



## **Hope Beyond the Hurt: Spirituality and the Dual Diagnosis of Acquired Brain Injury and Psychiatric Disorder**

**Rhonda Kane**

Waterloo Lutheran Seminary, Wilfrid Laurier University, Waterloo, Canada

### **Abstract**

This qualitative research study answers the question of how people with the dual diagnosis of acquired brain injury and psychiatric disorder access, develop, and use their spirituality. A phenomenological approach was chosen to capture a detailed understanding of the participants' perceptions of spirituality in the context of their diagnosis and everyday life. Data was collected from semi-structured interviews with nine adult survivors of acquired brain injury with a psychiatric diagnosis. The main findings of the study were as follows: (1) the importance of the synthesis of opposite poles of experience: The realization of the provisionality of life, profound loss and grief, intergenerational impact, disenfranchisement, and despair mark the trauma of the event. Simultaneous awareness of the spiritual dimension (an encounter with God) provides a paradigm shift in core values. (2) Born out of pain, relatedness and connectedness become the context for spiritual development and transformation. These results demonstrate the importance of spirituality in the recovery and rehabilitation of individual with acquired brain injury and psychiatric disorder.

### **Introduction**

Dual diagnosis, as it is used in this article, refers to the co-existence of both an Acquired Brain Injury (ABI), and a clinically diagnosed mental disorder. An Acquired Brain Injury, often referred to as Traumatic Brain Injury (TBI), is brain damage that is sustained at any point after birth. It can be caused by a physical trauma, such as a collision or fall, or by certain medical conditions and disease processes. It is one of the most common causes of disability and death, with young adult males, ages 15-35, being at greatest risk. Concurrent psychiatric problems, addictions, and behavioural issues can complicate the rehabilitation process. With dual diagnosis, the psychiatric disorder may have pre-dated or post-dated the ABI. Some are the result of chemical changes that occur progressively in the brain after the injury is sustained. These individuals endure numerous cognitive, psychological, emotional, and physical changes. Recovery from a severe brain injury often involves prolonged or life-long treatment and rehabilitation.

The experience of brain injury tears at the very fabric of one's identity and perception of what it means to be human. Distorted images of a life that once was, and can no longer be, torment and challenge those affected. Changes in body image, personality and behaviour, memory, attention, energy levels, motor control, social and communicative ability contribute to a sense of despair and an all too common desire to end one's life. The impact of such an event is often felt across three generations, including the parents, the affected person, and his or her children. It dramatically and permanently alters the family system.

### **Review of the Literature**

A comprehensive review of the literature was undertaken to identify the most pertinent issues as they relate to Acquired Brain Injury (ABI) with concurrent psychiatric disorder and spirituality. Systematic computer and manual library searches were used to ensure an adequate coverage of relevant literature. A total of thirty articles and five books were located and reviewed prior to designing this study.

Six of the articles reviewed, specifically addressed spirituality as it pertained to those with an Acquired Brain Injury. Although the term "dual diagnosis" was not specifically used, the co-existence of a psychiatric disorder, such as clinical depression, was acknowledged and discussed. Fourteen articles addressed spiritual and religious issues in psychotherapy, with ABI referenced in several. Of these fourteen articles, three relevant themes emerged. These were the soul and soul healing as a compelling focus of therapy, the importance of a social constructivist approach, and ethical considerations for practice. Ethical ways of discussing spiritual concepts and issues in therapy, the challenges involved, and recommendations on the inclusion of spirituality as a subject in the education and training of mental health professionals were sub-themes. Four other articles focused on general coping, hope and resilience, and were selected because they specifically discussed spiritual health and the value of having a transcendent belief system. These examined spirituality as a resource. One article addressed women's spirituality as its main subject.

Those articles pertaining directly to ABI and spirituality discussed the findings and results of qualitative research studies from a number of traditions including case studies, phenomenological inquiries and focus groups. These were of particular importance because they provided valuable insights on the spiritual dimension during the recovery and rehabilitation process. Descriptions of those concepts and relationships that reflected the lived experience of these individuals were explored.

There were many different definitions of spirituality referenced throughout the literature. Family therapists and educators, Thomas St. James O'Connor and Elizabeth Meakes (2002,62), indicate that these definitions focus on three areas: transcendence, meaning making, and core values. These three inter-related concepts emerged as central to all discussions on spirituality in this review as well. Religion, marked by an affiliation or identification with an organized faith group, was included as one possible component of spirituality.

