

A narrative review of hope after spinal cord injury: Implications for physiotherapy

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ABSTRACT

Spinal cord injury is a life-changing event that can affect both physical and psychological wellbeing. Frequently, physiotherapists working with patients with spinal cord injury are asked about prognosis and outcomes, leaving them unsure whether to be cautious in their responses or to promote hope for recovery. The purpose of this narrative review was to investigate the literature regarding the role of hope after spinal cord injury, whether hope is beneficial and if so, whether there are strategies that may be incorporated into physiotherapy practice to support or foster hope. Common themes regarding hope after spinal cord injury included the hope to walk again, that hope changed over time, images of past and present, and the power of hope. Cross-sectional studies report hope after spinal cord injury to be associated with reduced depression, improved coping, higher self-esteem and increased life satisfaction. Although no studies were located that specifically investigated either enhancing hope after spinal cord injury or how physiotherapists can support or enhance hope, strategies from other populations are discussed to illustrate how they could be utilised in a physiotherapy setting.

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INTRODUCTION

Spinal Cord Injury (SCI) can be a sudden and devastating event that changes a person's life forever. It often leads to permanent neurological injury and a range of associated consequences such as paralysis, loss of sensation, changes to bowel, bladder and sexual function, and loss of functional abilities such as walking (Harvey 2008). Furthermore, not only does SCI affect a person's physical function, but also their psychological wellbeing. Research has shown that after SCI, people have reduced subjective wellbeing (Dijkers 1997), life participation (Gerhart et al 1993) and quality of life (Craig et al 2009) and an increased likelihood of developing anxiety or depressive disorders (Craig et al 2009). This suggests that physical interventions alone may not be enough to lead to successful and comprehensive rehabilitation outcomes.

In New Zealand 30 out of every million people each year sustain a SCI (Derrett et al 2012). The majority of those people will be admitted to one of two specialised spinal rehabilitation units. There, they will have a dedicated interdisciplinary team comprising a number of health care professionals including physiotherapists.

One challenging aspect of SCI rehabilitation is the uncertainty surrounding recovery (Soundy et al 2010, Sullivan 2001). Depending on the level of SCI and impairment, some patients will have a much greater chance of improvement than others; with those with incomplete injuries tending to make the most gains (Vazquez et al 2008). Very few patients make a full recovery, although an increasing number will walk again in some form, thanks to improving emergency and acute care. Patients

often ask health professionals, physiotherapists in particular, about prognosis: "Will I ever walk again?", "Will I be able to use my hands again?" One can rarely answer these questions with absolute certainty, due to the variable nature of SCI and recovery. Conversations such as these often leave therapists with the dilemma of either encouraging hope and promoting what may be perceived to be "unrealistic expectations" or confronting the patient with the reality that these things may never happen. Hope in itself, however is a personal and complex phenomenon that is not easy to define.

The aims of the following review and discussion were to investigate the role of hope after SCI, whether hope is potentially beneficial in a rehabilitation setting such as a Spinal Unit, and to identify strategies or interventions that have the potential to be incorporated into physiotherapy practice to support or enhance hope. A literature search was undertaken between August and September 2011 to locate pertinent studies relating to hope, SCI and physiotherapy. Databases searched included: Allied and Complementary Medicine Database (AMED); Cumulative Index to Nursing and Allied Health literature (CINAHL); MEDLINE; The Cochrane Controlled Trials Register in the Cochrane Library; Physiotherapy Evidence Database (PEDRO); PsycINFO and Embase. Key search terms included combinations of *spinal cord injury, hope, physiotherapy, physical therapy and rehabilitation*. Due to the absence of strategies found to support or enhance hope within the SCI population or physiotherapy more specifically, the search was broadened for this aspect of the review to capture those implemented in a healthcare context more generally. Studies investigating hope within mental health populations were excluded to allow focus on the relationship of hope to more

physical rather than psychological impairment. Reference lists of key papers were also searched to identify other papers pertinent to the topic. The literature search was repeated in August 2013 to capture studies published after the initial search, with two further articles found to add further value in the context of this review (Bright et al 2011, Kortte et al 2012). The findings of this review have been summarised into four key sections: Defining the concept of hope, patients' experiences of hope after SCI, benefits of hope after SCI, and strategies that physiotherapists might use to support hope.

