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More Sick, More Spiritual? More Research Needed:

A Review of Spirituality in Youth with Chronic Illness Compared with Their Healthy Peers

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RTS5010: Introduction to the Study of Spirituality

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Abstract

Purpose: This review seeks to discover whether youth with chronic illness are more spiritual than their healthy peers.

Methods: A total of 111 articles were gathered via MackSearch and reference list evaluation. Of those, 63 were ruled out by title or abstract. Forty-three sources were appropriate for background reference, leaving five articles for review.

Findings: Based on the reviewed studies, any increase in spirituality among chronically ill youth compared to their healthy peers is minimal. There is suspicion that the majority of the assessment tools used were not adequately sensitive for the adolescent population.

Discussion: Assessments that are validated for youth are critical for confidence in research results. Implications for individuals and organized religion are explored.

Conclusion: There is limited evidence that youth with chronic illness use spirituality more than their healthy peers. More research is needed in this area that specifically applies assessment tools formulated for the adolescent population.

Introduction

Youth with chronic illness face challenges different from most of their peers, and the rate of such medical conditions is rising (“Tackling the Burden of Chronic Diseases in the USA” 2009). At the same time, the percentage of Americans who consider themselves ‘spiritual but not religious’ (Parsons 2018) or simply unaffiliated from religion is also increasing, especially in young people (Jones et al. 2016).

There has been a large amount of research on the spirituality of youth with chronic illness [for examples see: (Grossoehme, VanDyke, and Seid 2008; Atobrah 2012; Bakker, van

Leeuwen, and Roodbol 2018; W. de A. Alvarenga et al. 2021)]. As spiritual health is a vital component of overall well-being (Juškienė 2016), understanding the spirituality of chronically ill youth can aid in the treatment of their full psychosocial and physical health. With the increase of the religiously disaffiliated, research methods that transcend specific religious beliefs are vital for adequately evaluating spirituality in these populations (de Jager Meezenbroek et al. 2012).

Little research exists regarding the particular impact of chronic medical conditions on the spirituality of children and adolescents. Having a better understanding of the comparative spirituality of youth with and without chronic illness can allow care providers - healthcare workers, psychosocial supports, and clergy - to better support the overall health needs of this population. This paper reviews the existing literature, specifically looking to the hypothesis that youth with chronic illness are more spiritual than their healthy peers.

Definitions

Spirituality is a complex topic, defined differently in many studies. For the purpose of this study, it will be defined as an intrinsic aspect of humanity through which persons seek ultimate meaning and experience relationship to the significant or sacred (Puchalski et al. 2014, 643; Bakker, van Leeuwen, and Roodbol 2018). Religion is an organization of the collective spiritual experiences of a group into a system of practices and beliefs (Bernstein, D'Angelo, and Lyon 2013; Mueller, Plevak, and Rummans 2001). Spirituality / Religiosity (S/R) is a multidimensional measure that combines the internal experience and the outward expression (Cotton et al. 2012, 119).

Chronic disease is defined as a condition that “lasts one year or more and requires ongoing medical attention or limits activities of daily living or both” (“About Chronic Diseases”

2021). Chronic illness is the experience of living with chronic disease (Martin 2007). In practice, chronic illness is often used as a term for both the disease and the experience of having the disease.

This review is interested in the experience of all children and youth. For simplicity and to avoid repetition, the terms ‘youth,’ ‘young people,’ ‘children,’ and ‘adolescents’ will be used. Demographic information will further explore the age ranges covered in the studies.

Background

The intersection of spirituality with physical health in adults is well-researched. Publications like the *Journal of Religion and Health*, the *Journal of Holistic Nursing*, *Complementary Therapies in Medicine*, and the *Journal of Health Care Chaplaincy* bring forth various aspects of this topic with each issue. A correlation has been shown between spirituality and illness, generally revealing that higher levels of spirituality or use of spiritual practices or approaches decrease symptomology and increase quality of life and health outcomes (Kark et al. 1996; Miller and Thoresen 2003).