With respect to brain injured individuals, transcendence was regarded in two ways. First in connection with what was considered by the individual to be a higher power, or “God.” The second was as a function of “rising above” one’s circumstances through either a connection with the transcendent or through the process of “meaning making.” Being able to transcend one’s circumstances through a greater appreciation of self, others and God, is reported to provide meaning and the impetus to carry on in the face of otherwise overwhelming challenges (McCull et al, 2000,560). Several authors report how individuals with ABI “awaken to” the transcendent or spiritual dimension of life through the event of sustaining a brain injury itself. The often reported “near death experience” (NDE) is described by Harris as a marker event (in Tasker, 2003, 345) and “watershed in a person’s life which makes life after the injury, a more tangible whole” (McCull, 2000, 568). It is typically associated with an awakening of spirituality in the face of increased vulnerability, a deepened awareness, and a changed perspective (Tasker, 2003,338). “The individual with ABI has almost certainly, at some point walked consciously with death. When we become conscious of our involvement with death as a personal reality, the world is seen through sharpened lenses, the quest for meaning in new light” (Tasker, 2003,238). According to Adams, the typical NDE is marked by a peaceful state of separation from one’s body, transition through a dark tunnel, and a transcendent stage of entering the light where one meets loved ones and spiritual leaders. NDE experiences are “significant not so much for their immediate content, but for their enduring impact on the individual and family, and the meanings generated around them” (Adams, 1996, 82).

People with ABI and dual diagnosis describe the experience of a spiritual dimension uniformly as a call to depth. This call is probably best described by Austrian psychiatrist Victor Frankl, as the “quest for meaning.” While interned in a Nazi concentration camp during World War II, Frankl observed that many prisoners died when undergoing less hardship and suffering than those who did not. Survivors tended to be those who envisioned a future for themselves despite their present suffering. They believed that there was a meaning and purpose for their life and therefore could not ultimately surrender to despair. These individuals, according to Frankl (1959), knew *how* to suffer. Similarly, the growth or development of spirituality in people with ABI is cultivated in suffering and is viewed in the literature as involving many things. This would include (1) the attribution of both meaning and a positive appraisal to one’s life and life experiences, (2) the synthesis of two opposite poles of experience, such as hope and despair, suffering and grace, and (3), the integration of the ABI into the relational context of their lives.

The attribution of meaning and positive appraisal are two different but related processes (Adams,1996,75), each paramount to the development of genuine hope, one of the prime ingredients of a healthy self (Beavers and Kaslow, 1981,20). Positive appraisal, a key concept of cognitive behaviour therapies, refers to the ability to reframe trauma positively and more importantly, the ability to perceive that one’s resources are great enough to master the challenges that one is faced with (Adams, 1996, 75). The use of metaphors is particularly useful here. Peck (1993, 142) quotes the husband of a woman with ABI whose image is that of *looking up and down the ladder*, where “it’s too scary to look down or back at where we have been or how far we have come.” The only option is to “go on and look up.” The mutual decision to press on, even in the face of adversity,

reflects the couple's belief that they have the ability to overcome challenges that lay ahead. Tillich (1993) identifies several useful metaphors such as seeing *God as a stream* in which we are all immersed (in Prest and Keller, 1993,145). We can swim against it, represented by times of denial and struggle, or we can turn and allow the stream to carry us. Spiritual meaning then, can be located or discovered in metaphorical references. It is also talked about more directly, as part of the context of God's larger plan, as specifically purposed by God to benefit the self or others either relationally or supportively. (Adams, 1996,82; McColl, 2000,561; Uomoto, 1995,345). Appraising an experience positively, however, does not necessarily require that meaning be generated or discovered. When the sufferer sees the event as strictly senseless, meaning is often found in a sense of responsibility to loved ones (Adams, 1996,76).

That spirituality is cultivated, as well, in the tension that exists between two seemingly opposite and contradictory poles of experience is expressed by a number of authors (Adams, 1996, 77; Tasker, 2003,346; Uomoto, 1995,344). For example, the holding together of hope and despair, acceptance and non-acceptance, loss and growth, apostasy and faith, is a Jungian concept which advocates for both/and as opposed to either/or. White and Epston (1990,27) capture this sentiment in his description of the multi-storied experience which allows for the expression and telling of multiple levels of experience within the person's narrative. The synthesis of such opposites is often evidenced in an enormous growth and awakening of compassion and empathy for others, and an increasing capacity for connectedness, harmony and peacefulness. Adams (1996,81) observes that young males with ABI become noticeably more self-reflective and compassionate towards others. This reflects a transformation of core values.

Finally, spirituality is seen to develop and seek expression during the process of integrating the ABI into the relational context of one's life. McColl and colleagues (2000,559) discovered that people with traumatic-onset disability express spiritual issues in the context of three types of relationships, the intrapersonal (self), interpersonal (with others), and transpersonal (with God or a "higher power"). These three relationships are characterized by themes of awareness, closeness, trust, vulnerability and purpose. They found that individuals with brain injuries seemed to place greater emphasis on the importance of their families and the need for trust in light of their memory deficits (McColl et al, 2000,561). These researchers, found as well a remarkable ability in these individuals to grapple with and express complex spiritual concepts, in spite of their deficits (822). With this the authors found support for the defining of spirituality as the "propensity to find meaning in experience through one's relationship with the self, others, and a supreme power" (555).