What is hope?

Many authors have attempted to define hope in the literature, the majority originating from psychology and nursing fields. There is no universally agreed upon definition. However, there are common characteristics such as its future orientation and positive nature (Dufault and Martocchio 1985, Farran et al 1995, Lohne 2001, Snyder et al 2006). The word hope is often associated with other words and concepts such as wants, expectations, goals, desires, dreams and optimism (Bright et al 2011). It can be a noun "I have the hope of walking again", a verb "I hope that I will walk again", or an adjective "I am hopeful that I will walk again".

Dufault and Martocchio (1985) describe hope as a multidimensional and dynamic life force embodied by an expectation of a positive, realistically possible, yet uncertain future that is personally significant to the individual. These authors suggest hope can be a way of being (generalised hope), or related to a specific object or event (particularised hope). Farran et al (1995) also defined hope more generally and multidimensionally as a way of feeling, thinking, behaving and relating to oneself and the world.

Contrastingly, both Snyder et al (2006) and Lohne (2001) link hope more uni-dimensionally to goals with less emotional conceptualisation. Lohne, one of the few authors to define hope specifically in relation to SCI, outlined hope as a positive prospective phenomenon involving both the substance of hope (appearing as specific wishes and goals) and the process of hoping (Lohne 2001). Snyder also described hope as a positive motivational state comprising two distinct ways of thinking about goals. *Agency thoughts* involve the motivation or sense of determination to meet goals. The person believes that a particular goal can be achieved and they *want* to achieve it, with thoughts such as 'I can do it' and 'I will not let ... stop me from...'. *Pathway thoughts* concern how a specific goal is going to be achieved. These thoughts reflect the person's perceived ability to be able to find routes towards the goal and can involve self-talk messages such as 'I will find a way to do it' and 'I am going to get there by ...' (Snyder 2000, Snyder et al 2006). This conceptualisation of hope as an active process that is outcome oriented was also mirrored by Bright and colleagues (2011) in their systematic review of hope in people with stroke.

Given the multiple and varied notions of what hope is and how it might be conceptualised, no one definition has informed this review. However, drawing these definitions together, hope appears to be a way of thinking or being that is often both positive and oriented towards the future or goals.

The Experience of Hope after SCI

To determine whether hope should and could be supported after SCI, it is first necessary to better understand what hope means to people after SCI. A number of qualitative studies have investigated how people experience hope after SCI using a mixture of phenomenological and ethnographical methodologies (Dorsett 2010, Laskiwski and Morse 1993, Lohne 2009, Lohne and Severinsson 2004, Lohne and Severinsson 2005, Lohne and Severinsson 2006, Smith and Sparkes 2005). Methodologically, all the studies had clear objectives, appropriate and relevant research designs, and proposed themes that were well supported by raw data. Other than Dorsett (2010), all studies had two authors who coded data independently and then compared the findings and themes in an attempt to reduce bias. All participants had sustained SCI, although there was some variation in setting with some undergoing initial inpatient rehabilitation and others living in the community. Table 1 provides a summary of included papers. The literature revealed four themes regarding the experience of hope after SCI. Each of these is discussed in turn below.

"I hope that I will walk again"

The majority of participants from almost all studies expressed the desire to walk again one day (Dorsett 2010, Laskiwski and Morse 1993, Lohne and Severinsson 2004, Lohne and Severinsson 2006, Smith and Sparkes 2005). For many, this hope remained no matter what evidence was presented to them; even if they had accepted it was a remote possibility. This suggests that patients may still hold this particular hope, no matter what information their physiotherapist or other health care professional provides them with, and is an interesting finding in light of other literature that suggests walking is not always the highest priority after SCI, especially in those people with tetraplegia and chronic SCI (Anderson 2004, Simpson et al 2012). Hope of this type represents "concrete hope" as described by Smith and Sparkes (2005) who carried out interviews exploring hope with men who had sustained traumatic SCI's playing rugby. These authors found concrete hopes to be the most common type of hope, associated with specific material outcomes and often a "cure" or return to being "able-bodied".

