CRITICAL ILLNESS AND SPIRITUAL FAITH IN OLDER ADULTS: SURVIVAL FACTORS/WHY SPIRITUALITY MATTERS

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Critical Illness and Spiritual Faith in Older Adults: Survival Factors / Why Spirituality Matters

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"Harbor in the Storm: Beacons of Hope during Challenging Times"

Annapolis, MD

Isaiah 45:23 Bible King James Version

Turn to me and be saved,
all you ends of the earth;
for I am God, and there is no other.
23 By myself I have sworn,
my mouth has uttered in all integrity
a word that will not be revoked:
Before me every knee will bow;
by me every tongue will swear.
24 They will say of me, 'In the LORD alone
are deliverance and strength.'"

"Isaiah 45:23"

Artist: The Mountain Goats Album: The Life of the World to Come

If my prayer be not humble, make it so
In these last hours, if the spirit waits in check, help me let it go
And should my suffering double, let me never love you less
Let every knee be bent and every tongue confess

And I won't get better
But someday I'll be free
'Cause I am not this body
That imprisons me

If my prayer goes unanswered, that's alright
If my path fills with darkness and there's no sign of light
Let me praise you for the good times, let me hold your banner high
Until the hills are flattened and the rivers all run dry

Introduction

This talk will describe the importance of spiritual faith in determining physical survival and psychological recovery after critical illness for older adults. The research results reported here were part of a larger dissertation study conducted to fulfill the requirements of the PhD program at Smith College School for Social Work, supported by a grant from the California Chancellor's Doctoral Fellowship Program.

In the larger research study, social work clinical wisdom was used to evaluate quantitative and qualitative data; this mixed methods approach produced illuminating results. The current talk will present a subset of the research findings supporting the importance of faith in survival and recovery from illness. First, the literature supporting the importance of spiritual faith in healing from illness will be briefly summarized. Then, key concepts from the study will be defined and finally the effect of faith on the participants' coping patterns will be explored. Specific clinical recommendations will be provided.

Research on the Importance of Spirituality

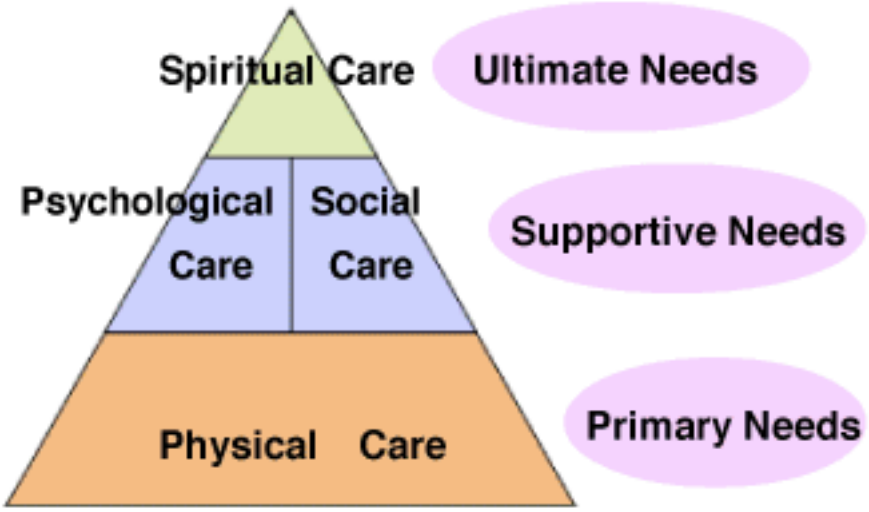
Many research studies since 1990s have shown a connection between religious practice and improved health (Koenig, King and Carson, 2012; Levin, 2001; Pargament, 1997). The idea that personal spiritual belief and religious practice can promote healing from illness seems intuitive to laypeople, especially people of faith. However the medical establishment has been reluctant to accept the idea that spirituality is important for healing (Levin, 2001). In fact, many medical providers believe that there is no evidence based research demonstrating the connection between spirituality and health, in spite of the existence of numerous rigorous quantitative studies which show a strong connection (Levin, 2001).

