Spirituality as a Determinant of Health for those with Disabilities

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ABSTRACT

Disability is commonly viewed as permanent loss of physical, cognitive and social aspects of self. Rehabilitation interventions are aimed to return the individual to full health by either restoration of past physical, cognitive or social capabilities or strengthening aspects of self to counter such loss. For many, rehabilitation interventions do not result in a complete return to past physical, mental or social health. Does this mean that people with disability can never be healthy? Or does it indicate that our perception and definition of health does not reflect the essence of health? We argue that when people with disability redefine themselves and their conception of health in terms other than levels of physical, social and cognitive functioning, good health is an attainable goal. We discuss evidence that suggests why spirituality could be a primary determinant of health.
Disability has been defined as any restriction, caused by an impairment (loss of health) that reduces the individual's ability to "perform an activity in the manner or within the range considered for a normal human being" (WHO, 1997). The reduction in physical, social or cognitive function, resulting from impairment often impacts negatively on individuals’ wellbeing. If we accept the WHO definition of health as “a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity”, then good health is an unobtainable goal for those with disabilities (National Health Standing Committee, 1998; WHO, 1980; 1997). We argue that if people with disability restructure their perceptions of self and health in terms other than levels of physical, social and cognitive wellbeing, then good health is an attainable goal for those with disabilities. In this paper, we draw a clear distinction between the concepts of spirituality and religion and propose a working definition of spirituality. We review research on spirituality and its relationship with overall health and wellbeing, and discuss why spirituality could be a primary determinant of health.

**Disability Defined**

Scientific advancements in health research have enabled many to regain health by treatment of disease and traumatic injury. However, health professionals frequently observe and comment on the discrepancies evident between patient's physical disease status and the level of illness that is experienced (Fitzgerald, 1997; Fuhrer, 1994). Disease is biological degradation resulting from causes that are attributable to physical, psychological and social malfunction or trauma and identified by objective diagnosis of symptoms and physical findings. Illness is the subjective experience of the disease, such as pain, depression, helplessness or physical disability (Broderick, 2000). Analysis of global health highlights the fragility and complexity of the health construct that cannot be fully defined as simply the absence of disease (Sen & Bonita, 2000). Within the
context of acute ill-health experiences, modern medicine is largely effective at addressing both the objective symptoms while the subjective experience of illness is generally short term. For patients with chronic conditions, that is disabilities, complete health appears to be an unattainable goal if good health is defined as 'the absence of disease, a state of complete physical, mental and social well-being (National Health Standing Committee, 1998). Health-care utilisation and expenditure for those with disabilities is, on average, substantially higher than those who are not categorised as disabled (DeJong, Batavia & Griss, 1989; Rice & LaPlante, 1992; Rice, Max & Trupin, 1995, Max, Rice & Trupin, 1996, Ministry of Health, 1999), suggesting that current health goals are targeting what may be unattainable for many with chronic conditions. Permanent loss of physical, cognitive or social function is assumed to indicate a loss or lessening of ability and therefore the individual is categorised as disabled. Such categorisation may reflect the mindset of the assessors as to what health is rather than the perspective of those people with disabilities (Ballard, 1994; Durie, 1996; Munford, 1995; Varian, 1991; Vash, 1981).

Tepper, Suton, Beatty and DeJong (1997) and others (Fuhrer, 1994; Gregory, 1998; Cwikel, 1999, Joslyn, 1999, Mehlman & Neuhouse, 1999; Kriegsman & Deeg, 1999) argue that definition of disability cannot be separated from the agendas of the definers and challenge the adequacy of any singular definition of disability as well as the appropriateness of a pathological approach to this issue.

Definition of individual health status based solely on social, cognitive or physical 'dysfunction', 'less than normal' or 'disease' does not consider that subjective factors may also be major determinants of health. Fuhrer (1994) proposes that a definition of disability not only needs to include the concept of disablement but also the subjective concept of enablement. Disability can be viewed as a two-sided coin, loss of
observable aspects of self but also an opportunity for growth and development of the more intrinsic aspects of self. The subjective side focuses on the individual's perception of their health and self rather than simply measurement of observable physical, social and cognitive health.

