

## RELIGIOUSNESS AND SPIRITUALITY IN COPING WITH A DISABILITY OF THE RELATIVES: QUALITATIVE STUDY

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**Abstract.** *The diagnosis of disability is always a critical and negative life event both for individual and family members. In many cases, this leads to complex psychological problems. The aim of this research was to add more understanding of the domain by using a interactional ethnographic approach to learn do (and how) spirituality and religion help individuals impacted by the relative person's disability survive and cope successfully with their lives in spite of overwhelming despair. Interactional ethnographic approach was chosen for this research. The results revealed that spirituality and religion help in creating emotional well-being, in finding and keeping hope. They help to make sense of disability and accept the disability. While participating in religious communities adds much to the emotional well-being and gives support from the community.*

**Keywords:** *disability, interactional ethnography, religion, spirituality, spiritual practices.*

### Introduction

The diagnosis of disability is always a critical and negative life event both for individual and family members. Negative health outcomes, where positive outcomes include well-being, happiness, hope, optimism, and gratefulness, and negative outcomes involve depression, suicide, anxiety, psychosis, substance abuse, delinquency/crime, and marital instability might follow negative health outcomes (Koenig, 2012). Care for those with disabilities in the West has its roots within monasteries and religious communities (Koenig, 2005). Religion, medicine, and healthcare have been related in one way or another in all population groups since the beginning of recorded history (Koenig, King, & Carson, 2012). Despite the negative views and opinions held by many health professionals, research examining religion, spirituality, and health has been rapidly expanding (Koenig, 2012).

Nevertheless, it is argued that research within the domain of critical life events, coping, and adaptation has been mostly fragmented, outcome-oriented, and neglectful of individual differences (do Rozario, 1997). Although literature on coping in families with disabled persons can be found, little is known about do people use spiritual beliefs to establish meaning for and respond to life with the disability of relative person. The aim of this research was to add more understanding of the domain by using a interactional ethnographic approach to learn do (and how) spirituality and religion help individuals impacted by the relative person's disability survive and cope successfully with their lives in spite of overwhelming despair.

Though there are many definitions, notions, and descriptions of religiousness and spirituality authors refer to the definitions used by P. Corrigan et al (2003), whereas religiousness is defined as participation in an institutionalized doctrine while spirituality is framed as an individual pursuit of meaning outside the world of immediate experience.

### **Literature review**

B. Johnstone, B. A. Glass and R. E. Oliver notice that over the past decade interest has increased in relationships among spirituality, religion, and health in both the mainstream media and scientific literature. In general, research has concluded that religion and spirituality are linked to positive physical and mental health outcomes. Most religion and health research has focused on populations with life-threatening diseases (e.g., cancer, cardiovascular disorders, AIDS) with minimal attention to persons with chronic, life-long disabling conditions such as brain injury, spinal cord injury, and stroke. However, religion is used by many individuals with disabilities to help them adjust to their impairments and to give new meaning to their lives (Johnstone, Glass, & Oliver, 2009). Research report that that 86 % of older disabled patients used religion as a coping resource for medical illness and disability. Among those patients who use religious activities, 98 % prayed, 94 % put their faith in God, 75 % read the Bible, 38 % were active with church friends, and 19 % attended church activities (Ortiz, 2006; Ayele, Mulligan, & Gheorghiu, 1999; Koenig, 2012). In another study, 1,824 people with serious mental illness completed self-report measures of religiousness and spirituality. They also completed measures of three health outcome domains: self-perceived well-being, psychiatric symptoms, and life goal achievement. Results showed that both religiousness and spirituality were significantly associated with proxies of well being and symptoms (Corrigan, McCorkle, Schell, & Kidder, 2003).

This is why spirituality appears with increasing frequency in the research literature, and a paradigm involving mind-body-spirit interaction is emerging. The

relationship of spirituality to disability and illness is at the center of a growing body of knowledge. A comprehensive literature review supported spirituality as coping method among individuals experiencing a variety of illnesses including hypertension, pulmonary disease, diabetes, chronic renal failure, surgery, rheumatoid arthritis, multiple sclerosis, HIV/AIDS, polio and addictive illnesses. Additionally, spirituality is a resource when dealing with critical illness as well as terminal illness and end of life issues, and it is utilized by both patients, and family members (Kaye & Raghavan, 2002). Furthermore, among various reports are descriptions of how religion and spirituality helped people to cope with a wide range of illnesses or in a variety of stressful situations. These include people dealing with general medical illness, chronic pain, kidney disease, diabetes, pulmonary disease, cancer, blood disorders, heart/cardiovascular diseases, vision problems, neurological disorders, HIV/AIDS, systemic lupus erythematosus, irritable bowel syndrome, musculoskeletal disease, psychiatric illness, bereavement, and end-of-life issues. In the overwhelming majority of studies, people reported that R/S was helpful (Koenig, 2012).