To explore the particular knowledge base about the spirituality of chronically ill youth, one need only look at the contribution of some key researchers, such as W.A. Alvarenga, D. Clayton-Jones, S. Cotton, and N. Reynolds. A.D. Bakker published an extensive review on this topic, finding in part that the spirituality of ill children is shaped by the search for identity and relationship, that they often imbue their illness with meaning, and that they use spirituality to cope with their illness in a variety of ways (Bakker, van Leeuwen, and Roodbol 2018). Reynolds has a selection of work examining the factors of positive and negative spiritual coping and their conflicting influences on health measures; that is, positive spiritual coping is of benefit to overall

health, where negative coping can be detrimental (Reynolds, Mrug, and Guion 2013; Reynolds et al. 2014, 2016).

For many of the researchers, a primary or secondary goal of their work was understanding the role of the medical provider in spiritual care. Many have found that youth with chronic illness would be open to having some level of spiritual conversation with their medical provider (doctor or nurse), with various nuances based on severity of illness, context, and language used (Cotton et al. 2012; Clayton-Jones et al. 2016; W. de A. Alvarenga et al. 2021).

In addition, the field is enhanced by the contributions of researchers from around the world who are doing similar work. In a Muslim population in Iran, H. Alijani Renani found that many subjects believed their asthma was an aspect of God's will, which helped them to have tranquility about it, along with patience and tolerance as taught as part of the Muslim religious model (Alijani Renani et al. 2014). A continent away, D. Atobrah worked with a selection of Ga patients. The Ga are the traditional people of Ghana's capital, Accra. The Ga subjects believed that their illnesses were spiritual, like the Iranian Muslims. However, this belief delayed their biomedical treatment, as they would often try to find the supernatural cause before eventually consulting a doctor (Atobrah 2012).

An under-researched element of this topic is the comparison of spirituality between chronically ill youth and their healthy peers. As such, this review seeks to explore the existing literature about this comparison in response to the question 'are youth with chronic illness more spiritual than their healthy peers?'

Methods

Eligibility for this review was intentionally broad. Preference was given to more recent studies, and only studies in English were considered. Age of the subjects was anywhere from child through adolescent, 0-21 years, and no geographic barrier was set.

The search for resources was based on the terms: “spirituality or spiritual,” “chronic illness or chronic disease,” and various synonyms of ‘youth’ - which included “child, children, young person, young people, adolescent/s, teenager/s, teen, pediatric, paediatric.” The comprehensive university search program MackSearch was utilized for this process in three different searches. The first search used the terms: (chronic illness or chronic disease) and (spirituality) and (youth or adolescents or young people or teen or young adults). After the system removed copies, 61 sources were found. The second search focused on the younger child population and used the terms: (chronic illness or chronic disease) and (spiritual) and (children or child or pediatric or paediatric). This search had 14 hits after copies were automatically removed. Duplicates from the first search were then removed, leaving 10 unique sources. For the third search, attention was paid to the verb, based on the recognition that ‘more spiritual’ could translate as ‘more frequent use of spiritual practices’ or ‘greater exploration of spirituality,’ among other options. The search terms were: (child or children or young person or adolescent or teenager or youth or young people) and (chronic illness or chronic disease) and (use or utilization or utilisation or usage) and (spirit*). Twelve hits emerged. Of those, one was a duplicate and two were repeats from the previous searches, leaving nine unique sources for analysis. When the search term (use, etc) was replaced with the word (explore or exploration), there were zero hits of either peer-reviewed or non-peer-reviewed studies. The presenting inquiry of our study was therefore amended from an ‘exploration’ of spirituality to a ‘usage’ of spirituality due to the data

available. In addition to the work in MackSearch, reference lists from highly relevant articles were evaluated. Thirty-three articles were gathered through this process.

The primary distinction for this review was the element of comparison of spirituality between healthy and chronically ill youth. Articles were ruled out if the primary demographic being studied was adults, the chronic illness was purely mental, the time-frame was end-of-life care, the focus was on spirituality as an intervention, or the study was simply too broad. Set aside for use as reference or background material was research on validation and age-adaptation of spiritual assessment tools, on spiritual development or on the spiritual needs or coping of youth, or on the role medical professionals could or should play in spiritual care of patients.

