social-psychological processes and the construction of personal meaning through social interaction, made it an appropriate methodology to reveal and explain the underlying process of adjustment (Nayar & Stanley, 2015; Stanley & Cheek, 2003). Specifically, the technique developed by Eaves (2001) was chosen to analyse data and inductively develop a framework to explain the findings. This is a comprehensive and systematic multi-step approach to data analysis (Figure 1) that brings together a combination of grounded theory approaches (Charmaz, 2006; Corbin & Strauss, 2008). Whilst systematic and rigorous, it lacks the complexity of some other methods (Corbin & Strauss, 2008), reducing the risk of failing to adhere to grounded theory principles (Eaves, 2001). True to these principles, the method involves simultaneous data collection and analysis. There is constant comparison, seeking similarities in findings across studies, leading inductively to a synthesised overarching theoretical framework .

<Insert Figure 1 about here>

Ethics

As the study involved secondary data analysis of published literature, ethics approval was not required.

Criteria for Selecting Studies

After consultation with a university librarian, the Cumulative Index of Nursing and Allied Health Literature Plus (CINAHL Plus), PubMed, OTSeeker, and Scopus databases were searched by combining the term “qualitative” with the terms recover*, resilien*, coping, or cope. No publication date limits were placed on the search. Only qualitative studies were included as it was determined these best revealed the subjective experience of adjustment, which was the focus of the research question. The search was limited to English-language peer-reviewed journals as the investigators were English-speaking. As the focus was the experience of the individual living with the condition, papers reporting parent or carer experiences were excluded. To exclude the influence of developmental and end of life concerns, studies of children, adolescents, people with cancer, and those receiving palliative care were excluded. Additionally, to provide a distinct and bounded scope

of the study in the first instance, papers focusing on mental health were also excluded, as were papers with a narrow focus on one specific element of adjustment such as interactions with health services or symptom management. Finally, meta-syntheses and other secondary reviews of primary papers were also excluded to enable a theory to emerge from the data presented in original papers. Reference lists of identified articles were checked in a snowballing approach.

Selection Process

Outcomes of the search process are depicted in Figure 2. The initial search identified 6,832 papers. Duplicate articles and those not meeting inclusion criteria were excluded, resulting in a total of 322 published papers. The abstracts of these 322 papers were screened by the first author and a further 134 papers were excluded as they did not meet the inclusion criteria of using qualitative research methodology for both data collection and analysis, being interpretive, using interviews, focus groups or other appropriate methods to explore participant perceptions and subjective experiences of adjustment. The remaining 188 articles which appeared to meet the inclusion criteria were read in full to ensure they were suitable for inclusion. Additionally, reference lists were checked for any previously unidentified papers and a further 6 articles were included after review. At this stage a total of 119 articles did not meet the inclusion criteria, so were excluded. The remaining 75 full text articles were then appraised by the first author using the Critical Appraisal Skills Programme tool (CASP; Critical Appraisal Skills Programme, 2013). This tool was chosen as it is a widely accepted tool with a systematic process involving 10 questions exploring rigour, credibility and relevance of qualitative studies (Hannes, 2011). The minimum quality criteria to be included in this synthesis were clear articulation, rigour and consistency of the research process in relation to aims, methodology, research design, recruitment, data collection and data analysis; together with consensus by the reviewing team in relation to the level of rigour, credibility and relevance. A final inclusion criteria was that findings were well supported with direct participant quotations. Rigour of this selection process was enhanced through having a random selection of articles appraised by two research assistants against the inclusion and CASP criteria. In total, 37 papers were included in the study. Table 1 provides a summary of the rationale for excluding before papers were read in full or as a result of the CASP review.

<insert Figure 2 about here>

<insert Table 1 about here>

Data extraction and synthesis

Data extraction and analysis followed the twelve-step process prescribed by Eaves (2001) as depicted in Figure 1.

Step 1: Line by line in-vivo coding was conducted on the results and discussion sections of the papers including direct quotations from participants. Key phrases were highlighted.