A more comprehensive definition of disability that incorporates the concept of enablement as well as disablement would enable the individual's perception of life in general to become the focus. Such a focus would reflect the 'individual's implicit standards rather than any particular objective condition and both cognitive and emotionally toned judgements are involved' (Fuhrer, 1994, p.359). What are the factors that determine whether or not those with disabilities achieve a state of complete wellbeing?

Determinants of Health for those with Disabilities

Social health or the strength, magnitude and degree of intimacy or closeness of relationships with others have been found to be strongly related to physical health status (Fratiglioni, Wang, Ericsson, Maytan & Winblad, 2000; Fuhrer, Rintala, Hart, Clearman & Young, 1992).

Similarly, cognitive health including level of self worth/esteem, degree that one can perceive meaning and make sense of life experiences also appear to impact physical health (Akkasilpa, Minor, Goldman, Magder & Petri, 2000; Benjamin, Morris, McBeth, Macfarlane & Silman, 2000).

The inter-relationships of stress, social support, cognitive and physical health have been the focus of a large body of research. Meaningful relationships with others, our interpretations and perceptions of experience are all factors that influence stress levels (Lazarus & Folkman, 1984; Scheier & Carver, 1988, Oulette-Kobasa, 1983). Also, strong relationship exist between the level and duration of stress and the
prevalence of illnesses such as cancer, cardiovascular diseases, chronic pain and fatigue syndromes, asthma, diabetes and some forms of arthritis (Cohen & Williamson, 1991; Frese, 1985; Jemmott & Magloire, 1988; Moss, Moss & Peterson, 1989; Taylor, 1991).

The evidence of relationships between overall wellbeing, defined as the subjective aspects of cognitive, social health with physical health suggests that subjective aspects of self are important determinants of health. The experience and perception of social relationships and connection as well as cognitive beliefs and values appear to be integral to health. For many, relationships, connections, beliefs and values are seen as derived from the spiritual dimension.

**Spirituality versus Religion**

Sloan, Bagiella and Powell, (1999) point out, there does not seem to be clear separation of the concept of religion from spirituality or even such intertwined concepts as social support, group identity, and self concept. Many studies indicate a relationship between religion and health status (for example, Idler & Kasl, 1997; Koenig, Hays, George, Blazer, Larson & Landerman, 1997; Levin, 1994, Park & Cohen, 1993, Pargament & Hahn, 1986). However Sloan, et.al. argue that there is a lack of rigorous, quantitative studies that clearly test possible relationships of spirituality with health. Often religion/health studies cite a link between church attendance, religious involvement and better health status, but do not address confounding variables that may provide other reasons for the association between health and religion. For example, attendance at church requires physical fitness and mobility or, at least, a high level of social support to enable such attendance. Hence, those who regularly attend church may be healthier simply because they regularly perform this social activity or may be a self-selected sample who receive high levels of social support. Likewise, there appears to be no studies that compare the health of those who regularly attend religious organisations
with others who regularly attend similar but secular social organisations. Hence, enhancement of self-worth and lowering of stress through group interaction, identity and role performance has not been accounted for.

The paucity of quantitative research on spirituality seems to be due to the lack of a clear definition of spirituality and unclear rationale and theory relating to the possible relationship of spirituality to health. These factors have been compounded by the lack of reliable and valid quantitative instruments to measure spirituality or measures that clearly focus on spirituality rather than religion (Jones & Faull, 1999; Sloan, Bagiella & Powell, 1999).

Religion is a collective or group concept that relates to common behaviours and beliefs (norms) while spirituality is an externally-orientated phenomenon that is individually unique but focuses on relationships and connections with other people, objects and phenomena to attain full self health. The fundamental difference is that religion is based on others spiritually-derived knowledge that binds individuals to a particular perception of self and the world while spirituality is based on direct connection with spiritual sources that results in individually unique knowledge about self and the world. Fitzgerald (1997) views it as freeing the individual to strive towards the experience of one's full potential and knowledge of one's place through accessing relationships and connections with external resources. Moustakas (1956) states that spirituality is about a self that is both externally orientated and sustained, about ‘being’ and 'becoming', and is defined by the spiritual connections of the individual, rather than by others. But if spirituality is such an individually unique concept, how does one construct a universal definition? The answer seems to be by not focussing on individual details such as particular beliefs or practices (religion) but by examination of the common intent or goal of these behaviours and thoughts.
Spirituality defined.