Levin (2001) has written a comprehensive book exploring how both public religious practice and private spiritual belief affect health. Levin cites multiple research studies which found that just attending religious services, even without a strong spiritual belief, can add 7 years to one's life. Levin states that attending religious services regularly is helpful because the members of religious groups offer fellowship and support to each other. Having sources of support who encourage healthy behavior can encourage people to follow a healthy lifestyle. A healthy lifestyle is promoted by many religious traditions which discourage unhealthy behaviors such as drinking alcohol. In fact, religions that make the "most strict behavioral demands", such as the Mormon and Amish faith, demonstrate the "most favorable health results" (Levin, 2001, p. 11) Attending religious services is also helpful because the process of disclosure and opening up to other members of the faith community can promote the process of becoming more health conscious. For example, discussing the wish to stop drinking alcohol in a church meeting may lead to an increased commitment to change the behavior. These health promoting behaviors in turn result in a longer life span.

For people who attend religious services and have a strong spiritual belief, Levin identifies several factors as being important. Hope is a core factor. People with a strong

spiritual belief, utilize hope in two ways, first as a hope for healing in this life and second as the hope for life after death. Levin also identifies spiritual traditions as tending to be positive and thus tending to teach learned optimism to people of faith. Other authors have found that religion promotes "positive illusions" such as the idea "I am sure my faith will cure me" (Taylor, 1989, p. 108). Research has shown that these positive illusions actually function in a manner similar to a placebo; the belief that "one will get better releases a number of chemicals in the body that may actually promote healing" (Taylor, 1989, p. 108). Thus utilizing the positive traditions of faith, to sustain a sense of hope can be instrumental in healing from illness.

While most hospitals in the US have chaplain programs and provide spiritual reading material, spirituality is not fully integrated into patient care. Tagami (2011) elaborates the ways in which faith is part of a multifaceted approach to medical care in a Christian hospital in Japan. Tagami's brilliant discussion of the role of faith in medical practice is based on a model which would be useful for Western hospitals to consider implementing.



Model from Tagami (2011)

A graphic of the model developed by Tagami is shown above. This model is an excellent framework for understanding the complex interactions between the medical, psychological, social and spiritual needs of the hospitalized patient. The model approaches the patient's needs in a stepwise manner. Tagami states that the hospital's first task is to care for the physical needs of the patient, for example providing surgery for a broken hip. The second task is to address the supportive needs of the patient by considering psychological aspects such as whether the patient needs counseling for PTSD from the accident in which the injury occurred.

Supportive needs would also include social aspects of care, such as whether the patient has someone to help with their basic needs when they return home. Building on these two levels of tasks, at the top of the pyramid is the patient's ultimate need; the need for spiritual care. At this level, medical staff would encourage the patient to use spiritual practices as an important part of their healing. This model is very helpful in visualizing the central importance of spirituality and the need for further integration of spiritual care into current medical practice.

Perhaps a central difficulty in bridging the gap between what we know as people of faith and what the medical establishment considers empirical evidence is the elusive nature of the faith experience. Faith is difficult to quantify. For people of faith, there are a multitude of ways to know that God is real, such as the experience of God answering your prayers, the intense experience of being born again or the insight which occurs from having God change your desires, resulting in a changed life. Thus a central question is how to translate the felt experience of faith into the quantitative realm of medicine. With a multitude of ways to experience and know that God is real, how do we combine what we know in our hearts with the need to produce empirical evidence and develop evidenced based practice?

There is promising recent research on integrating medical practices with the concepts of Christian faith. For example, Oxhandler (Personal communication, February 13, 2014) is currently studying how social work practitioners understand and utilize clients' spirituality in their practice. However, there is a need for more research in order to bridge the gap between people of faith, social work practice and the medical establishment.

