Institut Nazareth & Louis-Braille

Spirituality and Vision Rehabilitation

Information Monitoring Summary

Documentary research
Josée Duquette, Planning, Programming and Research Officer
Francine Baril, Documentation Technician

Prepared by
Josée Duquette, Planning, Programming and Research Officer

November 10th, 2011

Notice to readers

The information in the following pages is not intended to be an exhaustive review of the literature. The goal was to make directly relevant selected information more readily available. Accordingly, not all articles or documents dealing with the topic have been reviewed.

Spirituality and Vision Rehabilitation

Summary

Vision loss is a stressful event affecting many aspects of a person's life. An individual who is told their vision will not improve faces both physical and psychological adjustment [1]. Like any type of disability, visual impairment (VI) requires the person to have internal and external resources in order to adjust to their condition [25]. One of these internal resources is spirituality.

Spirituality gives a person a sense of transcending their immediate circumstances and an intrapersonal construction of purpose and meaning for their own life, with an inner sense of connection and confidence in their own internal resources [1; 3; 24; 25]. This allows for better adjustment by helping to fill the existential void that may arise after an event that is in itself senseless, as vision loss may be [3]. It can provide a framework for interpreting the impairment in a positive light, giving it meaning, and making it easier to accept, as well as for re-ordering priorities and adapting more successfully [24].

Spirituality blunts the negative effects of visual impairment and has a direct and positive effect on adjustment [1-3; 24; 25]. It is significantly associated with most dimensions of quality of life related to vision, the greatest impact being on the person's psychological health [7; 17; 24].

In a rehabilitation context, spirituality may take on a motivational role, encouraging the client to find a personal meaning for the experience. It can motivate the individual to achieve their rehabilitation objectives and make a connection between their beliefs, their sense of hope and their ability to transcend their immediate experience [3]. A study has shown that spirituality is positively associated with rehabilitation outcome in VI persons as regards training in daily activities [3].

Many research studies have concluded or recommended that spiritual and religious aspects should be taken into account during rehabilitation, among others for visual impairment [3; 4; 6; 9; 17; 21; 23-25]. This can be done at various levels and in different ways, from simply recognizing a person's spiritual beliefs to formally integrating spirituality into the clinical frame of reference. And in the interests of greater efficacy and effectiveness, gauging the spirituality of clients could prove helpful in identifying the extent of their internal resources for religious well-being, so that better support can be provided to those who need it most [17; 25].

Spirituality and Vision Rehabilitation

1. Spirituality vs. religion

Spirituality and religion are two distinct concepts but can be interrelated. While there is no consensus about the exact definition of spirituality, authors agree that it involves a personal sense of transcending immediate circumstances, an intrapersonal construction of purpose and meaning for one's own life, and an inner connection and confidence in one's own internal resources [1; 3; 24; 25]. Religion refers more to adherence to a system of ideological beliefs, rituals and practices associated with a social group, involving relations with a higher principle. Although religion may be an external manifestation of a person's internal spiritual life, spirituality can exist even when there is no religious affiliation; however, religion in itself is not a guarantee that a person's spirituality is well developed [1]. A few authors, cited by Brennan & MacMillan (2008), suggest that spirituality represents a personality trait whereas religion can be a manifestation of spirituality in a specific faith tradition.

Religious motivations may be of an extrinsic and/or intrinsic nature. According to Brennan & MacMillan (2008), individuals with a very pronounced extrinsic orientation may use religion as a means of achieving an end and focus on the instrumental and utilitarian values associated with being religious (e.g. maintaining a social position in the community). People with an intrinsic motivation are characterized more by an internalization of religious beliefs and the desire to live them to the fullest [3].

2. Adjusting to visual impairment

Vision loss is a stressful event affecting many aspects of life. For example, the person is no longer able to perform certain tasks as easily as before, which may mean they have to adopt new techniques or rely more on other people [25]. Getting involved in social situations or exploring a new environment may become difficult [25]. Feelings of depression, anxiety and inadequacy may develop, even when vision loss is gradual.

A person who finds out that their vision will not improve is faced with having to cope, both physically (functional limitations) and psychologically (redefining the future self) [1]. In this context, the term *coping* refers to all the cognitive and behavioural efforts the individual makes in order to adapt to a problematic situation and master, reduce or tolerate the internal and external demands that jeopardize or surpass their own resources. This is therefore a process whereby the person calls upon their own intrapersonal (cognitive and emotional), interpersonal and environmental resources, to deal with the stressful situation [10; 25].