Step 2: Shorter code phrases were developed from the list of key phrases, capturing the main idea of what had been said. At this stage, and every other stage of analysis, memos were written and peer review occurred to reveal and challenge biases and assumptions.

Step 3: Similar code phrases were grouped together, using the sensitising concepts as a point of reference.

Step 4: Groups of code phrases were further combined into clusters and then into labelled meta-clusters.

Step 5: Meta-clusters were formed into concepts.

Step 6: Concepts pertaining to similar phenomenon were grouped into categories. Consistent with grounded theory's constant comparison methods (Corbin & Strauss, 2008; Eaves, 2001), the nature of categories and their relationships were further developed and checked out within and across studies.

Step 7: Subcategories were identified where categories were related across a dimension or continuum (Charmaz, 2006; Corbin & Strauss, 2008; Eaves, 2001).

Step 8: Categories were compared and hypotheses tested against data to identify linkages or relationships amongst categories (Corbin & Strauss, 2008; Eaves, 2001).

Step 9: Core categories or themes were revealed.

Step 10: Underlying social-psychological processes were identified which were, as Eaves (2001) highlighted, shared by participants but not necessarily actually articulated by them.

Step 11: Mini-theories emerged from the core categories

Step 12: Mini-theories were pulled together into an explanatory theoretical model.

Throughout the analysis process, further support for potential relationships was sought through ongoing comparison and theoretical sampling, returning to papers for further analysis pursuing lines of enquiry and challenging analytical assumptions (Kearney, 1998).

The authors acknowledge the occupational science and discipline-specific lens they brought to this study. Peer debriefing with colleagues from differing paradigm and professional backgrounds provided an avenue for revealing, challenging, critiquing and accounting for assumptions, biases and perspectives. Although triangulation is not deemed mandatory in grounded theory (Nayar & Stanley, 2015), this added to the rigour of data analysis (Eaves, 2001; Kearney, 1998). Additionally, the first author wrote memos to reflect, discuss and explore emerging themes and develop theories (Charmaz, 2006; Eaves, 2001) on an ongoing basis. As a novice researcher, the memos were used as a tool in supervision sessions to facilitate reflexivity, reveal biases and assumptions, and review grounded theory and analytical skill.

Findings

37 papers were included in the synthesis (Table 2) covering a diverse range of diagnostic categories and study locations included Australia, United Kingdom, United States of America, Sweden, Norway, Japan, Taiwan, New Zealand, India, Canada, Korea and Iran. Across all studies there were 487 informants (208 females, 272 males, with 7 unidentified). Studies used various methodologies and data collection methods, primarily interviews or focus groups adopting either a grounded theory or phenomenological approach.

<Insert Table 2 about here>

The Adjustment Process

Whilst the experience of adjustment was unique to each individual, a central theme (core category) emerged of moving from an initial state of disruption and occupational loss to the regaining of occupational well-being involving adapting to changing occupational demands and re-construction of an occupational identity. Participants described absence or low levels of competence, motivation and confidence in the initial part of the process and described how improvements in these areas

contributed to their occupational adaptation and reconstruction of an occupational identity (Figure 3). However, progression along the path of adjustment was not linear, and participants reported moving backwards and forwards along the adjustment continuum, often in the face of relapse or new obstacles.

Acknowledging loss

Most informants reflected how their chronic disease or significant health event resulted in occupational loss, often accompanied by a change in occupational performance, engagement, identity, meaning and satisfaction.

I used to love driving, used to do all me own repairs and everything yeah, used to love it ... well I guess I can't drive now because, because of this (Thornhill, Lyons, Nouwen, & Lip, 2008, p. 162).

I am so sad, because I can't get up and do my usual activities. Now, with help of others, I can sit on the wheelchair. They help me eat; go to the toilet and other places (Dalvandi, Heikkila, Maddah, Khankeh, & Ekman, 2010, p. 250).