Key Concepts from the Literature

There are three key concepts from the literature on critical illness, which may not be familiar to the general reader. These concepts are: Hypnagogic states, Psychological Agency and Post Traumatic Growth. The research study found that these three concepts combined with spiritual faith were crucial in helping older adults cope effectively with critical illness. These concepts will be briefly defined in this section.

Hypnagogic states

Hypnagogic states are a state of consciousness which occur in a partially awake state. These states are what many people experience when they are drifting off to sleep. During a hypnagogic state, the person is still partially aware of the environment and may incorporate real objects from their surroundings into a daydream like experience. The sensations experienced during a hypnagogic state can be visual, auditory or kinesthetic.

Many inventors, artists and scientists have reported eureka moments which occurred during hypnagogic states. The chemist August Kekulé came to understand the structure of the benzene after falling asleep in front of the fire, and seeing molecules made out of snakes, each swallowing the other's tail. Thomas Edison and Salvador Dali both had methods for purposely causing hypnagogic states, with the hope that this would lead to creative discoveries.

Medical research has shown that patients in hospital Intensive Care Units (ICU) commonly experience hypnagogic states. The medical explanation of hypnagogic states is that they are caused by the lack of stimuli in the ICU, the lack of a day / night cycle, interrupted sleep and the white noise created by ventilators and other machines. Prior medical literature has described younger hospitalized patients who reported extremely distressing hypnagogic experiences. Often these patients developed PTSD and actively avoided hospitals in the future.

There is very little psychological research about hypnagogic states, especially concerning older adult patients. An example from practice: a medical social worker was called to the ICU to consult with an older patient. The patient stated that the semi-circle created by the curtain track above his bed was the "door to Heaven". He was asking the nurses whether he should go through the door and they were at loss about how to handle the situation. This example demonstrates the waking-dream-like aspect of hypnagogic states and the concept of autosymbolic phenomena. The patient was incorporating a real object from his environment (the curtain track) in to his hypnogogic state in a manner that created a personal (autosymbolic) meaning (door to Heaven).

Psychological Agency

Psychological agency is a recent concept, which is just beginning to be explored in the literature. It is composed of four components:

-The ability to reflect on experience

-The ability to act purposefully

-The ability to image and create new ways to be

-The ability to have the capacity for meaningful action

Current research indicates that having a sense of psychological agency is an important coping skill that can help individuals who are faced with difficult situations. Ongoing research focuses on understanding how a healthy sense of psychological agency develops during childhood and how patients or clients can increase their degree of psychological agency. There is no available research on psychological agency and older adults. Psychological agency was not included in the original conceptualization of the larger research study, but emerged during the research as being an important factor that predicted the participant's coping skills.

Post-traumatic growth

Post-traumatic Growth (PTG) was initially identified by Frankl (1959) and has recently resurfaced as an important area of study. Basically, PTG is the opposite of Post-traumatic Stress Disorder (PTSD); instead of being traumatized, some individuals are able to use difficult experiences as growth experiences. PTG is composed of four components:

-Trauma equals development of the self – the difficult experience is used as an opportunity for personal growth.

-Existential re-evaluation – the client re-evaluates the meaning and purpose of their life

-Reappraisal of life and priorities – as a result of this evaluation, the client's priorities change -- the client often increases their spiritual practice or returns to a spiritual practice

-New awareness of the body – the client has a new awareness of their body and takes better care of themselves – such as having regular check-ups, eating healthy food and exercising.

Similar to the concept of psychological agency, post-traumatic growth was not part of the original conceptualization for this research study, but emerged as an important factor during the analysis of the results.