Analyses of the literature on spirituality has identified four common themes (Dyson, Cobb & Forman, 1997; Selway & Ashman, 1998; Weaver, Flannelly, Flannelly, Koenig & Larson, 1998), these are:

1. **Relationships**: The strongest theme, is the existence of strong relationships within self, between self and others, external spiritual forces and nature.

2. **Relatedness/Connectedness**: This theme is intrinsically interwoven with relationships. It is not enough to intellectually acknowledge a relationship but the nature of the relationship must be such that it is experienced and perceived as an essential component of self. That is, the individual is perceived as part of a self system rather than the complete self system. The individual's health is dependent, to some extent, on the degree of connection with others, nature and external spiritual forces as well as the level of health of those one is connected to.

3. **Meaning**: The characteristic of the individual's relationships and connections determine the interpretation they have of the purpose of their life. Included in this construct is the concept of hope, which is evident in such attributes as a positive attitude, appreciation of nature, others and life in general.

4. **Beliefs/Clarity of Principles**: This does not refer specifically to religious beliefs but rather the preceding three themes enable the development of a personal belief system that is clear, strong, rigorously upheld and provides a structure for rationalisation of life purpose and experience. It is the presence of a strong belief system that is indicated by the clarity of interpretation of life meaning. It is the vehicle by which the individual comprehends, interprets and reacts to experiences.

These themes are reflected in New Zealand Maori models of health. For example, the health concepts of Durie's (1994) Whare Taha Wha and Pere's (1997) Te
Wheke. Both models emphasise the centrality and influence of spirituality over all dimensions of the self system. Relationships that are perceived as inherently connected to the individual self system are forwarded as determiners of one's perception, behaviour and interpretation of experience in line with the individual's unique life meaning and beliefs.

Spirituality research has been largely confined to qualitative studies that focus on what spirituality might be rather than what it might do with regard to health (Do Rozario, 1997; Fitzgerald, 1997; Vash, 1981). The scarcity of rigorous research on the effects of spirituality may result from the deeply personal and controversial nature of the topic, including beliefs that somehow spirituality is 'of another world', unapproachable or sacred. Another reason could be the tendency for the concept of spirituality to be viewed as the same as the behaviour termed religion. It seems that the aim of religion-health research is to prove that one set of collective beliefs and practices are more effective than others, rather than investigating the dynamics of the spiritual dimension’s effects on other dimensions of health. But what is the probable relationships of spirituality to health?

Rationale for the Relationship of Spirituality to Health.

Our individual identity or self concept is constructed through identification with others, life roles as well as self-perception of our physical form, mental and social abilities. We tend to view our identity as relatively stable and permanent where positive changes are seen as any experience that adds to our identity or self concept. Disability directly challenges both the permanence and sustainability of a self concept that is founded on our physical, social and cognitive dimensions. Challenge to self requires the use of coping strategies to adapt to such a threat.
Breakwell (1983) identified three coping strategies, firstly, Inertia or passive coping, entails doing nothing in the hope that the problem or challenge to self will resolve itself. Secondly, Action, which requires the individual to do something to address the challenge to self and assume control of the outcome. For those with disabilities an action strategy may include seeking knowledge of the disease, a focus on a return of physical flexibility and fitness, experimenting with various medications and supplements, the sourcing and use of functional aids, examination and change of attitudes and lifestyles or praying to seek a cure. While these two strategies are essential processes of rehabilitation, they imply that rehabilitation and any possibility for health must focus solely on the return of former function, occupational role and lifestyle. Pargament (1997) refers to these two options as the Conservation of Ends whereby the individual attempts to preserve who they perceive themselves to be (Inertia) or reconstruct and regain their pre-threat identity (Action).