Reconstructing an occupational identity

Central to the process of adjustment was the concept of re-establishing an occupational identity. Sudden change and occupational loss resulted in an altered body image and identity for most informants, causing a sense distress. For many, the altered self was seen as disabled and was often compared to the former self. Initially, many informants struggled with trying to hold onto their former identity.

I am changed from an active and hardworking man to a passive and isolated, bothered and handicapped man (Dalvandi et al., 2010, p. 251).

It's hard struggling with the loss of me, especially the strong, capable and always caregiver me (Murray & Harrison, 2004, p. 811).

As adjustment progressed participants described becoming accustomed to altered roles, forming an identity separate to the condition and adjusting to the altered body image.

I felt that I still had a lot to give, so what I do is do voluntary work because I thought I'm not going to be just a waste of space...I mean it's nothing like the amount I used to do before but it's something and that's important to me (MacDermott, 2002, p. 269).

<Insert Figure 3 about here>

a) Developing Competence

An important component of the adjustment process was developing competence and adapting to occupational demands. Competence represented much more than just occupational performance. It embraced having all the necessary internal and external resources to enable engagement in occupations. This included having skills, knowledge, emotional stability, acceptance, physical health, finances, assistance, and ability to overcome barriers. Participants spoke of initially lacking competence and having to rely on others for assistance to perform previously taken for granted occupations.

What makes me upset is the fact that I can't do the jobs I used to, I've lost my independence (Livingstone, van de Mortel, & Taylor, 2011, p. 26).

I had to be showered and toileted you know the whole lot, so I had no independence so and I hated it, cause I am quite an independent person I don't like people doing stuff for me (Ahuja et al., 2013, p. 39).

- i. *Mastery and acceptance* - Physical, cognitive and/or sensory deficits often impacted on an individual's independence and ability to engage in usual occupations. The adjustment process for many involved problem solving and practicing new skills and ways to manage occupations. This involved mastering occupations and/or acceptance of changed levels of performance.

While the housework is not what I used to do, I can keep it reasonable tidy... you can't have everything so you sort of just have to go down a level to what you used to have (Williams & Murray, 2013a, p. 44).

I've learnt to do all the things I need to do left-handed (Cater, 2013, p. 1149).

- ii. *Gaining knowledge* - Many informants initially experienced confusion and uncertainty with a desire for information. Actively seeking this knowledge and keeping informed during adjustment was often discussed. Some participants related becoming an expert through their own experience, developing a high level of knowledge from the experience.

I think part of the problem since then is all the confusion (Hilton, 2002, p. 23).

Suddenly the road ahead appears very uncertain and I knew enough about AIDS and HIV to know that this was a big problem but I didn't know exactly what it meant, what the prognosis was (Perrett & Biley, 2013, p. 210).

Once you have full information then you can actually help yourself (Caird, Camic, & Thomas, 2011, p. 552).

That education helped me improve the qualities in my life 'cause it taught me what to do, how to do it, what not to do, and what to continue to do to keep me alive (De Santis, Floram-Smith, Vermeesch, Barroso, & DeLeon, 2013, p. 40).

- iii. *Establishing emotional stability* – Initial emotional turmoil and loss of control over emotions were reported by many participants. Emotions commonly described were frustration, depression, grief, fear, anxiety, denial, pity, blame, and anger. Developing an ability to effectively manage these emotions was a key subcategory of gaining competence and being able to engage in occupations.

I couldn't believe it happened. I cried all the time. I couldn't stop the tears. I was very angry and hated myself (Liu et al., 2010, p. 2155).

It was overwhelming, I just cursed and was in tears and it was really hard to control it. I was very, very, very angry (Williams, Klock-Powell, & Davey, 2003, p. 64).

You've got to get a grip on it and manage through the depression, denial, anger and hate (De Santis et al., 2013, p. 42).