According to the literature review by Yampolsky et al. (2008), although the initial vision loss is in itself a stressful event requiring an initial period of adjustment, additional adjustments may be required further down the road when other stressful situations arise [25]. These may be triggered by difficulties associated with progression of the disease, changes in the environment, accessibility issues, restricted employment opportunities, etc. A person with visual impairment (VI) may be also be at risk for stigmatization and social isolation due to the negative perceptions of others. VI in an

adult is thus a chronic condition that may lead to disability situations for the rest of their life; it may therefore require significant psychological readjustments.

According to Horowitz & Reinhardt (1998), one of the aspects of psychosocial adjustment to vision loss is accepting the impairment and adjusting the concept of self and personal goals to fit the limitations imposed by the deficit [13]. As with any type of impairment, VI requires the individual to have internal and external resources in order for them to adjust or adapt to their condition [25]. One such internal resource is spirituality.

3. Spirituality and adjustment to visual impairment

Spirituality inspires a sense of personal transcendence over circumstances and an intrapersonal construction of purpose and meaning for one's own life; it allows for better adjustment by counteracting the existential emptiness that can follow an event that at first seems senseless [3]. It may, for example, offer a framework for interpreting vision loss positively, giving it meaning and making it easier to accept, helping the person to reframe their priorities and adapt better [24]. As reported by Chouinard (2009), it is not the event itself that determines the degree of contentment or misery but the way we interpret what we feel within ourselves.

Many studies show that spirituality plays a buffer role when visual function is lost, exerting a direct effect on adjustment [1-3; 24; 25]. "Buffer" is an apt term because spirituality has a *moderating* effect, for example by blunting the negative impact of visual impairment on quality of life. An individual may tend to develop a spiritual/religious type of adjustment particularly when they are confronted with serious, threatening or harmful situations involving a high degree of stress [1]. This type of adjustment can also *mediate* the relationship between the event and personal growth, by having a restorative effect and facilitating adjustment [1].

Spirituality is highly predictive of psychosocial development (psychosocial development evaluated with the Inventory of Psychosocial Balance, which measures the eight stages of psychosocial development described by Erikson: Trust, Autonomy, Initiative, Industry, Identity, Intimacy, Generativity and Integrity). This is clear from the study by Brennan (2002, 2004), conducted among 195 elderly people who had recently sustained vision loss and had been discharged from their rehabilitation program. Spirituality, measured with the Spirituality Assessment Scale, turned out to be a factor that was strongly predictive of psychosocial development. Its impact could be attributed to its direct and indirect effects and its role as a buffer in negative life experiences [1]. The buffer effect was more marked in individuals who had already gone through some adverse experiences, i.e. events beyond their control or that had a negative impact on their life [1]. Spirituality also predicted better adjustment, even when the religion variable was considered [2]. Note that spirituality was correlated with intrinsic religion but not with extrinsic religion, which shows that spirituality and religion are different from each other [3]. Age did not influence the effects of spirituality on adjustment [2].

A Chinese study also concluded that spirituality can play a major role in adaptation to visual impairment among elderly people (n=167) [24]. Spirituality was significantly

associated with most of the vision-related dimensions of quality of life, with the greatest impact being felt on psychological health.

In the study by Yampolsky et al. (2008), people with higher levels of religious well-being also adopted more adaptive behaviours (n=85 individuals aged 23 to 97 with VI). However, in this instance the existential dimension of spirituality was only slightly associated with adaptive behaviours. On the other hand, the Spiritual Well-Being Scale used in this research did not measure transcendence, unlike the Spirituality Assessment Scale used by Brennan [25].

Changes of a spiritual nature may occur after the onset of an incapacitating disability, as shown by Bickenbach et al. (2000). They interviewed 16 persons, each of whom either had a traumatic brain injury or spinal cord injury, who had been discharged from rehabilitation within the last 2 years. The subjects described many changes on the spiritual level, such as developing a sense of transformation of their perception of their own independence; the feeling of having a purpose in life, which they did not have previously; a new understanding of trust in other people, particularly in situations of dependency; a greater appreciation of and closeness to other people and the world [20]. Much of the testimony by clients of the Centre de réadaptation Estrie was in the same vein [6].

4. Spirituality and rehabilitation

Many studies have examined the impact of spirituality and/or religion on physical rehabilitation. A review of the literature emphasized the importance of spirituality in elderly people undergoing rehabilitation interventions, and its positive effects on their quality of life, life satisfaction, health, well-being and adjustment [7]. Moreover, Kim et al. (2000) showed that spiritual well-being, emotional well-being and life satisfaction are all interrelated throughout rehabilitation and after discharge (evaluation 3 months post discharge).