A total of 111 articles were gathered via search and reference gleaning. Of those, 63 were ruled out by title or abstract. Forty-three articles were appropriate for background reference, leaving five articles for review.

Findings

Demographics of the five reviewed articles included four American populations and one Canadian cohort (Losier, Taylor, and Fernandez 2005). Subject ages ranged from 0-21 years; three of the six studies focused on adolescence with a narrower age range of (11-12) to (19-21) (Bernstein, D'Angelo, and Lyon 2013; Cotton et al. 2009; Rubin et al. 2009). Four of the studies were in urban locations, and the fifth one (Wang, Li, and Gaylord 2019) was nationwide. Three studies had predominantly white participants, one had a majority of African American subjects (Bernstein, D'Angelo, and Lyon 2013), and the fifth did not collect racial data (Wang, Li, and Gaylord 2019). Four studies did not ask about or gather religious identification, while the subjects of the fifth were largely Christian (Bernstein, D'Angelo, and Lyon 2013). The research

included various chronic conditions, including cancer, sickle cell disease (SCD), asthma, irritable bowel disease (IBD), human immunodeficiency virus (HIV), otitis media, eczema, attention deficit hyperactivity disorder / attention deficit disorder (ADHD/ADD), severe headaches, depression, and respiratory allergy. In relation to gender, a majority of subjects were female in two studies, predominantly male in one study, and an unnamed mix in the other two studies.

A chronological review of these comparative studies begins in Canada. In 2005, Andrea Losier published her research on the use of Complementary and Alternative Medicine in a pediatric population (Losier, Taylor, and Fernandez 2005). Complementary and Alternative Medicine (CAM) comprises therapies that are not part of the conventional health care or medical approach of the United States and Canada. These commonly include nutritional supplements, chiropractic care, yoga, massage, ancient practices like acupuncture, and meditation, prayer and other spiritual practices (Losier, Taylor, and Fernandez 2005; Barnes, Bloom, and Nahin 2008). Recognizing that there was an abundance of data on CAM use in chronically ill populations (Losier, Taylor, and Fernandez 2005, 268), Losier set out to explore whether usage was the same in a non-chronically ill population, namely a pediatric emergency department.

Adapting a CAM questionnaire formulated by Fernandez for a pediatric oncology study (Fernandez et al. 1998), Losier asked parents to describe CAM usage by their children, who were there to receive treatment. Demographics, including the presence or absence of chronic illness, were also gathered. One sub-category within the study was 'prayer / spiritual approaches.' Losier found that CAM use in the population was approximately equal to that in a U.S. emergency department and a Canadian outpatient clinic at 12.8% (Losier, Taylor, and Fernandez 2005, 270). However, she found no correlation between the presence of chronic illness and increased CAM

use. No data was provided regarding any link between the specific measure of prayer / spiritual approaches and chronic illness.

Sian Cotton was next to pursue the question in 2009 (Cotton et al. 2009). She chose the Spiritual Well-Being Scale (SWBS), shortening it and adapting it for a more diverse population by expanding the definition of God to “God, Higher Power, or other spiritual being” (487). The SWBS includes two subscales, religious well-being and existential well-being, under the overall header of spiritual well-being. Cotton noted the reliability and validity of the full scale and that the measure has been used widely, including with adolescents (487). Focusing on the experience of adolescents with IBD, her results were nuanced. Existential well-being and religious well-being were equal between the subjects with IBD and those without. She noted a positive relationship between spiritual well-being and mental health as well as an inverse relationship between religious well-being and depressive symptoms. These held true in both the ill and healthy populations. However, chronic illness did have a role to play. In subjects where IBD was present, the strength of the relationships between well-being and mental health was more robust. IBD was providing a moderator effect; it wasn’t changing the relationship or the outcome, but it was strengthening it.