- iv. *Managing physical health* - Another subcategory of competence was gaining the ability to manage symptoms, medications and physical health to overcome barriers to occupational engagement. Early in the process, many informants experienced difficulty managing or coming to terms with symptoms. Managing one's symptoms and physical health was a common theme in the subjective sense of well-being.

The pain was endless. I could not imagine feeling 'normal' again (Liu et al., 2010, p. 2156).

Not very happy about it, I've never taken tablets...It's a new thing for me altogether taking tablets every day really (MacDermott, 2002, p. 268).

It's a hard journey, it's a long journey and some people never get rid of the pain it's just something they learn to live with (West, Stewart, Foster, & Usher, 2010, p. 1288).

- v. *Having financial resources* - The process of moving from loss of income and requiring funds for medical equipment or assistive technology, through to accessing financial supports and flexibility to enable occupational engagement was described in many narratives.

I didn't have any money; I had to put in for social security until I got my pension (Hilton, 2002, p. e23).

The cost of care and rehabilitation services is added to my other life expenses (Dalvandi et al., 2010, p. 251).

- vi. *Accepting help* - Initial difficulty accepting assistance to enable occupational performance was a common experience. As participants adapted they related experiences of learning to accept help and seeing a benefit in being helped. Some highlighted an appreciation and sense of gratitude for assistance provided.

The biggest hurdle I faced was actually asking for help, and once I allowed myself to get to that point and actually go beyond it (West et al., 2012, p. 1289).

I wanted to be able to look after myself, I didn't want to be too dependent on help...you can't say 'I don't need that' [assistance from others] ...because you do! Well I certainly do. And ah, that enables you to continue (Williams & Murray, 2013a, p. 44).

- vii. *Adjusting to change* - Moving from a state of denial, escapism and difficulty adjusting to occupational challenges and their underlying causes, through to adjustment and acceptance of the changed reality was another typical experience for participants. This included accepting the prognosis and coming to terms with physical changes, changed roles and responsibilities, environmental changes and social impacts. Many highlighted a process of self-discovery and reconstruction of an occupational identity, learning about limitations, becoming more realistic, discovering coping strategies and finding ways to adapt to occupational demands and help oneself.

I would love to be able to do things I used to do, but just accept what you can't change, and go from there (Hilton, 2002, p. e23).

You know that you cannot change, and you just have to learn to live with it for the rest of your life (Schanke & Thorsen, 2014, p. 1470).

b) Finding Motivation

The process of adjustment involved becoming more motivated or finding new motivators for engagement in occupation and participation in life. Factors impacting on motivation included a positive outlook, self-agency, being goal-focused and determined, and having a desire to belong and contribute or help others.

- i. *Building hope* - Informants reported initially experiencing hopelessness and an inability to feel positive about being able to engage in occupations and live the life they had planned. An ability

to adopt a positive outlook, have hope, see potential and anticipate improvements evolved as informants moved towards adjustment. An important factor in this process was an ability to reframe perceptions and focus on strengths and positives. Adopting a positive outlook also extended to perceiving oneself as more fortunate than others, or seeing benefits from the whole experience. Appreciating the small things in life was also a common theme. This increased hope, in turn, motivated participants to engage in occupation.

There was no hope for the future. It was the end of my life (Liu et al., 2010, p. 2155).

Staying optimistic and having a good attitude are the most important thing (Cater, 2013, p. 1451).

You have to look at the good side of it and know that you are lucky in some ways. It could have been worse (Williams & Murray, 2013a, p. 44).

There's always some poor sucker worse off than yourself (West et al., 2012, p. 1288).

- ii. *Perceiving options* - An initial sense of lack of options often impacted on an individual's level of motivation. However, a turning point in the adjustment process was often marked by participants recognising they had options. Having occupational choices was a theme often present in stories of well-being.

My son planned to send me to the institution because no family member could take care of me (Liu, Williams, Liu, & Chien, 2010, p. 2156).

I always try to do what I want. Now, I'd like to learn computer from my son (Hwang, Kim & Jun, 2004, p. 244).