"Hope for past and future"

Closely linked with the hope of walking again, was the frequent mention of hope for a return to life as it was before their SCI, to what was lost, to "normal" (Dorsett 2010, Laskiwski and Morse 1993, Lohne and Severinsson 2004, Smith and Sparkes 2005). This is also an example of concrete hope, usually related to physical goals such as regaining the ability to stand, dance, garden, and grasp objects with their hands. Often health professionals viewed these hopes as an unlikely possibility; while the media, family, and friends tended to reinforce them (Smith and Sparkes 2005). The popular belief held by others was that if you worked hard enough and stayed positive recovery was more likely (Dorsett 2010). In practice, this longing for the past may motivate the patient to engage in their rehabilitation to maximise any recovery they may make, or to better utilise any treatments or cures that become available. Alternatively it may also limit the person's acceptance of their disability. They may not see the point in participating in therapies that involve learning compensatory strategies when they are awaiting a return to their

Table 1: Overview of qualitative papers exploring the experience of hope after SCI

Authors	Methodology	Design	Key themes found
Smith and Sparkes 2004	Narrative Inquiry	Unstructured interviews in homes of 10 men living in community who sustained SCI due to rugby accidents in England.	Concrete hopes and the restitution narrative - hope for return to previous physical attributes and abilities. Transcendent hope and the quest narrative – acceptance of disability and generalised hope for the future not oriented to a specific or physical outcome. Despair and the chaos narrative – loss of hope altogether.
Dorsett 2010	Phenomenology	Longitudinal mixed method study of 46 women and men discharged from an Australian Spinal Unit. Semi-structured interviews at discharge, 6, 12 and 36 months and 10 years post-injury (qualitative findings only discussed in this article).	Participants hoped for a complete recovery, a cure and a satisfying quality of life. Hope identified as a key factor helping participants both adjust and cope after SCI. Improving self-esteem and self-efficacy and facilitating goal achievement may help to engender hope for the future.
Lohne 2009, Lohne and Severinsson 2004, 2005, 2006	Hermeneutic phenomenology	Longitudinal study of 6 men and 4 women admitted to a rehabilitation hospital in Norway. Interviews carried out during the first few months after SCI at the hospital, at one year post SCI and again at 3-4years post SCI in participants' homes.	Early after SCI: Images of the past and future and longing for former lives. Balancing between inner emotional dichotomies and the vicious circle of suffering. The power of hope. Chronic SCI: Hope focused more on "life" than on making specific improvements. Ongoing movement between suffering and being hopeful "the vicious circle".
Laskiwski and Morse 1993	Ethnography	Observations and unstructured interviews with the patients (3 women, 25 men), family and staff in an inpatient SCI rehabilitation unit in Canada. A written journal of the authors own reflections and suppositions was also utilised.	Hope to walk again. Hope modified throughout patients journey through rehabilitation, initially focussed on recovery and returning home and becoming more realistic and centred around coping in the community as they increasingly accepted the permanence of their injury. Feelings of despair expressed as swearing rather than crying.

former abilities and life roles. In this instance, physiotherapists have the potential to educate patients regarding therapy goals to encourage engagement in rehabilitation.

Alongside this hope for the past, some participants also held a vision of and hope for the future; that a fulfilling yet possibly different life from what had been expected was still possible after SCI (Dorsett 2010, Lohne 2009, Lohne and Severinsson 2004, Smith and Sparkes 2005). Smith and Sparkes (2005) linked this type of hope to the "quest narrative" in which people believe that something can be learned from their experience and termed it "transcendent hope". Hope in this form is different from concrete hope in that the participant had more acceptance of their injury, which offered them the chance to reconstruct a new identity/self, the hope of becoming a better person as a result. It possibly allowed participants to deal more effectively with a future that is still uncertain. Hammell's

(2007) meta-synthesis exploring the experience of rehabilitation after SCI also highlighted the importance participants felt in being able to envision future life possibilities. These authors found that peers with SCI played a key role in providing exemplars of what could be achieved after SCI. Physiotherapists could also potentially facilitate this vision by providing education, discussing their own experiences with similar cases, and giving reassurance that disability is not necessarily a tragedy, that a satisfying and happy future can still be achieved after SCI.