Often, the reality of disability is that there are radical and ongoing physical, social and cognitive health changes. In such a context, Breakwell's (1983) third coping strategy, Transformation, provides a option for positive development because (rather than in spite) of ongoing change. This strategy requires that the individual access personal resources that may have been previously dormant to allow the adoption of new definitions of self, health, occupational roles and lifestyle. It has been long argued that the only mechanism that will ensure such change or growth of self is by the sourcing of completely new self-knowledge only available through spiritual connection (James, 1890; Pettitt, 1988; Vash, 1981; Do Rozario, 1997; Matthews, 2000). The central assumption of this concept of self and health is that all people have an inherent spiritual core to their being but that, for many, this core may lie dormant and unacknowledged (Do Rozario, 1997; Fitzgerald, 1997).
For example, for those experiencing terminal cancer their perceptions of permanence, order, control and personal power is challenged in the extreme. It has been found that those with a strong spiritual dimension of self face death with more openness, honesty and preparedness. (Dyson, Cobb & Forman, 1997; Weaver, Flannelly, Flannelly, Koenig & Larson, 1998). Furthermore, those with 'healthy spirituality' were found to live longer and access coping mechanisms that assist themselves and significant others to adjust positively to death (Kazanjian, 1997). The evidence reviewed here suggests that there may be links between individuals’ spiritual self and coping.

In many instances, loss is not quite so dramatic but a cyclical process of loss, regain (or partial regain of loss) then further loss and so on. Such an uncertain process brings into focus the fragile nature and finiteness of the physical, cognitive and social dimensions of self. Collins (1998) identified the occupational therapists’ role as one of strengthening, or even initiating the connection between spirituality and outward behaviour. Egan and Delaat (1994) state that spirituality is ‘expressed through engagement in everyday life, that is, occupational performance in work, self-care, and leisure’ (p.100). They concluded that spirituality is not a component of self or being, but rather spirituality is the individual and therefore the true or core self and remains whole despite injury and illness. Furthermore, they provide a revised version of the model of occupational performance that places spirituality at the core and all other dimensions of self and influences on self (for example, the social environment, work, and leisure) radiating from this inner core. The implication is that when the spiritual self is robust then one has the means of coping with all circumstances that affect the individual.
Research specific to the experience of disability supports these views. Do Rozario (1997) states that ‘the person’s inner and interactional world of values, beliefs, attitudes and inspiration …helps to mediate, buffer and determine the process of successful coping’ (p.428). Do Rozario’s (1997) research identified a process of adaptation (or coping) from which she developed a five-step process of progression towards the attainment of health. This model attempts to encapsulate what she observed in people with disabilities when they experience dissolution and decay of their perceived selves. In essence, it is a spiritually based process whereby the individual chooses what she terms as either ‘death’ or ‘resurrection of self’. Attempts to retain or regain pre-disability cognitive, social or physical health without a central focus on growth of the essence of self (spirituality), Do Rozario claims are the path towards self-destruction. Similarly, Vash (1981) concludes that the adversity of disability is a positive opportunity for the development of the potential and truth of self.

Conclusion

The physical, cognitive and social dimensions of health have all been acknowledged as determinants of health (WHO 1980, 1997). However, a large body of research have supported the role of spirituality as a determinant of health, especially for people with disabilities. Such findings support theories of positive coping with change, spiritually focused self-theory and arguments for a more comprehensive definition of health and disability than that proposed by WHO. We argued in this paper that often people face adversity that leads to permanent loss of former physical, social or cognitive functioning. From a traditional WHO health perspective, such dysfunctional states are perceived and defined as ill health.
However, if spirituality is viewed as the core and essence of life, indeed the only permanent dimension of self, then health would be perceived and defined somewhat differently than just optimal functioning of the objective dimensions of self. Indeed, if overall health is dependent on the health of the spiritual dimension as we have argued here, then accessing this dimension ought to lead to positive effects on the health status of the cognitive, social and physical dimensions.

What does this mean for rehabilitation counselling? The magnitude of relationships, connections, life purpose and sustainable belief structure would be indicators of present spiritual acknowledgement and utilisation. The argument forwarded here is that all people have the inherent potential to access these resources. Therefore, a focus on moving perception away form a focus on loss of self to those aspects of self (for example, relationships with self, other and nature) and purpose in life will facilitate the individual to explore themselves and their place in the world. A spiritual focus does not rely on the health professional raising such issues directly (unless prompted by the client) but to provide a catalyst for the individual to begin their own journey of discovery if they so wish.

References


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Biographical Note

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