The literature review by Brennan & MacMillan (2008) suggests that in a rehabilitation context, spirituality takes on a motivational character as the person attempts to find personal meaning in what they are going through. Spirituality can motivate the person to achieve their rehabilitation goals and forge a connection between their beliefs, their sense of hope and their ability to transcend what is happening to them, particularly when they face a problem. Cultivating and maintaining a feeling of hope is also paramount in promoting successful rehabilitation. By inspiring positive expectations about the future, hope can counterbalance the feelings of depression that may otherwise exacerbate functional incapacities and undermine the person’s receptiveness to rehabilitation. In a study by Jackson et al. (1998) involving 63 veterans admitted to a vision rehabilitation program, being more hopeful was associated with a more positive perception of the level of functional skills and a more social and proactive style of adjustment. A greater sense of hope can produce more optimism, more effective problem-solving strategies and greater determination, and enhance the capacity to achieve personal goals [16].

In the study by Brennan and MacMillan (2008), spirituality and intrinsic and extrinsic religion were positively associated with the rehabilitation outcomes of VI individuals as

regards training in daily activities (e.g. preparing meals, housework, financial management, taking medication). On the other hand, intrinsic religion was, to a surprising and unexpected extent, negatively associated with the achievement of low vision rehabilitation goals (prescription and dispensing of optical aids). The hypothesis is that people who hope their visual impairment will be cured or eventually improve may not be inclined to comply with low vision services. They are perhaps imbued with extreme hope that interferes with their acceptance of the incurable nature of their functional vision problems.

5. Integrating spirituality into a rehabilitation setting

A lot of research has concluded or recommended that spiritual and religious aspects should be taken into account during rehabilitation, among others for visually impaired persons [3; 17; 21; 24; 25]. These aspects can be integrated at various levels, in a variety of ways.

Fundamentally, this involves recognizing the client's spiritual and religious values when they surface during interventions. However, clinicians should be aware that there is a very fine line between validating an individual's spiritual beliefs and introducing their own beliefs into the situation [3]. Something else they should remember is that not all clients need or want spiritual support. And in certain cases, spiritual support is simply a matter of being available and being there for someone when they face new problems and challenges [3].

The spiritual dimension may also be incorporated via rehabilitation activities that have meaning and purpose for the client [3; 23]. For example, a deeply religious person may be more motivated to learn to use vision aids if this will help them to read their religious material. Another one may want to learn to move about independently if this means they can attend mass or visit their preferred place of worship. Moreover, spirituality underlies the whole frame of reference for Canadian occupational therapists, in the *Canadian Model of Occupational Performance*. It is central to the occupational performance of individuals, through occupations that give their daily lives meaning and purpose [4]. And it is this meaning attributed by the culture and the individual themselves that has to be considered. Spirituality is manifested through the person's various types of occupations, whether at the personal care level or through productive or leisure activities. However, when a personal crisis occurs, a long-term disability for example, individuals may feel their life no longer has any meaning, and this may affect their spirituality. At this juncture it is key for them to engage in activities that are both meaningful and functional, to help them make the transition between their past and future occupational performance [23].

Certain institutions, like the Centre de réadaptation (CR) Estrie, have decided to integrate spirituality directly in their clinical frame of reference [8]. For its clinicians, the success of rehabilitation is closely linked to the meaning that the client can assign to this episode in their personal journey. Their challenge is to help the person to discover the *positive by-products* of their condition through new ways of expressing their lifestyle. They help him to transform day-to-day challenges into opportunities for development and growth, find meaning in their new roles and occupations, and

understand that they still have their place in society and life is still worth living. With this in mind, they have developed an intervention tool called the *Fil d'Ariane*. The name refers to the thread used to find a way through a labyrinth in Greek mythology. The tool comprises a semi-guided interview framework used to encourage the client to talk about themselves with various themes as their starting point (e.g. previous challenges they have faced; transformative experiences; aspirations; connections linking them to other people, to nature, to a supreme being). This narration gives him a chance to become aware of potential links between their past, their present and what could be their future after rehabilitation, and to learn about and identify the personal, spiritual and external resources that have helped them through other difficult times in the past. A deliberately positive, hopeful narrative is then drafted by the rehabilitation professional, highlighting the common thread that has guided the client in their past choices and experiences, and all the factors favourable to their rehabilitation and growth. Once this narrative has been validated, it is presented to the family and the clinicians, who then try to give their therapeutic interventions the same perspective so as to pursue this common thread and render them more meaningful. Examples of narratives are found in the article by Chouinard (2009-10) and the testimony of a CR Estrie client [22].