Concerning spiritual and religious issues in therapy, there is now a significant body of knowledge and literature that addresses the spiritual dimension. The three main themes that emerge are described next.

### **The soul and soul healing as the necessary focus of therapy**

Bergin (1980) cites disillusionment with science as the dominant source of truth as the catalyst of a broad-based movement to bring the spiritual more fully back into the realm

of psychology (in Shanfranske and Gorsuch, 1984,238). According to Uomoto (1995), the concept of soul care provides a context within which to understand suffering and dissipate some of the meaninglessness that comes with human finitude. Uomoto uses the theology of Nouwen to inform the development of soul care providers and the provision of psychotherapy to the sufferer (345). For many like him who work in rehabilitation psychology, all converges on the concept of the soul. For the sufferer of ABI, this approach is a meaningful response to the *call to depth* reported in their narratives. The resultant communion with one's soul may very well represent protection against a flight into madness as the best defence against emotional death. Ross (1995, 461) suggests that there are both vertical and horizontal elements inherent in this view. The vertical encompasses the transcendent, and the horizontal, the working out of the vertical in the individual's approach to life and relationships. Elkins (1995, 80) believes that a theory of psychology from the perspective of the soul would legitimize other approaches to knowledge rather than just the scientific empirical, which is not the only path to truth. He focuses on the soul as the central organizing construct for psychotherapy with the psychotherapist positioned as the servant attendant work and believed that the recovery of the soul was essential for both the individual and western society. He describes therapy as a safe container for soul making and healing and the therapeutic relationship as the "royal road to the soul" (Buber, 1970).

*Social constructivism* as a tool for thinking and an approach in therapy whose sentiments are echoed in the needs expressed by those with ABI. Useful because there is such a significant need to empathize and understand their position, it provides a lens by which meanings other than one's own can have validity in their given context. This is useful from an ethical perspective. Holding a *not knowing* perspective with clients gives them room to discuss meanings that are most significant to them (Thayne, 1998,19). We are, however cautioned to avoid ethical relativism and may do so, where it is felt useful, by naming our own motivations and ideas, making it explicit from our own subjective thinking and by having integrity with our own values (Thayne, 1998,22).

*Ethical considerations*, paramount to practice, emerge from an integrated approach to spirituality in therapy. The key issues, according to Haug (1998,183) include i) *Autonomy and the power dimension in respecting client's rights to self-determination*. This involves sensitively opening space in therapy for the discussion of spiritual beliefs and values, addressing power issues in families where they occur, being mindful of spiritual developmental needs when individuals and couples who determine to re-connect with their original faith traditions, and assessing when it is in the client's best interest to refer to clergy (Haug, 1998,187; Thayne, 1998,20; Uomoto, 1982,352; Ross, 1995,458). ii) *Beneficence and Nonmaleficence: promoting clients' well being and protecting them from harm*. This would include a collaborative approach with the larger religious/spiritual community, sensitivity to the client's spiritual language and terminology, an awareness of the potential for boundary violations for religiously engaged therapists and for those whose personal beliefs make it difficult for them to treat persons struggling with those same beliefs. Care must be given not to persuade the client towards therapist preferred attitudes and beliefs (Haug, 1998,188; Woody and Woody, 2001,157-158). iii) *Justice and fidelity or caring without discrimination*, in consideration of multicultural plurality

and diversity. The perception of spirituality in therapy and spiritual beliefs and values are relevant here. The essential relevant factor is the therapist's spiritual self-awareness and their personal stance towards it (Bergin, 1991,396; Shanfranske and Gorsuch, 1984,238; Haug, 1998,190; Frame, 2000,73). To facilitate spiritual literacy and competence, the intentional inclusion of spiritual issues in training and supervision is advocated in a number of therapy models (Aponte, 1994; Becvar, 1997; Prest and Keller, 1993,138). Hickson and Phelps (1998,44) propose a therapy model that is sensitive to the unique aspects of women's spiritual journeys and involves relevant themes of exploration, interdependence, balance, transformation, and wholeness in the context of a "relational" dialogue between practitioner and client. The omission of specific training in spirituality from the professional education of the therapist increases the potential for problems and complications (Benningfield, 1998,41).

For the person with the dual diagnosis of ABI and psychiatric disorder the process of accessing and developing their spirituality becomes a conscious project with conscious workings. Fitzgerald (1997, 409) eloquently draws us to the conclusion of this effort. She describes a people who remain outside of the norm, largely unaccepted and different and yet strangely enough they represent a threat to the security of the able-bodied perceptions of self, which are embedded in a culture of perfection and control. They are readily subjugated by society because they no longer operate within the dominant communicative discourse and behavioural style and yet they challenge us with their ability to enter into the sacred place which draws us deeper and deeper, away from the comfort of busy-ness toward the still place of reflection where they find their humanity, their soul.