- iii. *Seizing control* – Regaining a sense of control was another significant factor contributing to motivation during adjustment. Initially there was generally an experience of helplessness and feeling out of control. However, a turning point in the adjustment process was often marked by participants making a decision to take action, assuming personal responsibility and moving towards self-reliance. Many reported feeling they regained control over their occupations, and ultimately, their life.

Other people decided my fate. I totally lost control of my condition (Liu et al., 2010, p. 2155).

I needed to be involved in my recovery. Not only involved, but directing it. I want to be in the driver's seat (O'Connor, Young, & Saul, 2004, p. 211).

Whatever happens now is down to me, it's my responsibility. It was my responsibility before and it is still my responsibility.... I'm not going to turn up at the clinic and say "here I am, you fix it", because that's not their job. That is my job so that's what I'm doing (Perrett & Biley, 2013, pp. 211-212).

- iv. *Setting goals* - Setting and working towards goals were major sources of motivation. Often these goals involved regaining independence and occupational engagement. Participants in many studies described a process of becoming determined and persistent.

Setting small goals. Making plans to be social, etc. It's something to look forward to (Monden et al., 2014, p. 199).

I just get up and get on with it...no matter how bad it is (West et al., 2012, p. 1287).

I thought bugger this! I ain't going to sit and be like some other person and just die, so got up and really... got aggressive ...not aggressive...determined, yeah! (Ahuja et al., 2013, p. 40).

- v. *Belonging* - Another motivation subcategory was the need to belong, fit in and be accepted. A fear of rejection and not meeting societal expectations appeared in many narratives. A sense of belonging influenced and, at the same time, was influenced by the person's occupational identity. The comfort from shared experiences, especially from peers with similar conditions, together with a sense of being understood and accepted, were pivotal factors in the reconstruction of occupational identity.

I worried about other people's judgement.... I thought they would not accept my appearance (Liu et al., 2010, p. 2156).

The fear of being rejected makes you reject yourself (Schanke & Thorsen, 2014, p. 1468).

It's like heaven in some way to meet others with the same [experience of illness]. You can recognize yourself all the time (Olsson et al., 2008, p. 423).

Everybody with the same condition in that group is like a family to me. When I have these good people around me, it helps (De Santis et al., 2013, p. 40).

- vi. *Feeling needed* - Several participants related an initial concern that needing assistance with everyday occupations resulted in them being a burden to others or that others were negatively impacted by the experience of assisting them to complete necessary occupations. As adjustment progressed, a perception of being needed by others motivated them to take action. Being encouraged or even challenged by others was fundamental in motivating to resume active participation in occupation.

My husband has suffering from many things. He is washing dishes, clearing room. He does anything for me (Hwang et al., 2004, p. 244).

The children have been my reason to struggle. If I had not had them, I would just have stayed in bed. So in a way they have been my rescue (Olsson et al., 2008, p. 423).

She couldn't live without me. I felt she really needed me and it was my responsibility to take care of her. Since that day, I never said I wanted to give up. I must live for my family members (Liu et al., 2010, p. 2157).

- vii. *Making a contribution* – Another key subcategory of motivation was a strong desire to make a contribution especially through productivity-related occupations, adding to a sense of purpose. This ranged from having clear occupational roles and responsibilities, feeling needed, inspiring others, helping others or contributing to the community.

Mentoring, talking to people, going up to the rehabs, trying to encourage them that it's going to get better (Monden et al., 2014, p. 199).

That was my emotional healing, that I wanted to go help someone (Williams et al., 2003, p. 69).

c) *Becoming Confident*

In describing their adjustment experience, participants also spoke of factors which contributed to a state of certainty or security that was important for engaging in occupation. This extended beyond self-confidence. It also embraced confidence in the environment, such as support networks, and

feeling comfortable to face challenging situations, take risks or make mistakes whilst engaging in occupation.