Description of the Research Study

This report is abstracted from a larger dissertation research study exploring critical illness in older adults. The purpose of the larger study was to explore participant's reactions to the process of becoming ill and recovering, as well as the psychology meaning they ascribed to their survival. For patients, the process of becoming critically ill and being hospitalized is often a sudden and shocking experience. New medical technology has been developed which can save patients who would have died 10 years ago. As a result, older adults can now survive previously fatal illnesses. However, the shock of being hospitalized combined with the intrusive modern hospital technology which helps patients survive may traumatize patients. Thus the central question for the larger study was: What happens when the patient is critically ill – expected to die – and survives?

Sample Demographics

The research sample consisted of 32 participants: 16 female / 16 male. Two of the female participants were persons of color. The average age was 78. The sample was highly educated with 13% of the participants holding a PhD. All participants had a history of being critically ill in the ICU unit, to the point that they were expected to die. At the time of the study all of the participants were at least one-year post discharge.

Methodology

The study utilized a mixed methods approach. All 32 subjects completed three quantitative scales measuring their symptoms of anxiety (HADS-A Scale), depression (HADS-D Scale) and PTSD (ETIC-7 Scale). The quantitative results were analyzed using the Mini-tab software program. Each participant also participated in a qualitative interview which was analyzed for themes and coded using the Atlas.ti software.

Four Groups of Participants Identified

A significant finding of this study was the identification of four categories of participants. These four groups will be described below. It is important to point out that these four groups were identified using social work practice wisdom combined with the qualitative and quantitative results. This multifaceted approach allowed new viewpoints to emerge.

Avoiding

This group of 4 participants avoided the purpose of the interview. They did not answer the questions in the qualitative interview and often talked at length about a different agenda. For example, one man seemed to be flirting with the interviewer, while a woman focused at length on her past recovery from mental illness, but ignored her current medical illness.

This group scored low on the anxiety, depression and PTSD scales, but these low scores appeared to be due to their avoidance of the subject of critical illness. In fact their scale responses seemed to be false positives, because they claimed not to be anxious or depressed, when it was evident during the interview that they were experiencing these emotions. In a larger scale quantitative study these participants would have been identified as people who were coping in a positive manner based on their high scale scores. Without the qualitative interview and the interpretation of the interview using social work wisdom, the true response of this group of participants would not have been identified.

Depressed

This group of 10 participants presented as very depressed. Their scale scores were low and matched their presentation during the interview. A significant attribute of this group was that 6 of the participants were atheists and the remaining 4 participants did not practice their faith. In addition, all of the participants had all lost an important function, such as walking and had not been able to regain their functioning. For 6 of 10 participants, this was their first serious illness and they had amnesia for the initial weeks of their hospitalization. This “hole” in their memory contributed to their depression. The 4 other participants had experienced chronic long-term illnesses or multiple episodes of diseases such as cancer. These chronic, multiple episodes contributed to their depression.

Denial

This group of 8 participants appeared to have a high level of denial about their illness, but this denial was actually adaptive. In their interviews the participants often used the phrase “You just go on” and explained that when life hands you difficulties you need to stubbornly keep trying to improve your situation. An example was a man who was told by his doctor that he would never walk again. He developed his own physical therapy program using two kitchen chairs and was walking by the end of the year.

A significant attribute of this group was that all the participants were 79 or older, which meant that they were born during the period between World War I and the Great Depression. Being born into this generational cohort may have taught them their stoic coping skills when faced with adversity. In addition, the participants in this group all spontaneously mentioned childhood trauma. For example: "Surviving my three open heart surgeries was not as difficult as surviving the beatings my Dad used to give me." These reports of childhood trauma were an unexpected outcome of the study, but the presence of childhood trauma may also explain their stoic coping style.

Of the 8 participants in this group, 6 practiced a spiritual faith and 2 were atheists. There was no clear pattern of differences in physical recovery or psychological adjustment between participants with a spiritual faith and those who were atheists. Several participants had hypnagogic experiences which they regarded as puzzling but not traumatic. All participants in this group had complete memories of their hospital experiences. The participants scored lower on the scales, compared to their affect in the interviews, probably because of their tendency to deny unpleasant feelings.