"The transformation of hope over time"

Although the majority of participants had some form of hope most of the time, it also emerged that hope was not always consistent (Dorsett 2010, Laskiwski and Morse 1993, Lohne 2009, Lohne and Severinsson 2005). Participants hoped for different things over time as circumstances, understanding, and acceptance of their condition changed (Laskiwski and Morse

1993). Lohne and Severinsson (2004, 2005, 2006, 2009) conducted a longitudinal qualitative study in Norway following 10 individuals with SCI from initial rehabilitation through to four years post injury. Participants felt hope was most important in the early stages of rehabilitation and essential for recovering from the initial trauma (Lohne 2009). During this time hope tended to involve more particularised, specific hopes for physical recovery as mentioned above. Both the Lohne study (2009), and another longitudinal study carried out by Dorsett (2010) over 10 years found that as time since injury elapsed, hope became more generalised, focused more on having a good life and “living in hope” (Dorsett 2010, Lohne 2009). There was a shift from “having” hope to “being” hopeful with hope becoming less centred around specific goals. This resonates with both Dufault and Martocchio’s (1989) and Lohne’s (2001) definitions of hope. A similar modification of hope over an even shorter time was also found in an ethnographical study by Laskiwski and Morse (1993). These authors explored adaptation to injury in participants undergoing SCI inpatient rehabilitation, and found that even in the transition from acute settings such as intensive care early after injury to inpatient rehabilitation and then during preparation for discharge back to the community hope evolved and changed, almost on a daily basis.

Hope over time was also punctuated by periods of suffering and despair or loss of hope altogether. This occurred particularly when the consequences of the injury were initially comprehended, and also as functional and physical gains plateaued after the first year or two post injury and long-term outcomes became more certain. (Lohne 2009, Lohne and Severinsson 2005, Smith and Sparkes 2005). Participants described having good and bad days, ups and downs. Contrasting emotional dichotomies were linked with narratives of hope: feelings of strength versus vulnerability, helplessness versus independence, pride versus shame (Lohne and Severinsson 2004, Lohne and Severinsson 2005). Yet most reported that throughout all stages, even the smallest physical improvements would make them hopeful again that there was a possibility for future improvement (Dorsett 2010, Lohne 2009, Lohne and Severinsson 2006). Assisting patients to set meaningful and achievable goals may help to highlight those small gains. See Snyder (2000) for a more detailed discussion regarding the relationship between hope and goals.

“The power of hope”

To participants, the power of hope often represented not giving up (Lohne and Severinsson 2006, Smith and Sparkes 2005). It motivated them to persevere with their rehabilitation and therapy which in turn led to functional improvements. As mentioned previously, these improvements then inspired hope even further, perpetuating the cycle. This “power of hope” has also been likened to “weathering a storm” (Hammer et al 2009) where hope provides the determination and drive to keep fighting, believing a positive and worthwhile future is still possible in the face of adversity. This idea implies that attitude or state of mind may give further strength to hopes, mirroring the agency component of Snyder’s Hope Theory (Snyder et al 2006).

Is hope beneficial after SCI?

It appears from the findings above that hope is a non-physical factor that plays a significant role in both the rehabilitation and lives of people who have sustained a SCI. In addition,

correlational studies investigating the relationships between hope and other variables have also found significant associations with a number of positive factors such as improved life satisfaction, coping, and self-esteem, and reduced depression and psychosocial impairment. Generally most studies investigated participants with SCI who had only recently sustained their injury and were undergoing rehabilitation in Spinal Units similar to those found here in New Zealand, although no studies were actually completed in either New Zealand or Australia (see Table 2 for an overview of the papers discussed).

Kortte et al (2010) found that in 87 participants undergoing acute inpatient SCI rehabilitation, participants with more hope as measured by the Snyder Hope Scale (Snyder 2000) on admission, had improved life satisfaction both at admission and three months post discharge. Unfortunately the authors only assessed hope at baseline not at the three month reassessment; they did not take into account the fact that hope may change over time. Therefore, one can only conclude that hope *on admission* was correlated to life satisfaction, not hope throughout the rehabilitation process.

Kennedy et al (2009), using a cross-sectional survey study design, investigated the relationship between hope, coping, and cognitive appraisals (how an individual interprets or views a situation) in 54 people (80% men) who were less than one year post SCI. Hope was assessed using Snyder’s State Hope Scale which assesses the agency and pathways components of hope (Snyder 2000). Agency score was associated with higher acceptance levels, while higher pathways scores were related to improved coping in the form of fighting spirit. Participants with lower levels of hope viewed their injury as more threatening. Further, those participants with higher levels of hope were more persistent when faced with challenges. A longitudinal qualitative study by Dorsett (2010) also supported the relationship between hope and coping, with 70% of participants clearly identifying hope as an essential factor in helping them cope after their injury, even though no specific questions were directly asked about hope itself in the interviews.