### **Purpose and Rationale of the Study**

The purpose of this study was to examine how people with acquired brain injury and psychiatric disorder experience spirituality. The main research question is *how do people with the dual diagnosis of acquired brain injury and psychiatric disorder access, develop, and use their spirituality?* Elkin's definition of spirituality is utilized in this context as a "way of being and experiencing that comes about through an awareness of a transcendent dimension that is characterized by certain identifiable values in regard to self, other, nature, life and whatever one considers to be ultimate (Elkins,1990, 4). Knowledge of spirituality as it pertains to individuals with this diagnosis can inform the way that health care professionals address the spiritual dimension in therapy and can increase their confidence level in dealing with spiritual issues, to the benefit of clients and significant others.

### **Description of the Sample and Access to the Sample Field**

Nine participants were involved in the study, eight men and one woman. All were in-patients of a large psychiatric facility attached to a teaching hospital in Southern Ontario. Admission criteria required that patients present with both an acquired brain injury and a psychiatric disorder, such as depression. The mean time from the date of injury to the time of this investigation is 23 years (range, 1981 to 2004), and their mean age is 42 years (28 to 56). Brain injuries and psychiatric disorders ranged in severity and participants were selected, based on their developmental and cognitive capacities to

understand and describe their own personal experience. The randomness of the sample was of less importance since the purpose of the study was to procure an accurate understanding of meaning rather than to report generalized findings. All participants were Caucasian and middle class. Most were university educated and previously engaged in a professional career. Some were trades people. All received a Christian orientation in their families of origin. The limitation on diversity of faith group is incidental. Two identified themselves as agnostic, one Anglican, five Roman Catholic, and one as First Nations spirituality. Although gender imbalance in the sample is not ideal it does reflect the naturally higher prevalence of ABI in young adult males. Prospective subjects were approached initially by the unit social worker who was well known to them. A descriptive letter of invitation, detailing the project, and confidentiality procedures was shared with them and a signed, informed consent to their participation was secured. The principle investigator then arranged to meet with and interview each person through their respective prime workers. The informed consent was reviewed prior to each interview to ensure a clear understanding and willingness on behalf of each participant to engage in the process. Participants were allowed the option of discontinuing and withdrawing their involvement and contributions at any point in the project. All procedures received approval for ethical conduct for research involving humans from the hospital Research Ethics Board.

The principle investigator is a female pastoral counsellor, assigned to the unit to provide multi-faith spiritual care to both clients and staff. She is uniquely positioned to study this phenomenon and to meet the on-going spiritual needs of project participants. The researcher has specialized training in the area of spiritual care, has an undergraduate degree in Health Sciences, is a candidate for a Master of Theological Studies in Pastoral Care and Counselling, and practices privately as a pastoral counsellor.

### **Methodology**

This is a qualitative research design. A phenomenological approach was selected to get a deep understanding of the participant's perspective. Primary data was collected through the use of semi-structured interviews, based on the questions outlined in Table 1. These questions served to guide the interviewer in eliciting the interviewees' experience of spirituality. They were designed to be open-ended, flexible and broad to allow for a full range of expressed responses. The interviewer refined and focused the questions as each interview progressed and according to the needs of each participant. The interviews took place on the unit where the participants were admitted. Each interview was audio taped.

**Table 1 Interview questions**

1. Did acquiring a brain injury cause you to view your life differently? Describe.
2. How might the timing of this event (ABI) be significant to you?
3. What is different about you now? Are there differences in how you relate to others, how you relate to yourself, and how you relate to God?
4. In what way does this experience add meaning to your life?
5. What do you think your soul might be communicating to you through this situation?
6. What opportunity for learning does this situation provide for you?
7. How do you think your situation might facilitate your growth?
8. Which resources that you possess have been stimulated by this situation?
9. How might you use this situation to benefit yourself and others?
10. What has helped or hurt your spiritual development?

### **Data Analysis and Results**

The primary investigator transcribed the audio taped interviews. These transcriptions constituted the data. Notes taken during the interview and field notes taken over nine months were added to the transcriptions to enrich and refine meanings and represent data triangulation (Sprenkle and Moon, 1996, 95). Interviewees were asked to read and edit their responses. The interviewer reviewed the responses with each interviewee and participated in the co-construction of meaning. Interviewees offered letters, diaries and photographs as part of the data as well. “Phenomenological methods of data collection, allow participants to define phenomenon for themselves and to describe the conditions, values and attitudes they believe are relevant to that definition for their own lives” (Sprenkle and Moon, 1996, 96). This approach lends itself well to the study of this particular population, as they often need to rely upon diverse forms of expression. Data collection continued until theoretical saturation was reached. The data underwent several levels of analysis that identified similarities and differences, categories, themes and patterns that were then compared, contrasted and finally classified and categorized in answer to the research question proposed. Table 2, illustrates a sample of the data analyzed at level 1. Immersion in the data, by the researcher, is characteristic of the phenomenological approach. The goal of “objectivity” is substituted for the goal of “connection” in order to enable accurate and meaningful communication of the experience of each of the participants.