Previous researches revealed that religion and spirituality when facing disability help creating some positive emotions. Positive emotions include well-being, happiness, hope, optimism, meaning and purpose, high self-esteem, and a sense of control over life. Related to positive emotions are positive psychological traits such as altruism, being kind or compassionate, forgiving, and grateful (Koenig, 2012). Moreover, family members of adults with disability agree that spiritual beliefs stabilized their lives, providing meaning for the experience of disability, assistance with coping and other benefits (Treloar, 2002).

Participation in religious and spiritual activities may be personal (informal) or participation in formal activities. It was reported that participation in formal religious activities was important. Participants of the study highly valued the support they received from religion community as well. Moreover, participants were highly satisfied with these activities and support. A significant relationship was found between frequency of attendance, amount of support, and satisfaction with activities and support. Only in the case of formal ceremonies was the frequency/satisfaction relationship not significant (O'Hanlon, 2013). Support from the community was highlighted in another study as well. This study explored the relationships between spiritual meaning and social support from the religious community and problem behaviors, anger and depression in 128 dementia caregivers. The results suggest a mediating role of anger in the relationship between the appraisal of problem behaviors and depression. Support from the religious community is directly and negatively associated with anger, but the relationship between spiritual meaning and anger is mediated by caregivers' appraisals of problem behaviors, suggesting that spiritual beliefs might help caregivers to find meaning in caregiving experiences and thus appraise care

recipients' behavioral problems as less stressful (Marquez-Gonzalez, Lopez, Romero-Moreno, & Losada, 2012).

However, religion is also used to make meaning of the diagnosis of disability. God is imagined as active, benevolent, and interventionist. Religion helped to find hope in the beliefs, people felt supported by God and related religion to their motivation to adhere to the treatment plan (Grossoehme et al., 2010).

Research suggests that spiritual beliefs and organised religion were both beneficial as a stabilising force, helping parents to cope with psychological and physical stressors of parenting. Furthermore it was highlighted that due to its personal nature, spirituality is perceived a stronger source of support than organised religion by parents of children with intellectual disabilities (Pillay, 2010).

Nonetheless, despite a long history of the impact of disability to person's religiousness and spirituality studies, most research efforts have focused on conceptualizing and measuring disabled individual's religiousness and spirituality (Poston & Turnbull, 2004) with drawing attention to the religiousness and spirituality of the relatives of disabled person's only recently. Hence, in order to better understand spiritual needs of the relatives and draw the strategies for better coping with the diagnosis more research are needed.

## **Methodology**

Interactional ethnographic approach was chosen for this research. The logic of interactional ethnography guides outsider (ethnographer) as he or she seeks to develop understandings of what insiders need knows and understands (Green & Bridges, 2018). Ethnographic studies are a good way to really understand insiders and the challenges they may face while going about their everyday lives.

Contextual interviews where the researcher was interacting with the participants while observing them going about their everyday tasks were held. The interviews were held in a natural environment, so as not to feel too formal. The researcher was observing the participants of the study going about their everyday tasks and asked questions to gain insight. Thus interviewing was guided by interactional ethnographic principles and included a life history, a walk-along conversation, and participant observation.

Study sample consisted of four participants facing the disability of their family members. In order to keep the anonymity of the research participants, the study report uses their nicknames. Short description of research participants is provided in Table 1.

Table 1 *The characteristics of research participants*

| Nickname | Gender | Age | Living area | Disabled relative | Disability                                              |
|----------|--------|-----|-------------|-------------------|---------------------------------------------------------|
| Violeta  | female | 44  | city        | daughter          | mental disorder                                         |
| Nuta     | female | 33  | small town  | daughter          | developmental disorders, optical vision disc subatrophy |
| Kvietka  | female | 44  | city        | uncle             | mental disorder                                         |
|          |        |     |             | son in law        |                                                         |
| Giedre   | female | 46  | rural       | both parents      | cancer                                                  |

Data analysis was held to generate domains and categories. The research team read interview transcripts and reviewed notes to identify text segments that appeared eligible and able to answer the research aim.