Certain rehabilitation institutions have set up a meditation and prayer space for clients. The CR Estrie is one such establishment, with its *Inukshuk* room [6]. Devoid of any religious reference and with the idea of a crossing as its theme, this room is at the disposal of people who need a place where they can take time out, meditate and reflect on their progress [5]. The layout and decor are designed to facilitate an inner journey, relaxation and reflection. Clients and the parents of children undergoing rehabilitation have free access to the room, and certain clinicians can reserve it for interviews and group therapy. Personnel and volunteers also make use of this space for various purposes.

Pastoral services are also offered at many Québec physical rehabilitation hospitals [12; 14; 15]. Their main role is to provide support and accompaniment for spiritual and religious life, for rehabilitation clients and their families [11; 14]. Durand (1985) points out that a person facing a disabling impairment following an accident or illness will go through an existential crisis that usually triggers an upheaval in their value system; life, love, money, space and time no longer have the same meaning as before. Pastoral support seeks to help the person tap into the spiritual resources that will help them to rebuild their value scale, carry on, rediscover and enjoy life, and find and acknowledge that life still has beauty and richness to offer. In addition to organizing eucharistic celebrations, certain pastoral services also have pastoral volunteers who visit hospitalized persons and give them guidance, a sympathetic ear and encouragement, to help them in their search for meaning as they struggle to cope with their loss. The testimony of rehabilitation clients reported by Durand (1985) shows that religion or pastoral services enabled them to better accept their new condition and adapt to it. For certain individuals, having a priest or volunteer available to listen to them was very comforting and helped to rebuild their confidence. For others, the pastoral service represented a meeting place where they could go to talk things over with other people with impairment, somewhere where they could find the encouragement, openness and mutual help that was so important to them.

Yampolsky et al. (2008) believe that for efficacy and effectiveness, assessing spirituality could be helpful in identifying the degree of internal resources for religious well-being in rehabilitation clients. According to these authors, individuals displaying a high degree of religious well-being could be encouraged to continue deriving comfort from their relationship with a higher power; these persons would probably not require exhaustive psychological interventions. However, those with a low level of religious well-being and no belief in any form of higher power could benefit more from therapeutic support encouraging them to use other internal resources, such as cognitive restructuring, which can lead to more adaptive adjustment behaviours [25]. Research is still needed in order for us to distinguish behaviours that are maladaptive from those which are not [17]. The scientific evidence regarding the positive effects of spirituality on rehabilitation outcomes could serve as a basis for developing interventions to support clients' spirituality and spiritual well-being [17; 25]. It may also be helpful to implement a system for evaluating spiritual well-being within rehabilitation departments [3; 17; 24; 25]. Various measuring tools have been developed for this purpose, like those already mentioned, in addition to other qualitative methods using a narrative mode to tackle the spiritual dimension [18; 19].

Finally, it is important to mention that integrating the spiritual dimension into rehabilitation requires therapeutic competencies that some clinicians may not have; they should take the time to think about this issue and their own spirituality, and be aware that they may need tools and guidance [9].

6. Conclusion

There is scientific proof that spirituality has a major impact on a person's adjustment to visual impairment and their quality of life. In a rehabilitation context, spirituality assumes a motivational role, helping the person to rediscover meaning and purpose in what they are going through, as well as an inner connection with their own resources. Evaluating the client’s spiritual dimension at the beginning and during the course of rehabilitation can be useful and fulfill various goals: assessing the person's desire for, and receptiveness to, spiritual interventions; identifying persons in need of spiritual support; determining the risk of eventual decline in spiritual well-being and offering the appropriate support; helping clinicians to understand and recognize the client’s spiritual dimension and integrating this into rehabilitation interventions. However, research is still needed to explore how clinicians can evaluate spiritual status, identify individuals at risk and intervene to boost spiritual well-being and provide support during the adjustment process. Further studies could also give us more insight into the impact of spirituality-related interventions in the rehabilitation context; it will then be possible to develop interventions that are more accurately targeted and appropriate.