Eight of nine participants (88.9%) emphasized the ways in which spirituality contributed positively to their recovery and rehabilitation process. These individuals used spiritual language and/or “God-talk” in their narratives, and metaphors to capture the essence of what some specifically referred to as their spiritual journeys. These storied expressions of their spirituality often contained themes of struggle, faith-based perseverance, meaningful connectedness and relatedness, a transformation of core beliefs, and an emphasis on spiritual values that promote ethical (equitable, fair, just) relationships.



**Table 2, Sample of data display (level 1 analysis)**

<b>Interview Question:</b>	<b>Patient A</b>	<b>Patient B</b>	<b>Patient C</b>	<b>Analysis</b>
<p>In which ways does this experience of having a brain injury add meaning to your life?</p>	<p>We are obviously here for our loved ones, for the relationships that we develop with them, to help them and to try to create something better than what went before.</p> <p>I am far more empathetic, tolerant, trusting, and compassionate than before. People are closer to my heart now. This event taught me to cherish others.</p> <p>I know now that there is something bigger in control than me. God? I am now more open to possibilities.</p>	<p>My spirituality (developed in the context of ABI) has given me an over-all sense of love and loving compassion, the ability to want to help people in their struggles, to help them to get along. I have been saved/spared for this purpose.</p> <p>I have gone from feeling judged, punished and abandoned by God to believing that life is about free will and choice. With this comes great responsibility for myself and for others.</p>	<p>It has taken away meaning. I have lost everything! My life has contracted instead of expanded. I don't know what goals to set for my relationships anymore, but I would like to. That would make a difference.</p> <p>I am more compassionate with others.</p> <p>I choose not to believe in God. He is just a construct.</p>	<p><b>Similarities:</b></p> <p>Relationships are meaningful</p> <p>Purpose and desire is to help others</p> <p>Awareness of the divine</p> <p>Relationship with the divine</p> <p>Increase in compassion</p> <p>Struggle with God</p> <p>Awareness of both loss and gain</p> <p><b>Differences:</b></p> <p>Negative appraisal of meaning to life and God.</p> <p><b>Categories/Themes/Patterns:</b></p> <p>Meaning and purpose is located in relationships with self, others and God, including in times of struggle</p> <p>Responsibility and ethical conduct in relationships is an important value</p> <p>Compassion with components of love, empathy, tolerance, and trust is an important value</p>

### **Findings relevant to *accessing spirituality*:**

Seven of the nine participants (77.8%) reported mystical, near death experiences that represented an encounter with the divine or higher power. In each case, these experiences served to awaken the participant to a transcendent, spiritual dimension. For some, the near death experience marked the beginning of a relationship with the divine, for others it served as a confirmation, providing the assurance of hope and meaning in one's life. Although the struggles and challenges were great, the memory of near death experiences often provided the courage to go forward, and served as a deterrent to suicide. An instantaneous belief in the value of life was conferred, in these cases. Religious themes were common. The memories of near death experiences were easily recovered and shared in all but one of the seven who reported them, even though these participants demonstrated marked memory deficits in other areas. The narrative of the one, who reported not having an NDE, was marked by despair and hopelessness. Following are examples of near death experiences that illustrate common themes:

Patient A: After having the mystical experience of a deceased friend watching over him and taking care of him during the acute phase of his recovery one man said, *so you can kind of think that even the most non-believer (Sic) has to believe that there is something there. In this area, I have changed. Where before I would have likely dismissed that as a delusion or something...now I am more open...to believe.... and I am Science Guy, requiring proof for everything.*

Patient B: *It was almost like a dream state...seeing snapshots or visions of my life as a child doing good, doing bad, doing good...I felt that maybe our Creator was in a sense judging me...That's when I realized that there is a God. God chose for me to live!*

Patient E: *I saw Saint Bernardo pass outside my window and knew that God had saved me, that He loved me so much that he sent this blessed Saint to protect me. I am reminded from this that suicide is not an option.*

Patient D: *I actually recall seeing Jesus Christ standing in the bathroom with His hands extended out like that...(gesturing with her arms) and I remember saying "I will help you." His hands were cut up. It was a very powerful experience that caused me to view my life differently.*

Near-death experiences allowed for the expansion of and the reframing of the old belief system. Old, unproductive beliefs were replaced by new, more life-giving beliefs. The new core beliefs indicated how they would go on to interpret and interact with the world. NDEs, or encounters with the divine, were often regarded as a summons to change. Table 3 lists a sampling of new core beliefs identified by participants

**Table 3, New Core Beliefs**

1)	Life is extremely valuable
2)	We all are valuable. We all have inherent worth
3)	There is a reason and a purpose for each person's life
4)	Change (transformation, renewal, regeneration) is possible
5)	I have been protected, kept safe, preserved
6)	God/Higher power does exist
7)	We are here for others (to care for others in both a <i>doing</i> and a <i>being</i> capacity)
8)	God is good
9)	People are worthy of respect
10)	Suffering has a positive value

It is significant to notice the shift from an egocentric position to that of the collective. For example, *we* are all valuable; as opposed to strictly *I* am valuable. Participants reported that they began to view themselves as connected to or part of the universal whole. This served to decrease their sense of isolation and promote well being. They felt that they were somehow being cared for and that this contributed to an ability to trust others more. One participant reported that he could *release into a blanket of security that only a sense of the divine could provide*.