Limitations of the study. The research questions focused on the understanding do (and how) spirituality and religion help individuals impacted by the relative person's disability survive and cope successfully with their lives in spite of overwhelming despair. We believe it was entirely appropriate to use interactional ethnographic approach given the exploratory nature of our research. The major limitation in terms of describing the impact of spirituality and religion to the individuals impacted by the relative person's disability was participants from a wide range of spiritual and religious backgrounds were not included in the research. We did not recruit participants according to diverse spiritual backgrounds, nor did we ask participants to indicate their spiritual or religious affiliations. Though it was clear from comments that most of the participants were Christian.

Another limitation is the translation of responses into English. Some relevant information might have been lost during the translation process. In order to avoid lost of information, two independent interpreters translated the responses, and the research team summarized the information.

## Research results

Themes resulting from participants' answers and comments were organized into six domains (Different kind of meditation, Hope, Making sense of disability, Acceptance of disability, Participating in church service, and Support from religious community). Participants' comments concerning spirituality generally fell into three main categories: (a) spirituality for the personal emotional well-being, (b) religion for getting answers about fate, and (c) participating in religious

communities.

### **Spirituality for personal emotional well-being**

Some participants talked about spirituality and did not have in mind any religion, but certain state of mind, psychological state and calmness. It is agreed that emotional well-being can be reached when using different practices.

#### *Different kind of meditation*

People agree that when they are desperate, hopeless, and sad they look for some activities that are somehow ceremonial, ritual and need concentration.

*“When I despair when I find it very difficult, I go to my garden. I'm talking with flowers, weeds, hugs, and fruit. This makes me feel better. This is my best meditation” (Giedre)*

Sometimes there is a need to find unusual practices.

*“When I learned my daughter's diagnosis, there were many emotions. I realized I had to deal with them because I had to be strong for both of us. I started looking for practices that would help me to calm down and concentrate. So I found meditation, breathing exercises, incense. This helps me feel better” (Violeta)*

Natural elements work well also.

*“When I look to the fire - candle or fireplace - it is so calming. I talk with the fire and ask to take my pain away. I can say the same about the wind and big water” (Nuta)*

#### *Hope*

Participants spoke about the importance of having hope and believing in something greater than themselves. They indicated that hope gave them strength.

*“I like walking by the sea. Sometimes it is very wavy and sometimes calm and quiet. So when my negative emotions rise and I feel desperate, I know and I am full of hope that they will calm down and everything will be fine again” (Nuta)*

*“The girl is growing, learning, and doing well. That is what I say that God sends difficulties, but gives hope” (Violeta)*

*“I have prayed heavily for the surgery. We have been waiting for a long time, but the date is already set. I know for sure that God will not leave us now, that everything will be good” (Kvietka)*

### **Religion as getting answers about fate**

For many families with disabilities religion plays an important role. It helps make sense of disability and accept the disability.

#### *Making sense of disability*

Religion helps families to understand the meaning of disability, and some consider life with the disabled person as a gift.

*“My daughter taught me so many things...” (Violeta)*

*“I say... if God destined you can not do anything against God. If God has given it so, it will be so, no one else can change it” (Kvietka)*

*“You can read in the Bible that Jesus suffered. And his relatives suffered too. We all suffer in certain way. My way, probably, is this...” (Giedre)*

*“Some people are destined to suffer and live a life with the disability. But they couldn't do it alone. Therefore, God places the test of life to raise a child with a disability or take care of the disabled person only to the strongest and most loyal people” (Kvietka)*

#### *Acceptance of disability*

Religion often refers to reconciliation with destiny. This provision helps people accept disability of a relative person.

*“It is God who has given them a great burden to carry in this life” (Kvietka)*

However, it indicates that acceptance of disability often comes after great anger.

*“When I learned that my daughter had a developmental disorder, I got extremely angry on God. I asked why he had chosen my family for such a misfortune. Why we can't live a happy life. But later, when I saw my daughter's smile, when I realized how deeply can love a disabled child, I realized that we are different but very happy” (Nuta)*

#### **Participating in religious communities**

Participants of the study also talked about participation in official activities of the religious communities. Most told about participation in the religious service and the support from community.

#### *Participating in church service*

Participating in church service is seen as the escaping from everyday life.

*“Taking care for the disabled old person I call as a chronic burden of care. Sometimes I just need to do the break. Going to the church service is contemporary escaping out of my fate” (Kvietka)*

Participating in church service adds much to the emotional well-being as well.

*I left my mother in the hospital. I felt very lonely and hopeless. I went to church. Service just began. It was just me sitting in a row. I was listening to the prayers, choir singing, and organ music. And I felt better. And there is a piano in that church. After the service I went to that piano and start playing. I played my feelings. Few people came back to me to thank” (Giedre)*

#### *Support from religious community*

Support from the religious community plays great role in helping people also. The support can be both - emotional and physical.