Concurrent with Cotton’s research was a similar inquiry by Daniel Rubin (Rubin et al. 2009). Rubin formed a study using the SWBS as well as a similar measure, the Spiritual Involvement and Beliefs Scale (SIBS). As a major difference from Cotton, Rubin’s primary goal of the study was to assess the applicability and validity of these two tools in the adolescent population, before using them to try to gather data. Rubin had one more piece to his study: he decided to include a short consumer satisfaction survey. In addition to asking whether the SWBS and SIBS were easy to understand, the survey asked if participants thought the questionnaires

were an effective means of measuring their spirituality. This small but brave addition would prove to be perhaps the most important piece of the work.

Rubin worked with a population of adolescents with cancer or SCD, giving both assessments and the survey to patients and to their parents. He found no differences between the spirituality of healthy and chronically ill adolescents. It is possible that there really were no differences. However, he suggested a second theory. The consumer satisfaction results regarding the adequacy of the tools to measure spirituality were eye-opening. The rating of effectiveness given by adolescents was 42 percent and by parents, 53 percent. Fewer than half of the adolescent population felt that the questionnaires were useful measures of their spirituality (40). It was possible that the neutral results were due to inadequate scales for the population.

Karen Bernstein entered the story of comparisons of spirituality in 2013 with her exploration of the spirituality of HIV+ adolescents (Bernstein, D'Angelo, and Lyon 2013). Bernstein chose to use the Brief Multidimensional Measure of Religiousness/Spirituality (BMMRS), a 36 item survey. Bernstein, echoing Cotton, comments that the BMMRS "has been shown to have good internal consistency in adolescents and has been successfully used in other adolescent studies" (1256), but she does note that there are no adolescent norms available (1262). Her basic conclusion regarding comparisons is that "few differences emerged in the teens studied with and without HIV" (1253). In fact there were only three items out of 34 in which HIV+ youth were statistically higher than HIV- youth: "feel God's presence," "feel they were part of a larger force," and feel like "God has abandoned them" (1258).

In 2019, Claudia Wang joined the conversation with a completely different approach (Wang, Li, and Gaylord 2019) and produced the strongest positive result of this review. Wang used the data from the 2017 National Health Interview Survey, a survey conducted by the

Centers for Disease Control (CDC) and the National Center for Health Statistics (NCHS). From this data, Wang was able to analyze data from 6,925 children aged 4-17 (272), by far the largest sample size in this review. She broke down the concept of ‘medical conditions and symptoms’ based on the survey options; thus the categories were ‘frequent or severe headaches (including migraines),’ ‘depression,’ ‘ADHD/ADD,’ ‘asthma,’ and ‘respiratory allergy,’ in addition to ‘regularly taking prescription medication in the last 3 months,’ which was grouped with questions about access to medical care (274). She chose to focus specifically on meditation, which is a mind-body form of spiritual practice. For her study, she used the categories of ‘any meditation use,’ ‘mindfulness meditation,’ ‘mantra meditation,’ ‘spiritual meditation,’ and ‘meditation used as part of yoga, tai chi, or qigong’ (272).

Comparing the use of meditation among children and youth with and without chronic illness, she found some positive correlations. Results included that the use of any meditation was higher in youth who had regularly taken prescription medication as well as in children with headaches or depression. In addition, mindfulness meditation and any meditation use were higher in children with respiratory allergy or ADHD/ADD. There was no correlation between asthma and any form of meditation use (274). None of the medical conditions were associated with spiritual meditation use. As the one relevant negative relationship, youth who took prescription medication were less likely to use mantra meditation (274). After adjusted regression modeling, Wang found that “children with chronic medical conditions/symptoms were more likely to use mantra meditation and mindfulness meditation than those without these medical conditions” (275). This was the highest state of correlation between chronic illness and spirituality of any of the reviewed articles.