- i. *Feeling capable*- Adjustment involved gaining confidence and overcoming initial apprehension to participate in occupations. Many were eventually able to see themselves as capable, empowered, and able to overcome adversity, celebrating achievements and recognising strengths they had brought into the experience. Common experiences included moving from a lack of confidence to being able to see oneself as strong, resilient and capable, taking pride in accomplishments and having these recognised by others.

You get insecure in yourself many times.... I try Can I manage this? ... will I have enough strength to walk that distance? Insecure...insecure (Olsson et al., 2008, p. 421).

While the housework is not what I used to do, I can keep it reasonably tidy (Williams & Murray, 2013a, p. 44).

- ii. *Feeling supported* - Encouragement and support from others to engage in occupation were additional subcategories of confidence. For many, there was an initial sense of isolation and altered social relationships. Re-building social connections and support systems was often part of the adjustment process. Engaging socially and having strong social networks encouraged and supported participants to engage in occupation and face the future.

I lost a lot of friends and that's hurt me quite a bit.... When there is an illness, serious illness in the family like that, people stay away.... I don't go out socially, I stay in. I don't have any social life (Kaba, Thompson, & Burnard, 2000, p. 933).

I don't like mixing too much or being in crowds, I don't go to the pub anymore because I can't cope with the noise and crowd My pub friends, I think they don't know how to handle it. It would only embarrass them so I don't go (Murray & Harrison, 2004, p. 813).

My friends sometimes supported me. For example, they advised me how to do a certain thing or in some cases they comforted me in difficult times (Valizadeh, Dadkhah, Mohammadi, & Hassankhani, 2014, p. 234).

Surrounding yourself with family and friends... your support system is huge (Cater, 2013, p. 1451).

- iii. *Overcoming fear* – Many informants described an initial fear of the future due to uncertainty, lack of information, and fear of relapse or recurrence. As adjustment progressed, increased certainty fostered confidence to confront factors impacting on occupational performance such as fluctuating ability, deterioration and decline, co-morbidities, and ongoing occupational challenges.

I am worried that even [my] normal arm will be affected. I can't do anything, if it happens. I am in fear (Hwang et al., 2004, p. 243).

It's fear really, you know, the main thing that stops you doing even those things that you might possibly, er, could do. You feel as if you don't want to do it just in case you did something more serious" (MacDermott, 2002, . 269)

You're more confident in whatever happens. I know I'll get through. I always have (Manning, 2013, p. 572).

- iv. *Forming routines* – Daily routines and/or routine ways of performing occupations provided a sense of security and familiarity for many informants. Participants described moving from a state of significant disruption to usual routines and this often involved the development of new routines. Other participants drew on habits, rituals and customs from community, culture and religion to provide a sense of comfort and security as they engaged in occupation.

They come to the bedroom so they are still there with me...it doesn't change the "way the family are", it changes "where the family are" (West et al., 2012, p. 1287).

- v. *Making sense* – Many participants highlighted making sense, or finding a cause or rationale for what had happened. This, in turn, helped them develop confidence for occupational engagement. For some, this culminated in seeing a positive justification or purpose for the suffering and finding meaning in the experience. Religion and spirituality often provided a vehicle for this.

There must be a reason and maybe eventually it will be unfolded to me (Kaba et al., 2000, p. 933).

It just could have been the lesson I needed to learn and become a much richer person (Williams et al., 2003, p. 67).

HIV was the best thing that ever happened to me. It gave me a kick up the ass. I've achieved so much since being diagnosed (Perrett & Biley, 2013, p. 213).

I do believe in God. I think he's kept me here for a purpose (Caird et al., 2011, p. 551).

- vi. *Re-evaluating priorities* – Many participants also highlighted a re-evaluation of priorities and values and putting experiences in perspective. This included changing the importance or personal meaning attached to occupations.

And you realize that priorities change, and you become aware that some things are more important than others (Kaba et al., 2000, p. 933).

It makes you concentrate on your priorities...you have to appreciate the time that you've got (Williams & Murray, 2013a, p. 44).