In the absence of the memory of a near death experience, spirituality was reportedly discovered in the context of relationship. This was an on-going experience shared by both groups. Themes included valuing, cherishing, being present to the other, authenticity, and unexplained feelings of peace.

Finally, eight out of nine participants emphasized a full realization of the dichotomy of the co-existence of both good and bad, hope and despair, belief and non-belief. This was expressed in the narratives that they shared. The telling of their stories and the sharing of spiritual ideas appeared to have enabled them to recognize the fact of the tension that existed between the opposite poles of their experience.

**Findings relevant to the *development* of spirituality:**

The context for the development of spirituality for each participant was connectedness and relatedness. It was achieved in dialogue. Transformation took place during the exploration of spirituality within a relational context. Self-awareness, reflexivity, the capacity to share feelings, an increased willingness to trust others, and qualities of tolerance, empathy, love and compassion were evidence of an expansion in relational ability, and new ways of being. Meaning and purpose were located in relationships with self, others, and God, in the midst of struggle, loss and grief.

Most reported a quick sense of the ethical balances and imbalances in relationships and a drive towards accountable human relating. The struggle in this was recognizing and confronting one's own destructive sense of entitlement within the context of one's own family of origin. For example, one man, who experienced severe abuse at the hands of his father, exacted the same against others whom he perceived to be a threat to those who were weaker. He carried this same behaviour forward into his expectations of his care providers feeling enraged and violent when they did not meet his expectations. Over

time, he worked at applying his new spiritual identity, values and beliefs to those relationships, gained valuable insight into his behaviour, and was able to modify his expectations in fairness to others. He strove to replace the image of his “earthly” father with that of God, his “heavenly” Father. For him, this resulted in a new way of being. He reported and demonstrated a more peaceful, intuitive spiritual inner core. Working against this were the manifestations of psychiatric disorder requiring both cognitive and behavioural therapy. Integrating the new spiritual identity into his personhood and having this reflected consistently in behaviour was a challenge akin to the old adage *two steps forward, one step backwards*.

Meaning making became a spiritual endeavour for all participants. Faith explanations of past and present experiences contributed to a positive re-framing of recovery stories. Participants became more than just wounded storytellers. Participants reported that the telling of these stories was a powerful validation of a profound human experience that held deep meaning for them and their loved ones. Metaphors for these spiritual journeys were a common part of this and appeared to exact a stabilizing effect on the participant’s view of themselves and their life. The attribution of meaning to experience was felt to frame the future. Some metaphors revealed a therapeutic need for the participant to reclaim a voice over the medical voice and a life beyond their medical diagnoses. Following are examples of some of the metaphors shared. Three different participants are quoted:

Patient D: *I see myself as a strong and courageous spiritual warrior. I am on the warpath entering into battle with the belief that I will win because I have faith. God is with me.*

Patient A: *I would liken myself to a forest with the tall spruce and deciduous trees and all of the animals. Then there was a blazing forest fire and yet the forest still developed itself in time. This is a story of hope. My advice to others with ABI is, never give up! There is hope!*

Patient B: *I was drowning and now I have broken free. I am on the surface now. My spirituality, my belief in God keeps me afloat.*

Patient B: *Medicine as opposed to spirituality: There’s only so much that doctors can do. You must open yourself to the Holy Spirit. He is always present in the creation of life, birth, in the passing on, our journey from birth to death. I see the grace of God in every person and every event.*

Following are excerpts from narratives that depict common themes. These narratives were tragic stories of loss with all the elements of confusion, fear, anger, and despair. Common to many was the recognition of the transcendent, and a radical shift in core beliefs that allowed them to reframe the story of their lives. Two participants were non-theists and did not find the language of God to be useful. A reverence of life was the language of their spirituality. Four different participants are quoted:

Patient A: *This event has created meaning for me. We are obviously here for our loved ones. We are here for the relationships that we develop with them. We are here to try to help them out the best that we can and try to create something better than what went before.*

*Patient D: In the beginning I viewed myself as power woman. I could do everything and anything that I wanted. With the ABI I lost so much (career, relationships, social status) and I realized that I could no longer do it on my own. I needed my spirituality, which I nourished through the practice of my spiritual rituals. I derived strength from it. It was because of my spirituality and spiritual beliefs that I got through. Through it all, the one thing that did not change was my faith. It only got stronger.*