Discussion

On the surface, the results of this review look inconclusive at best. There was a moderation effect (Cotton et al. 2009), a positive connection on three out of 34 measures (Bernstein, D'Angelo, and Lyon 2013), and an increase in two kinds of meditation but not a third (Wang, Li, and Gaylord 2019). No correlation was found between the use of CAM with chronic illness (Losier, Taylor, and Fernandez 2005); no differences were found between the spirituality of chronically ill and healthy adolescents (Rubin et al. 2009); and there were no differences in meditation use for children with asthma. There was an inverse correlation between prescription medicine use and mantra meditation (Wang, Li, and Gaylord 2019). It would appear that any increase in spirituality among chronically ill youth compared to their healthy peers is minimal.

A slightly different story emerges when the assessment tools are evaluated. The Spiritual Well-Being Scale (SWBS) was used by Cotton (Cotton et al. 2009) and Rubin (Rubin et al. 2009), at which time Rubin showed that both adolescents and their parents felt that it was a mediocre tool for the evaluation of spirituality (40). In describing the assessment tool, Rubin noted that “although the SWBS has been used in several hundred studies with adults and shows high internal consistency, validity, and test-retest reliability, the instrument has been criticized for being too narrow in scope because of its Judeo-Christian religious perspective and its focus on spiritual beliefs rather than on behaviors” (Hatch et al. 1998; Rubin et al. 2009, 38). His second assessment tool, the Spiritual Involvement and Beliefs Scale (SIBS), was said to be broader than SWBS and “based on principles shared by multiple spiritual approaches and attempts to use less culturally or religiously biased language. It also includes both beliefs and behaviors” (38). Specific to the point of this paper, Rubin also said “no instrument has been developed and validated to measure [spiritual coping mechanisms and treatments or religiosity]

in subjects less than 18 years of age” (38).

Cotton had been aware that the SWBS had not been adapted or specially verified in adolescents, however she noted “the reliability and validity of the full scale are well established, and the measure has been used widely in various samples, including adolescents” (Cotton et al. 2009). About her use of the BMMRS, Bernstein said something almost identical (Bernstein, D’Angelo, and Lyon 2013). While recognizing the lack of adolescent-specific validation, they both used the measures designed for adults.

In 2009, Cotton wondered if chronically ill adolescents might have differences from their healthy peers in other dimensions of spirituality that were not captured in her study (Cotton et al. 2009, 491). This is the direction that seems most salient. The response by both adolescent and parent subjects to Rubin’s consumer satisfaction survey (Rubin et al. 2009) indicates that assessments not specifically created or at least adjusted for an adolescent population are not reliable. The research done by Cotton, Rubin, and Bernstein (Cotton et al. 2009; Rubin et al. 2009; Bernstein, D’Angelo, and Lyon 2013) add to the field of research, particularly in terms of how adolescents practice and experience spirituality. However, their results are suspect due to the insufficiency of any adult measure to capture the fullness of adolescent spirituality without adjustment or external validation.

Losier, in contrast, did use an assessment tool that had been created for a pediatric population (Fernandez et al. 1998; Losier, Taylor, and Fernandez 2005). She compared overall CAM use by patients with and without chronic illness, but - unfortunately for this review - she did not analyze any connection specifically with prayer / spiritual approaches (Losier, Taylor, and Fernandez 2005, 269–70). As this subcategory of CAM was used by 19.7 percent of the caregivers for their children, the second largest percent after homeopathy (269), there is still a

possibility that a correlation exists in her data between prayer / spiritual approaches and chronic illness.

Wang's study, analyzing the results of a pool of data, thus produced the most reliable comparison research available out of this set (Wang, Li, and Gaylord 2019). There was no patient assessment nor existential or religious questions, just a report of behavior. Still the results were nuanced. There was not an absolute increase of all spiritual measures (all meditation use) associated with all medical conditions; asthma was an outlier. Spiritual meditation was also an outlier. Nevertheless, the conclusion stood that children with medical conditions/symptoms were more likely to use mantra and mindfulness meditation (276).