Coping

This group of 10 participants all had complete memories of their hospital experiences. They also all had a spiritual faith and 8 of the 10 attended religious services. All participants in this group had a hypnagogic experience which they interpreted as positive and spiritual in nature. In the interviews this group appeared to be coping very well and their scale scores were also positive. Many of the participants in this group had lost an important function, such as walking, but they had been able to regain their functioning.

Significant Results Related to Spirituality

The core purpose of this report is to explain why spiritual belief is important during recovery from a critical illness. The description of the Coping group above, illustrates the importance of spirituality in physical and psychological recovery. These participants scored low on scales of anxiety, depression and PTSD. In the qualitative interviews they had positive affect and related how they had recovered from their illnesses. Most of the participants in the Coping group related that their life had changed as a result of their recovery from their critical illness. An example is a man who woke from a comatose state in the ICU with a desire to rekindle his relationship with his wife and return to his church. He was able to accomplish both goals and became a mentor in the church youth program.

Earlier research had found that having hypnagogic experiences in the hospital caused PTSD in younger patients. However, the older adults in this study found their hypnagogic experiences comforting and supportive. For example, the Coping group reported a variety of hypnagogic experiences such as being held in God's arms and supported, feeling a healing mist surrounding them and going on a journey in which they reconciled with departed loved ones. Other members of the Coping group reported more classic near death experiences of going

down a hallway toward a figure of light and seeing departed loved ones. These reports suggest that hypnagogic experiences may have a different impact on older adults. Indeed a finding of this study is that older adults with a spiritual faith used that faith to structure and provide meaning for their experiences during recovery from illness.

Looking more closely at the process of recovery for the Coping group will help explain the importance of spiritual faith and how the process of creating structure by using faith may work. Because the Coping group all had a spiritual faith, they used this faith as a framework to understand their hypnagogic experiences. They understood these experiences as being a message from God that they would be taken care of and that they would survive their illness. In addition, they decided that there was a meaning to their survival and there was a purpose that they were meant to serve after their recovery. This understanding of their experience gave them a sense of psychological agency.

As mentioned earlier the first characteristic of psychological agency is the ability to reflect on experience; often the patients reported contemplating on their illness experience in the first few days after they woke up in the ICU. They described reviewing the narrative of their illness and trying to make sense of their hypnagogic experience. The next characteristic of psychological agency is the ability to image and create new ways to be; after patients returned home from the hospital they reported that they began to imagine the ways in which they wanted to change their life. Patients were often shocked at their slow rate of physical recovery; it often took a year before they were physically able to create new ways to live their life. The final characteristics of psychological agency are the ability to have the capacity for meaningful action and the ability to act purposefully. As the patients regained their psychological health, they regained the cognitive skills to initiate meaningful action. As they regained their physical health they were able to put their plans for life change into action.

Because the Coping group patients used their hypnagogic experiences to create a sense of psychological agency, they were able to experience Post Traumatic Growth (PTG). All 10 participants in this group reported major life changes after their illness. The most frequent major life change involved becoming more religious or returning to spiritual practice. Other life changes were reconnecting with family members and repairing family rifts, volunteering in the community and creating artwork.

The experiences of the participants in the Coping group suggest directions in which to focus social work case management and clinical practice. Concrete suggestions will be provided at the end of this report.

Directions for future research

This report is based on a study of 32 participants in California. Due to the small sample and lack of diversity, these results may not apply to other populations. The results should be replicated in a larger, more diverse population sample. This study suggests many areas for future research. An initial suggestion is that more mixed methods studies are needed to avoid

the drawbacks of exclusively qualitative or quantitative research. The results detailed in this report would not have been found without a mixed methods approach and the use of social work clinical wisdom.