*Patient G: There is good and bad, hope and despair. They co-exist. I can handle this now. My spirituality is the mediator. This has allowed me to be more tolerant of other people, more compassionate. I have a terrible sadness about all of the loss and great hope as well. I have a future...a destiny of some kind.*

*Patient B: I had too many times when I just wanted to kill myself and be dead, but now I have a spirituality in which I believe. Now I need to live. I want to live.*

*Patient A: Priorly I had started to neglect the significant relationships in my life. I was taking it all for granted. This event helped me to turn all that around and to cherish those relationships, to work on developing and maintaining them.*

*Patient B: I feel that I beat the devil by seeking God's wisdom and direction. I feel that God is beside me to guide me in the journey of life. As a result I have an overall sense of love and loving compassion, the ability to want to help other people in their struggles.*

Participants also reported that they struggled with the fact they would revert back at times to the old belief system. Cognitive therapy techniques were useful in facilitating the return to the new, more desired belief system. For one participant, carrying a list of spiritual beliefs, accomplishments and goals was incentive to remain hopeful. Wanting to set relationship goals reflecting new, spiritual core beliefs was common.

#### **Findings relevant to the use or application of spirituality:**

Eight out of nine participants (88.9%) engaged in spiritually informed activities that expressed both core beliefs and existential goals. One example involves a man who successfully restored the chapel cross that had priorly been burned in an act of vandalism. This activity served as an act of atonement, a Roman Catholic rite of passage that brought closure to many of the spiritual and religious concerns generated by his experience of dual diagnosis. Other examples included, looking for ministry opportunities with troubled youth, forming support groups, designing a web-site for sufferers of ABI, doing community service at shelters and food banks and sharing their personal testimonies at conferences and work shops. The desire to be in the service of others by listening, witnessing, affirming, commending and encouraging was a common theme.

Spirituality was used, as well, as a means to cope with stress and to make decisions, to strengthen and to comfort oneself in the face of adversity. Many spoke of using their spiritual morality to inform their behaviours and actions. Many had made a conscious decision to use their newly expanded spiritual identity to promote ethical relationships, through discussions on values and spiritual awareness, and by mentoring family, particularly children and grandchildren. Passing along a spiritual legacy to the next generation became a focus. Several participants described attempts to mediate conflicts

among other patients on the unit where they were admitted. They expressed a desire to instil similar spiritual values in others. These individuals desired to teach by example. Five of the nine participants (56%) expressed a new interest in social justice issues and the desire to set goals for action. Table 5 presents the classification of the spiritual themes identified in the areas of awareness, development and application and concludes the data analysis.

**Table 3, Classification of Spiritual Themes**

Awareness	Development	Application
<p><b>Goals:</b> Acknowledgement of spiritual dimension, acceptance, and openness to believe.</p>	<p><b>Goals:</b> Intimacy and ethics in relationships.</p>	<p><b>Goals:</b> To impact both the present and the future. Confer a legacy.</p>
<p><b>Themes:</b> Mystical and Near Death Experiences</p>	<p><b>Themes:</b> The context is relatedness/connectedness</p>	<p><b>Themes:</b> Engaging in spiritually informed activities that express core beliefs and values</p>
<p>Acknowledgement of an encounter with the divine (connectedness with God/Higher Power)</p>	<p>Expansion of relational ability  Increasing capacity to extend compassion, empathy, tolerance, and trust to others.</p>	<p>Promotion of ethical relationships  Defining and sharing a spiritual legacy with the next generation</p>
<p>Change in some core beliefs</p>	<p>Drive towards accountable human relating. Forging relationships that reflect spiritual beliefs and values.</p>	<p>Drawing on spiritual resources in times of adversity and for on-going strength, comfort and direction</p>
<p>Realization of opposite poles (hope and despair)</p>	<p>Moral awareness  Personal responsibility for and beyond oneself, from local to global concerns.</p>	<p>Reaching out to others (sharing personal testimonies, providing support, serving in the community)</p>
	<p>Meaning making as a spiritual endeavour</p>	<p>Involvement in social justice issues</p>
	<p>Claiming a voice over the medical voice</p>	
	<p>Struggle with insight into behaviour, and integrating new spiritual beliefs</p>	

## Discussion

Spirituality emerged as a powerful element in the recovery and rehabilitation of those with acquired brain injury and psychiatric disorder. An expansion of awareness, openness to new experiences, new meanings of experiences, and new self-organization came with the territory of encounters with the divine or the spiritual dimension. Once recognized, individuals desired to actualize and integrate spirituality into the whole of their life. The components of hope, meaning making, connectedness, and perseverance contributed to an overall sense that one could transcend the adversity and pain of their circumstances.