- vii. *Feeling understood* - Being understood by others was another common theme impacting on confidence to engage in occupation. Many participants spoke of not being understood by others. Having an ability to disclose to others and help others understand was an important experience supporting adjustment and occupational engagement. Informants discussed the confidence gained when they felt understood by others, often others who shared experiences.

All I want is understanding. To be treated as normal but understanding that there is a problem because of the stroke (Murray & Harrison, 2004, p. 811).

You could speak about everything, and no one found you stupid. Everyone had the same experiences. When I say the same things at home, well, they kind of listen, but I feel like they don't understand what I'm talking about (Carlsson et al., 2009, p. 779).

Occupational Adaptation and Reconstruction of an Occupational Identity

For many participants the adjustment process culminated in an ability to adapt to the change and the reconstruction of an occupational identity, facilitated by sufficient levels of competence, confidence and motivation. Informants spoke of having a clear purpose, direction, and meaningful

roles. They rejoiced in their independence and ability to perform and engage in occupation. Recognition both by self and others of an occupational identity separate to the condition was important.

It's not everything I am and it's not everything I'm going to be.....and it's not everything I wish to be (Caird, Camic, & Thomas, 2011, p. 551).

This does not define me. It does not make me (De Santis et al., 2013, p. 40).

Discussion

These findings reiterate the impact serious illness or injury can have on a person's occupational performance, disrupting usual occupational engagement and reducing levels of competence, confidence and motivation. Participants revealed changed roles, routines and participation. Social engagement and the social environment in which occupations were performed were likely to be disrupted or significantly changed, with changed networks and/or decreased interaction with regular social networks. Additionally, the meaning attached to occupations often changed. Findings supported the positive impact on occupational performance and engagement of motivating and confidence-building factors such as occupational choice, competence, satisfaction from occupational engagement, having goals, purpose and direction, social engagement and experiencing a sense of pride and accomplishment (Doble & Caron Santha, 2008).

The inherent link between occupation and competence, confidence and motivation has been previously reported (Braveman, Kielhofner, & Helfrich, 2006). Kielhofner (2009) described occupational competence as the capacity to fulfil one's occupational identity and meet occupational demands in a personally satisfying manner. Holahan (2014) defined it as the degree to which there is an acceptable, reliable and agreeable transactional fit between person, occupation and environment. Levin and Helfich (2004), in their study exploring homeless adolescent females' self-perceptions of competence in their role of mother, identified themes of personal performance standards, meeting role expectations and being goal-focused. These themes of developing competence were also present in the studies within this synthesis. Further, recognising oneself as competent, then served to enhance confidence and motivation. This highlights how the three components are inextricably linked.

Other authors have discussed the role motivation plays in occupational engagement (Emmerson, 1998; Jacob, Guptill, & Sumsion, 2009; Scheerer, Cahill, Kirby, & Lane, 2004). The findings in this synthesis support and expand those of Scheerer et al. (2004), who identified that motivation for occupational engagement may come from recognition by others of one's skill and receiving compliments, giving to others, and having options. Additionally, some motivational factors identified by Jacob et al. (2009) such as needing to belong, and seeking a sense of accomplishment, were also findings in this study. Jacob et al. (2009) also highlighted the sense of security which comes from participating in occupation as a member of a group as an important factor facilitating occupational engagement. This is similar to the concept labelled confidence in this review.

The role confidence plays in occupational performance has been discussed to some extent in occupational science literature, especially in relation to occupational adaptation (Braveman et al., 2006; Kielhofner, 2008; Schkade & Schultz, 1992). Insights from this review support findings from previous studies exploring occupational adaptation. Christiansen and Townsend (2010) defined occupational adaptation as the "adjustments and changes in the methods, tools, locations, and other forces that determine participation in occupations" (p.420). Subcategories within the categories of developing confidence, finding motivation and becoming confident align with the state

and process of occupational adaptation (Schkade & Schultz, 1992). Occupational adaptation strategies identified in previous studies which have been further verified in this synthesis include overcoming negative emotions (Wells, 2015; Williams & Murray, 2013b), adopting a positive outlook (Parsons & Stanley, 2008), overcoming barriers through engaging in occupation (Bontje et al., 2004; Parsons & Stanley, 2008; Wells, 2015) and drawing on support systems (Mansson Lexell et al., 2011; Parsons & Stanley, 2008; Williams & Murray, 2013b).