References

1. Brennan, M. (2002). Spirituality and psychosocial development in middle-age and older adults with vision loss. *Journal of Adult Development, 9*(1), 31-46.
2. Brennan, M. (2004). Spirituality and religiousness predict adaptation to vision loss in middle-aged and older adults. *International Journal for the Psychology of Religion, 14*(3), 193 - 214
3. Brennan, M., & MacMillan, T. (2008). Spirituality, religiousness, and the achievement of vision rehabilitation goals among middle-age and older adults. *Journal of Religion, Spirituality & Aging, 20*(4), 267-287
4. Carignan, M. *Modèle canadien du rendement occupationnel.* Retrieved on June 9th 2011, from http://reseauconceptuel.umontreal.ca/rid=1285037871765_11284169_6260/MCRO_th%C3%A9orie.cmap
5. Centre de réadaptation Estrie. *Spiritualité* (video). Retrieved on June 9th 2011, from http://www.centredereadaptationestrie.org/spip.php?rubrique329&fsize=14&lang=fr and from http://www.centredereadaptationestrie.org/spip.php?rubrique164&fsize=14&lang=fr
6. Centre de réadaptation Estrie. *Spiritualité.* Retrieved on July 26th 2010, from http://www.centredereadaptationestrie.org/spip.php?rubrique329&fsize=10&lang=fr
7. Chally, P. S., & Carlson, J. M. (2004). Spirituality, rehabilitation, and aging: a literature review. *Archives of Physical Medicine and Rehabilitation, 85*(Supplement 3), 60-65.
8. Chouinard, J. (2009-10). Résilience, spiritualité et réadaptation. *Frontières, 22*(1-2), 89-92.
9. Chouinard, J. (octobre 2009). *Inukshuk. La quête du sens.* Communication presented at 8th congrès québécois de réadaptation, St-Hyacinthe.
10. *Dictionnaire de psychologie*. Retrieved on July 28th 2010, from http://www.dicopsy.com/coping.htm
11. Durand, R. (1985). La pastorale. Une réponse à un besoin fondamental de la personne. *Extrait de Propos de réadaptation, vol. 6, no 2, décembre 1985, p. 2-7* Service international scientifique de réadaptation sur l'autoroute de l'information (SISRAI). Retrieved on June 14th 2011, from http://www.med.univ-rennes1.fr/sisrai/art/pastor.html
12. Hopital juif de réadaptation. *Service religieux.* Retrieved on June 14th 2011, from http://www.hjr-jrh.qc.ca/servicesaux_services-religieux.php
13. Horowitz, A., & Reinhardt, J. P. (1998). Development of the adaptation to age-related vision loss scale. *Journal of Visual Impairment & Blindness, 92*, 30-41.
14. Institut de réadaptation en déficience physique de Québec. *Pastorale.* Retrieved on July 26th 2010, from http://www.irdpq.qc.ca/services_clientele/pastorale.html
15. Institut de réadaptation Gingras-Lindsay-de-Montréal. *Commodités.* Retrieved on June 14th 2011, from http://www.irglm.qc.ca/fr/services-clientele/commodites.php
16. Jackson, W. T., Taylor, R. E., Palmatier, A. D., Elliott, T. R., & Elliott, J. L. (1998). Negotiating the reality of visual impairment: hope, coping, and functional ability. *Journal of Clinical Psychology in Medical Settings, 05*, 173-185.

17. Kim, J., Heinemann, A. W., Bode, R. K., Sliwa, J., & King, R. B. (2000). Spirituality, quality of life, and functional recovery after medical rehabilitation. *Rehabilitation Psychology, 45*(4), 365-385.

18. Kirsh, B. (1996). A narrative approach to addressing spirituality in occupational therapy: Exploring personal meaning and purpose. *Canadian Journal of Occupational Therapy, 63*, 55-61.

19. Larson, E. A., & Fanchiang, S. C. (1996). Life history and narrative research: Generating a humanistic knowledge base for occupational therapy. *American Journal of Occupational Therapy*(50), 247-250.

20. McColl, M. A., Bickenbach, J., Johnston, J., Nishihama, S., Schumaker, M., Smith, K., et coll. (2000). Changes in spiritual beliefs after traumatic disability. *Archives of Physical Medicine and Rehabilitation, 81*(6), 817-823.

21. Pitts, J. (2008). Spirituality in the physical therapy curriculum: effects on the older adult. *Topics in Geriatric Rehabilitation, 24*(4), 281 - 294.

22. Valiquette, J. M. (2009). Le projet du fil d'Ariane. *L'Actif. Journal de l'Association des accidentés cérébro-vasculaires et traumatisés crâniens de l'Estrie, Printemps-été 2009*.

23. Vrkljan, B. H. *Le rôle de la spiritualité dans la pratique de l'ergothérapie.* Association canadienne des ergothérapeutes. Retrieved on June 9th 2011, from http://www.caot.ca/otnow/march2000-fr/march2000-fr-pitp.cfm

24. Wang, C., Chan, C., Ng, S., & Ho, A. (2008). The impact of spirituality on health-related quality of life among Chinese older adults with vision impairment. *Aging & Mental Health, 12*(2), 267-275.

25. Yampolsky, M. A., Wittich, W., Webb, G., & Overbury, O. (2008). The role of spirituality in coping with visual impairment. *Journal of Visual Impairment & Blindness, 102*(1), 28-39.