Hope’s relationship with coping after SCI, particularly those hopes perceived as unrealistic, has been likened by some to denial (Dorsett 2010). It has been suggested that unrealistic hope may hinder participation in rehabilitation, leading to false expectations (Elliott et al 1991, Soundy et al 2010), and poorer long-term outcomes after SCI (Wegener and Kortte 2004). However no studies have yet clearly demonstrated these associations with hope. Unrealistic hope may play an important psychological protective role in the earliest stages after sustaining injury (Elliott and Richards 1999, Elliott et al 1991, Wegener and Kortte 2004). It may serve as a mechanism to reduce distress, trauma, and anxiety until the person is ready to accept the potential seriousness and permanency of their condition (Dorsett 2010). Therefore, destroying hope for recovery because it is seen to be “unrealistic” may possibly be more psychologically damaging than loss of hope altogether.

An important point to note is that defining what is “unrealistic” is in itself not easy. To be unrealistic or false, it is assumed that the likelihood of obtainment is far-fetched or impossible (Coulehan 2011). Yet there is often uncertainty around prognosis after SCI, particularly for patients with incomplete injuries. At present, a significant amount of effort and

Table 2: Overview of correlational research papers investigating the relationship between hope and outcome after SCI

Authors	Participants	Outcome Measures	Key Findings	Strengths and Limitations
Elliot et al 1991	57 men and women with traumatic SCI receiving treatment at a rehabilitation centre	Hospital Anxiety and Depression Scale (HADS) Snyder's Hope Scale	- ↑ hope negatively correlated with ↓ depression and psychosocial impairment.	HADS validated in SCI but not Snyder's Hope Scale. No clear inclusion criteria other than sustained traumatic SCI. Minimal description of patient characteristics, especially type of injury or in/outpatient status. Large variation in time since injury (1-452 months) and stage of rehabilitation, however hope is thought to change over time which may affect results.
Kortte et al 2010	87 rehabilitation inpatients	Snyder's Hope Scale Satisfaction of Life Scale	- ↑ hope on admission associated with ↑ life satisfaction at admission and 3 months post discharge.	11 participants not followed up at 3 months. Inclusion of this data may have influenced results. Neither scale validated with SCI. Detailed description of patient characteristics.
Kennedy et al 2009	54 (80% men) who were <1 year post SCI	HADS Pakenham Scale (cognitive appraisals) State Hope Scale Spinal cord lesion related coping scale	↑ agency score associated with ↑ acceptance. ↑ pathways scores associated with ↑ coping. ↓ hope associated with view of injury as threatening. ↑ hope predicts ↑ persistence against challenge, and ↓ depression.	Coping scale has not been previously psychometrically tested. Use of self-report measures in an interview format may contribute to social desirability bias.
Kortte et al 2012	174 patients undergoing acute rehabilitation including SCI, stroke, amputation and orthopaedic injury	Snyder's Hope Scale Functional Independence Measure (FIM) Craig Hospital Assessment and Reporting Technique (CHART)	Hope was a predictor of functional role participation (CHART). Positive affect was not a predictor of functional role participation. Neither hope or positive affect predicted functional skill level (FIM).	Large sample size. Patients other than SCI also included in analyses. Although no significant differences were found in hope or positive effect scores between the subgroups, significant differences in FIM or CHART scores may have influenced the correlation results which analysed the entire sample as a whole. Measures validated in general rehabilitation populations, but not all with SCI specifically.
Piazza et al 1991	77 patients undergoing SCI rehabilitation	Miller Hope Scale Rosenberg Self-Esteem Scale Personal Resource Questionnaire	Hope associated with social support, education level self-esteem, race, inpatient versus outpatient. Hope not associated with sex and employment status.	Detailed description of patient characteristics. Unclear if any of measures validated with SCI. No description of data analysis methods.

resources is being directed at research aiming to identify better treatments, rehabilitation strategies, and even a “cure” for SCI (Tate et al 2011). It is becoming increasingly difficult to accurately and categorically say there is no chance someone may realise certain recovery hopes, calling into question this notion of “unrealistic” hopes.