The inherent link between occupational adaptation and occupational identity (Bontje et al., 2004; Braveman et al., 2006; Kielhofner, 2009; Mansson Lexell et al., 2011) is also highlighted in the findings of this study. Mansson Lexell et al. (2011) defined occupational adaptation as a lifelong dynamic process of balancing identity and competence. Being confronted with a chronic disease, injury or significant illness can significantly disrupt this balance as it impacts on an individual's life direction and identity. Individuals shape their personal identity as their life story unfolds (Christiansen, 1999; Clark, 1993), and it is this identity which gives meaning to experiences and life. As Christiansen (1999) describes, it is through occupation that individuals primarily express their identity, and also how they are typically identified. All too often, an individual's sense of self may shift from a competent occupational being to a "disabled" self when first confronted with illness or injury. Further, one's sense of self is very much influenced by social validation or how others respond to one's actions (Christiansen, 1999). The theme of reduced confidence through fearing rejection or not being able to live up to others' expectations appeared in many experiences. The establishment of a sense of belonging, often to a new peer group who have shared experiences, was an important element of many people's adjustment and fostered motivation and confidence. This resonates with occupation-based theoretical frameworks embracing a dynamic balance between doing, being, becoming and belonging (Doble & Caron Santha, 2008; Rebeiro, Day, Semeniuk, O'Brien, & Wilson, 2001; Wilcock, 1999).

Christiansen (1999) suggests that a sense of well-being comes when an individual's identity and life story are coherent and provide purpose and even future possibilities. This study has shown that reconstructing one's occupational identity and re-establishing purpose and meaning are central to adjustment after chronic disease, sudden illness or injury.

Limitations of the study

A limitation of this synthesis is the exclusion of studies exploring adjustment from mental illness. The rationale underpinning this decision was to assemble a manageable dataset from which to construct a theoretical model which could then be verified with other populations. However, rather than threatening the rigour of the study, it is seen that this exclusion criterion ensured an initial deep and rich dataset. Ongoing verification of the emerging theoretical framework across a wider scope, including mental health, is strongly urged to move towards a more broadly applicable formal theory.

The search strategy could also potentially have limited the study. Additional key words, such as adapt* or adjust* may have yielded additional papers. Although theoretical saturation appeared to have occurred with this sample, additional analysis involving a wider search strategy would have strengthened the findings.

As the analysis in this synthesis involved information in published reports rather than original participant interviews, some readers may consider this a limitation as it is influenced by how original researchers categorised data and reported findings, reflecting their own particular biases, judgements, experiences, values, and preferences, together with contemporary concerns and publication requirements. However, as Kearney (1998) highlighted, this is akin to the same

judgements and lenses interview participants impose when sharing their story and it is the task of the researcher to “bring their viewpoint faithfully along with others’ and one’s own into the broader, longer, collective story line” (Kearney, 1998, p 184). The validity of this synthesis will be discerned as the emerging theory is verified through further investigation and as readers identify relevance and applicability.

Conclusion

The occupational well-being framework evolving from this synthesis aligns with that posed by Doble and Caron Santha (2008), who identified that occupational well-being is orchestrated through a balance of personal factors, opportunities and drive to meet one’s occupational needs. Adjustment can be defined as the process of regaining occupational well-being through occupational engagement and construction of an occupational identity supported by a process of developing competence, motivation and confidence. Gaining an insight into how individuals construct their occupational well-being, and appreciating where on the continuum to well-being a person is, can inform ongoing efforts to promote adjustment.

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