This study identified four participant groups: Avoiding, Depressed, Denial and Coping. Further research is needed to confirm if the groups would be found in a larger more diverse sample. The finding that some participants used denial in an adaptive manner is interesting and needs further study. Classic clinical practice is to confront denial and to try to reorient the patient to reality. The results of this study indicate that supporting adaptive denial might be a better clinical practice.

The finding in this study the Denial group spontaneously reported childhood trauma is another interesting area for further research. The subject of childhood trauma and the impact of this trauma in later life has not been investigated and needs further exploration. An additional finding was that in the Depressed group several participants had been ill with various chronic illnesses across their entire lifespan. The impact of chronic illness beginning in childhood and continuing into old age has not been investigated and needs further exploration.

Summary

This study demonstrates how the three elements of spirituality, psychological agency and Post Traumatic Growth joined together to promote healing for the Coping group. Using a spiritual framework helped the Coping patients to feel the “deliverance and strength” of the Lord as they recovered. They found spiritual meaning in their hypnagogic experiences; experiences which the medical establishment dismissed as hallucinatory. They used this spiritual experience to claim the power of their own psychological agency and to make significant life changes. These changes resulted in the transformation of the traumatic situation of critical illness into an opportunity for Post Traumatic Growth.

Medical providers need to acknowledge the important role of spirituality in healing, by understanding that patients are more than “this body that imprisons me”. Therefore, It is critically important that researchers of faith continue to conduct evidenced based research. As more evidence based research accumulates, the medical establishment will truly understand that healing the body depends on healing the spirit.

Clinical Recommendations

1) **Spiritual faith is important.**
    a. Research shows that spiritual faith is important and helps patients cope. Data on the importance of faith needs to be acknowledged. Spiritual faith should be fully integrated into hospital practice. At a minimum, hospital patients should have access to a spiritual counselor and religious material. If patients without a spiritual faith express an interest in beginning or returning to a faith based practice, the social worker should encourage this interest.

2) **Help normalize hypnagogic experiences in a positive manner. Include spirituality.**
    a. Social workers who encounter critical ill patients should specifically ask about hypnagogic experiences and offer reassurance that these experiences are normal.
    b. Patients should be allowed to discuss their unreal experiences. If the patient is interested, the social worker can help the patient explore the autosymbolic and spiritual meaning of their unreal experiences.
    c. If patients are fearful or experience PTSD symptoms as a result of their unreal experience they should receive counseling and support in the hospital and referrals for counseling at discharge.

3) **Denial is not necessarily a bad thing.**
    a. Some participants in this study used denial in an adaptive manner, in order to remain positive and continue coping. If the patient shows signs of denial, the social worker should consider supporting this denial or confront it gently.

4) **Illness Narratives are important. Follow up with patients in outpatient settings.**
    a. This issue is not covered in detail in the current talk. However, research results showed that participants who had no memory of their time in the hospital, had a "hole" in their life and were more likely to be depressed or in denial.
    b. Social workers can help patients to create illness narratives, which restore their memories of their illness experience. In the hospital, patients can be orientated to their situation each day. "This is the ICU Unit, you have had a major stroke".
    c. The patient's family can be urged to keep an ICU diary – a notebook in which daily events are recorded. Pictures can be taken documenting the patient's progress in activities of daily living such as eating and walking.
    d. When the patient is discharged it can be very helpful for them to tell the story of their illness. An important function of outpatient counseling can be to hear the story and help the patient put the pieces that they remember into a coherent narrative.

Learning Objectives

1) Course participants will be able to identify the 4 coping patterns found among the older adults in this study.

2) Course participants will be able to define the concept of hypnagogic hallucinations and describe appropriate clinical responses to help older adults process a hallucinatory experience and interpret the spiritual meaning of the experience.

3) Course participants will understand the importance of spiritual faith for patients who are critically ill. Participants will be able to formulate possible approaches to using spiritual faith to counsel critically ill patients

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