Both the aforementioned Kennedy et al study (2009) and another by Elliot et al (1991) found higher levels of hope were also associated with lower levels of depression. Elliot and colleagues found a significant negative correlation between total hope score (measured by Snyder’s Hope Scale) and both depression and psychosocial impairment measures in patients with traumatic SCI. The pathways component of the Hope Scale in particular was a significant predictor of depression.

A common limitation in many studies looking at the phenomenon of hope after SCI is the lack of description of patient characteristics, particularly injury level or completeness. Piazza et al (1991) is one of the only studies that explored the influence of patient demographics on hope. These authors original intention was to analyse the relationship between hope and self-esteem in inpatients undergoing rehabilitation after SCI. They found social support, education level, and self-esteem all to be strong predictors of hope measured using the Miller Hope Scale (Miller 1988). When looking at other variables, sex and employment status did not cause significant difference in hope levels. These authors did however find significant differences in hope according to ethnicity and whether participants were ‘outpatients’ or ‘inpatients’. Unfortunately they did not look at the relationship between hope and injury level and type. As such, there is no literature available that states empirically whether these factors influence hope. It is possible for example that people with incomplete injuries, and therefore an improved prognosis of recovery, may have higher levels (and different types) of hope. Interestingly a positive association has been found between hope and functional role participation in acute rehabilitation populations (Kortte et al 2012). This study did not exclusively investigate people with SCI however and also comprised conditions such as stroke, amputation, and orthopaedic injury. As SCI participants were not analysed as a subgroup it cannot be concluded that these results are directly applicable to that population but warrants further investigation.

When discussing the quality and general applicability of the reviewed studies in relation to SCI rehabilitation, it is important to first note that none of the measures used to determine hope levels were designed specifically for the SCI population. For example Snyder’s Hope Scale and State Hope Scale are derived from Snyder’s Hope Theory, originating in psychotherapy (Snyder 2000). The Miller Hope Scale was designed for people who were critically ill (Miller and Powers 1988). The Herth Hope Scale, another popular hope measure, originates from research in oncological and palliative care (Herth 1992). To date, no literature actually determines if these measures have true validity for measuring hope in someone who has sustained a SCI. As such, one needs to be cautious when interpreting findings. The variability in definitions, conceptualisations, and measures of hope used within these studies makes comparisons difficult.

In summary, although there have only been a limited number of studies investigating the relationships between hope and

other variables, significant positive correlations have been found between hope and life satisfaction, coping and self-esteem, and significant negative correlations found between hope, depression, and psychosocial impairment. No evidence has yet demonstrated potential negative effects of hope, even though some authors have voiced concern regarding the effects of unrealistic hope. It must also be noted that because the majority of studies linking hope with positive outcomes are correlational rather than longitudinal in design, the causal direction of the relationship cannot be determined. Possibly greater hope contributes to better outcomes or alternatively better outcomes may foster greater hope. While further research is needed to confirm hope as a predictor of outcome in SCI, there is enough evidence linking hope to better outcomes in this population to warrant further consideration of how practitioners could support or enhance hope in the inpatient setting.

Facilitating hope after SCI

Despite descriptive and discussion articles that offer suggestions for enhancing hope, there have been no specific studies that explicitly investigate either how physiotherapists can support or enhance hope within their practice or how hope is enhanced in the SCI population. Studies have more commonly been carried out in the nursing and medical professions and in populations such as mental health, oncology, palliative care, and critical illness. While there are similarities between these different practice areas and patient populations, there remain significant differences which we must take into account when assessing the relevance and contribution of the literature findings.

However, with the lack of current evidence available in the physiotherapy and SCI field, it is still worth taking account of what evidence there is in these other populations. The following discussion focuses on medical populations rather than mental health, because they are more likely to have physical issues and this was considered to be more generalisable to the SCI population.

Implementation of strategies that foster hope into physiotherapy practice

Herth (2000) and Rustoen et al (1998) each carried out a randomised controlled trial investigating the effectiveness of two similar hope-enhancing programmes in cancer patients. Sessions focused on topics such as strengthening relationships with significant others, exploring spirituality and learning cognitive strategies to enhance hope such as goal refinement, and recognising negative thinking. Both interventions led to a significant improvement in hope on programme completion, but only Herth’s participants maintained these improvements at follow up. These two studies did however use different hope assessment tools (the Herth Hope Index and the Nowotny Hope Scale) which may have contributed to the contrasting results.