One can discern both a positive tone and a remarkably articulate nature to the transcribed comments of the participants. This type of clear communication would not be typical of severely brain injured people and can be explained in three ways. First, most participants interviewed had achieved graduate level degrees and worked in professional careers prior to incurring their brain injuries. Second, one of the participants had experienced an unexpectedly higher degree of recovery. Lastly, these results would appear to speak to the intensity and richness of meaning that spiritual concepts hold for those with dual diagnosis. Similarly, researchers in a study on changes in spiritual beliefs after traumatic disability observed that participants “were able to provide cogent and thoughtful responses to very abstract and demanding ideas” (McColl, 2000,822). One interpretation offered to explain this was that people had spiritual experiences that were profound and largely positive. As well, they were considered to have a “well-developed spiritual life”, whether they were aware of it or not (McColl, 2000,823).

Although the interviews were quite positive, field notes indicated that incongruence between the newly formed spiritual beliefs and values and one’s behaviour was quite common. Individuals struggled with the integration of spiritual meaning into their lives. As one’s spirituality developed, the continuous process of transformation was experienced as *two steps forward and one step backwards*. The process of gaining insight into and changing inappropriate, destructive or self-destructive behaviour, and becoming more aware of one’s impact on others, was accomplished with the help of a multidisciplinary team dedicated to consistently implementing both cognitive and behavioural therapy. The role of the pastoral counsellor assigned to the unit was to provide counselling that gave special attention to the spiritual dimension. Chaplains and pastoral counsellors are specially trained to discern which spiritual and religious concerns are problematic and worthy of clinical attention and which ones do or do not attribute to psychiatric disorder. Fallot emphasizes that spiritual beliefs and behaviours be placed in the context of the person’s ability to function in social, educational, familial and vocational roles; of overall psychological organization; and of physical or biological findings (Fallot,2001, 111). In light of the many challenges faced by those with dual diagnosis, including with some, delusional, grandiose or self-deprecating thinking, this role is of particular importance.

The ability to understand and work with individuals from a diverse range of spiritual backgrounds allows for the co-construction of meanings that facilitate health and healing. Recognizing and opening up space in therapy to discuss such universal spiritual concepts as the meaninglessness of trauma and suffering, is required. For example, a spirituality

that embraces paradox is particularly important for those with dual diagnosis. The willingness to wait in ambiguity while spiritual transformation occurs is cultivated in the tension that is sustained between the opposite poles of despair and hope, the provisionality of life and the assurances that faith offers. This concept is perhaps best captured by Dickens who coined the phrase, “It was the best of times; It was the worst of times.” The pastoral counsellor comes along side individuals as they persevere and journey through the meaning making process, facilitating discussions on spirituality, responding to faith-based questions, and supporting the exploration of various stages of faith.

The person with dual diagnosis engages readily in the spiritual endeavour of meaning making and this generally works itself out in the relational context, particularly in the marital relationship and in family life. The adjustment to having a brain injury involves all family systems, intergenerationally. The contextual model of family therapy popularized by Ivan Boszormenyi-Nagy, with its distinct emphasis on the ethical dimension (trust, loyalty, entitlements and indebtedness) in family relationships as they extend over generations has particular application here. With acquired brain injury any psychotherapeutic leverage anchored in relational determinants would benefit the person and promote change in the system. The person who has dual diagnosis looks for new ways to relate to their loved ones. Healing comes from connectedness. In many ways they return as a stranger to their families so that the re-working of relationships becomes necessary to accommodate and adjust. Adaptive functioning depends on their ability to negotiate new role allocations and definitions to suit their new circumstances. Posterity becomes important, driven by the existential goal *to triumph*, as a legacy to pass on and inform the destiny of the next generation. Such an effort would appear to satisfy the need to exact fairness, to achieve balance and to trust in the universe again. Redeeming an intolerable situation through spiritual transformation and relational intimacy becomes the focus for many. With this the challenges are great requiring on-going support and counselling for the family to transcend the identifications and the constraints of both the past and present changes in circumstance.

In light of the information garnered by this study a variety of desired outcomes for individuals with dual diagnosis can be considered, such as the exploration of spiritual experiences, an increased capacity for self-reflection, the integration of losses and lost possibilities, separation from embeddedness in the past, an increased capacity for accepting ambiguity and embracing polarities, the tolerance of uncertainty and emotions, an increased awareness of one’s impact on others, an increased relational ability, and finding richer meaning in life through spiritual endeavours.

### **Further areas to research**

An expansion of this study to involve more participants of both differing faith groups and women would provide more balance and ensure that the perspective of these groups were adequately represented and considered. This study would appear to reflect similar themes to those identified by Hicksen and Phelps (1998) concerning women’s spiritual journeys. These include exploration, interdependence, balance and wholeness in the relational context.



A further area to explore would be that of forgiveness. Hargrave (1994) offers us valuable information on the role and accomplishment of forgiveness in life. Because of the nature of their circumstances, those suffering with ABI often struggle with a lack of forgiveness towards self, others and towards God. The exploration of Hargrave's four stations of forgiveness including insight, understanding, opportunity for compensation, and the overt act of forgiveness can be useful. Using one's spiritual beliefs and values to work through these stages is a recommendation. His emphasis on love and trust as well as destructive entitlement applies.

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