*“My religious community gave me great emotional support” (Giedre)*

*“There is a certain social stigmatization for the people with disabilities. But our the community of our church wants to escape it. It provides emotional support for disabled person and his/her relatives, organizes social activities to cheer everyone a little bit, offers social service few hours a day, etc. This support means a lot for me. I do not feel alone with my problems and concerns” (Kvietka)*

## Conclusions

Interactional ethnographic approach was chosen for this research. And it seems to be the right choice for the developing of understanding do and how spirituality and religion help in coping with life for persons who are impacted by the disability of the relative person.

It needs to be mentioned, that spirituality is not always related to religion. It is a state of the soul associated with the search for spiritual peace. Nevertheless, spirituality and religion help in creating emotional well-being, in finding and keeping hope. They help to make sence of disability and accept the disability. While participating in religious communities adds much to the emotional well-being and gives support from the community.

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## References

- Ayele, H., Mulligan, T., Gheorghiu, S., et al. (1999). Religious activity improves life satisfaction for some physicians and older patients. *Journal of Ameican Geriatric Society*, 47, 453–455.
- Corrigan, P., McCorkle, B., Schell, B., & Kidder, K. (2003). Religion and Spirituality in the Lives of People with Serious Mental Illness. *Community Mental Health Journal*, 39(6), 487–499.
- do Rozario, L. (1997). Spirituality in the lives of people with disability and chronic illness: a creative paradigm of wholeness and reconstitution. *Disability Rehabilitation*, 19(10), 427–34.
- Green, J. L., & Bridges, S. M. (2018). Interactional Ethnography, in *International Handbook of the Learning Sciences* ed. Frank Fischer, Cindy E. Hmelo-Silver, Susan R. Goldman and Peter Reimann (Abingdon: Routledge), accessed 16-01-2019, Routledge Handbooks Online.
- Grossoenme, D. H., Ragsdale, J., Woolridge J. L., Cotton, S., & Seid, M. (2010). We Can Handle This: Parents’ Use of Religion in the First Year Following Their Child’s Diagnosis with Cystic Fibrosis. *Journal of Health Care Chaplain*, 16(0): 95–108. doi:10.1080/08854726.2010.480833
- Johnstone, B., Glass, B. A., & Oliver, R. E. (2007). Religion and disability: Clinical, research and training considerations for rehabilitation professionals. *Disability and Rehabilitation*, 29(15), 1153–1163.
- Koenig, H. G. (1998). Religious attitudes and practices of hospitalized medically ill older adults. *International Journal of Geriatric Psychiatry*, 13, 213–224.

- Koenig, H. G. (2005). *Faith and Mental Health: Religious Resources For Healing*, Templeton Press, Conshohocken, Pa, USA.
- Koenig, H. G. (2012). Religion, Spirituality, and Health: The Research and Clinical Implications, *ISRN Psychiatry*, vol. 2012, Article ID 278730. <https://doi.org/10.5402/2012/278730>.
- Koenig, H. G., King, D. E., & Carson, V. B. (2012). A history of religion, medicine, and healthcare,” in *Handbook of Religion and Health*, Oxford University Press, New York, NY, USA, 2nd edition, 15–34.
- Marquez-Gonzalez, M., Lopez, J., Romero-Moreno, R., & Losada, A. (2012). Anger, spiritual meaning and support from the religious community in dementia caregiving. *Journal of Religion & Health*, 51, 179-186
- O'Hanlon, E. E. (2013). Religion and Disability: The Experiences of Families of Children with Special Needs. *Journal of Religion, Disability & Health*, 17(1), 42-61.
- Pillay, D. (2010). *Spirituality and organised religion in supporting parents of children with Down syndrome and intellectual disability*. Retrieved from [https://ro.ecu.edu.au/theses\\_hons/1358](https://ro.ecu.edu.au/theses_hons/1358)
- Reyes-Ortiz, C. A. (2006). Spirituality, disability and chronic illness. *Southern Medical Journal*, 99(10), 1172-1173. Retrieved from <https://doi.org/10.1097/01.smj.0000242805.02180.63>
- Senthil, J. K., & Raghavan, K. (2002). Spirituality in Disability and Illness. *Journal of Religion and Health*, 41(3), 231–242.
- Treloar, L. L. (2002). Disability, spiritual beliefs and the church: the experiences of adults with disabilities and family members. *Journal of Advanced Nursing*, 40(5), 594-603.