Duggleby et al (2007) also carried out a randomised controlled trial with older terminally ill cancer patients in which the participants watched a video of other patients describing how they maintained hope and carried out one of three hope-enhancing activities over one week, such as making a hope collection. Hope was found to significantly improved. No follow up assessment was carried out to determine the long-term effects but this is not surprising as the participants were at the end stages of their disease.

Each of these interventions incorporated multiple approaches for enhancing hope. In their entirety they would be challenging for physiotherapists to carry out due to time constraints and difficult to incorporate into standard physiotherapy sessions. There are however a number of individual strategies within these interventions that have been explored in the qualitative literature (Buckley and Herth 2004, Chi 2007, Herth 1990, Koopmeiners et al 1997, Miller 1989, Raleigh 1992, Wong-Wylie and Jevne 1997) and which could be incorporated into physiotherapy practice in a rehabilitation setting. These studies were mixed in terms of research design and methodology, predominantly using semi-structured interviews as their primary form of data collection. Common sources of hope included *relationships* between family, friends, and health professionals, *spirituality*, the *therapeutic relationship* and *goal setting*. Each of these and their applicability to physiotherapy practice will be discussed in turn below.

Relationships and support from family and friends have been reported qualitatively to be an important source in fostering hope after cancer diagnosis (Chi 2007), critical illness (Miller 1989), chronic illness (Raleigh 1992), and in the terminally ill (Buckley and Herth 2004, Herth 1990). These findings were mirrored quantitatively by Piazza and colleagues (1991) who found hope to be positively associated with level of social support after SCI. Miller (1989) found that stronger family bonds were perceived to inspire hope in people who had been critically ill. Family provided a sense that the patient was still cared about and needed, that there was someone to live for and who could share their difficulties. Family could help identify when a patient's hope was waning and assist strengthening it again.

In a Spinal Unit environment, working with families is a part of the rehabilitation process. Families may be involved with goal setting, planning for leave and discharge, and assisting with functional activities. Family and friends are often visiting while patients are participating in physiotherapy sessions. Inviting them to observe therapy sessions and even participate may enhance their involvement with the patient's rehabilitation, enabling the patient to feel more supported. Family integrity may be enhanced by ensuring support people are aware and take advantage of visiting hours, are invited to attend relevant meetings, are listened to with respect, and by facilitating quality time together (Kautz and Van Horn 2009).

Spirituality is another common source of hope identified in the literature (Buckley and Herth 2004, Chi 2007, Herth 1990, Miller 1989, Raleigh 1992). Although often directly connected to religious beliefs, it also included other non-religious beliefs and philosophies about life and death. This finding regarding the role of spirituality may have particular relevance in the New Zealand context and in particular for Māori who have had a SCI given spirituality, or *taha wairua*, is identified as one of four core dimensions of Māori well-being in the now well-known Māori health model, *Te Whare Tapa Whā* (Durie, 1998). In practice, drawing out deeper discussions around an individual's spiritual side is not necessarily something all physiotherapists would feel comfortable about. Yet in a Spinal Unit environment, especially one with connections to a larger tertiary care service, there is often the capacity to link the patient with other services who could offer support if this is identified as something that might be of value to the patient. Spirituality can be supported by informing the patient about the chaplaincy service and cultural

support services, and/or making the Spinal Unit's counsellor available to patients. However, it should not be assumed all patients regard spirituality as important. Providing opportunities for the patient to go on leave to attend a church service may also have advantages in terms of encouraging community participation and reintegration, and strengthening the bonds with their church if they live locally.

Aspects of the *therapeutic relationship* may be important. For example, how health care professionals communicate with and relate to their patients has been perceived by patients to influence hope both positively and negatively (Buckley and Herth 2004, Koopmeiners 1997, Miller 1989, Wong-Wylie and Jevne 1997). Koopmeiners (1997) conducted semi-structured interviews with 32 men and women with various stages of cancer. These authors found that hope was inhibited by providing information in an insensitive, disrespectful, or contradictory way. Yet hope was also facilitated by health care professionals by:

- Being present – taking time to talk and be helpful.

- Giving information and answering questions in a positive, honest, and compassionate manner.

- Demonstrating caring behaviours such as thoughtful gestures, showing warmth, being friendly, polite, and sympathetic.

Similar findings were found by Wong-Wylie and Jevne (1997) who looked at the interactions between physicians and HIV sufferers. How the patient perceived the patient/doctor relationship influenced whether interactions were hope-enhancing or hope-diminishing. Doctors who treated their patients as human beings rather than cases and who listened and talked *with* the patient rather than *to* the patient were seen to influence hope more positively. This highlights the importance of how health professionals interact with their patients. Unfortunately neither of these studies specifically looked at how physiotherapists interacted with patients, though the characteristics described are likely also applicable in a physiotherapy setting. These findings suggest that features of care naturally assumed to be good practice such as compassion, honesty, and the ability to listen may nurture hope. Showing a genuine interest in patients' needs and responding to their concerns demonstrates listening. Although physiotherapists are often constrained by session time, discussion and discourse is still a natural part of physiotherapy practice. The findings of this review would suggest physiotherapists would be well advised to take at least a few minutes where possible to just talk to the patient about things other than the actual intervention; maybe while they are having a rest between exercises or at the start of a session. Even a small act such as smiling can communicate caring.

Physiotherapists often provide education and information; they should think about how information is communicated, aspiring to be realistic and honest yet remaining compassionate and positive. If patients ask specific questions, including ones about prognosis, they should be informed truthfully about possible outcomes and likelihood of recovery, yet allow acknowledgement of uncertainty and possibility.

Physiotherapists can have an additional role in facilitating *goal setting* and attainment, which has also been observed to

foster hope (Buckley and Herth 2004, Chi 2007, Miller 1989). Similar to hope, some participants reported goals that may be perceived to be more realistic than others. Yet being able to achieve personal goals further enhances hope; therefore, it could be suggested that having no achievable goals may diminish hope. Particularly in people with less realistic hopes and goals, physiotherapists may try to facilitate setting smaller, possibly shorter term goals that are more achievable. Engaging the patient in small achievable tasks might help them to see that a future can be developed. This links again with Snyder's Hope Theory, where setting smaller goals could be seen as enhancing pathways towards larger goals. Goal setting is not a new concept for physiotherapists and is something most physiotherapists already incorporate into their practice. These findings would suggest that goal setting is not simply a means to an end, but may also be an intervention in its own right. One should be cautious of ensuring goals are kept patient-centred and meaningful versus therapist-centred (Hammell 2007, Randall and McEwen 2000). Strategies such as identity-oriented goal training, which aids identification of what matters most to the patient, may be worthy of consideration for use in a Spinal Unit setting (McPherson et al 2009, Ylvisaker et al 2008).

CONCLUSION

It is becoming increasingly clear that hope plays a significant role in patients' experiences of rehabilitation after SCI, particularly in the early stages. These experiences of hope appear to be multidimensional and reflect elements common to published definitions of hope. Although there is still some debate as to the potentially damaging impact of what may be perceived to be "unrealistic" hopes, the evidence presented in this review would suggest the benefits of hope outweigh the perceived dangers. People with SCI have subjectively reported the importance of hope, and research has demonstrated hope to be associated with positive factors such as coping, enhanced life satisfaction, and lower rates of depression. While evidence of hope-enhancing strategies is limited in the context of SCI and/or physiotherapy practice, evidence in other populations suggests that hope can indeed be influenced or improved. Strategies adopted in other populations and by other health professionals could be incorporated into physiotherapy practice. The effectiveness of such strategies in the SCI population would warrant further investigation in the future. Other areas for future research could include: how specific comments that health care professionals make contribute to hope, what is the relationship between hope generally and different types of hope to specific functional and rehabilitation outcomes, and does injury level and type have an influence on hope levels. Psychometric testing of hope assessment tools in the SCI population is also necessary.

Notwithstanding the need for further research, the findings of this review highlight that physiotherapists need to give more explicit consideration to the role of hope in recovery following SCI. Physiotherapists may inadvertently impact hope through the course of rehabilitation, for better or for worse. As such, a greater awareness of the role of hope and factors that may help or hinder hope, along with the adoption of related strategies, is likely to optimise the potentially beneficial effects of hope for people following SCI.

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