Studies have been conducted to externally validate spirituality assessment tools in adolescents. Dora Clayton-Jones put forth an article describing the use of the Spiritual Development Framework (SDF) in a study on adolescents (Clayton-Jones et al. 2019). The questions in the SDF are asked in an open-ended question style as part of an interview format, then the answers are coded for analysis. Not only was the SDF originally created for use in adolescents, but Clayton-Jones put forth extra effort to make sure the tool was appropriate for those who indicated no religious beliefs. In a similar move to Rubin (Rubin et al. 2009), Clayton-Jones also asked adolescents to give their feedback on the interview guides and process. Some of the adjustments made in response to their suggestions were changing the wording of one question, providing a stress ball during the interviews, and holding the interviews in a room with a window (Clayton-Jones et al. 2019).

Willyane Andrade de Alvarenga went a number of steps further in her treatment of another spiritual measurement tool in Brazil (W. A. de Alvarenga et al. 2019). The 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-Sp-12) is

well-known for use in adults for taking a broad view of spirituality not based on specific religious beliefs and practices (2220). It has been translated into at least 27 languages and validated in multiple countries and religious contexts (W. A. de Alvarenga et al. 2019; Peterman et al. 2002; Morita et al. 2004; Lazenby et al. 2013; Jafari et al. 2013; Fradelos et al. 2016; Agli, Bailly, and Ferrand 2017). Alvarenga started with the Portuguese version of the FACIT-Sp-12, which was already validated for Brazilian adults. The measure was brought through a seven-step process, including creating a parallel caregiver-observer measurement; assessment by a panel of experts; and a test round of answering by a sample group of adolescents (carefully distributed in gender, age, and illness) and their caregivers. Five items out of 12 were modified in both the adolescent and caregiver self-reports (2225). The adolescents were asked their opinion, as they were by Rubin and Clayton-Jones. The scale was considered good, relevant, and comprehensive by both youth and parents, and the majority did not want to change or add anything to it (2226). However one more item was adjusted at this phase of the process, changing the phrase “peace of mind” to “inner peace” (2226). Considering that half of the questions were adjusted during this lengthy process, the necessity of adjusting or designing assessments to meet the contextual and developmental levels of adolescents seems clear.

Youth with chronic illness use spirituality more than their healthy peers - and the nuance is difficult to parse. Mindfulness and mantra meditation use is greater, but spiritual meditation use is equal (Wang, Li, and Gaylord 2019). A ‘feeling of God’s presence’ is greater, but the sense of ‘feeling close to God’ is equal (Bernstein, D’Angelo, and Lyon 2013). In the emergency room, there apparently is no difference between the use of spirituality (as an aspect of CAM) for chronically ill youth compared to healthy youth (Losier, Taylor, and Fernandez 2005).

Perhaps this nuance is due to the intensely personal experience of spirituality. Even how

one understands the language of spirituality can vary from person to person. As the demographic of children and youth become less formally religious and less likely to use the more traditional language of spirituality, and as the population in the United States becomes increasingly diverse, it is important for researchers to adapt assessment tools to match the needs of the population. Only in this way will the data gathered be accurate. Tools like the FACIT-Sp and SDF, with their joint emphasis on a broad and multicultural definition of spirituality, will be critical.

This review is limited in its breadth. There are a small number of studies specifically looking at the comparison of healthy and chronically ill youth and their experiences with spirituality. Many of these studies were done in an urban medical setting and with assessments that were not specialized or adapted for adolescents. Although comparisons with various cultures and religions would be helpful with these questions, only articles in English have been reviewed. Most studies were geographically narrow and sometimes demographically narrow, allowing for the potential for each study to have biased results.

Although other reviews of the spirituality of youth with chronic illness have been performed (Bakker, van Leeuwen, and Roodbol 2018), the perspective of this paper is unique in its focus on the comparison to healthy peers and the key role played in the choice of assessment tools. This work serves to encourage other researchers to be intentional and careful in matching their assessment measures to their study population.

Further implication awaits clearer results. Accurately measuring a comparison between the spirituality of chronically ill and healthy youth is the first step toward a similar correlation of spiritual development. There has been speculation in the literature that childhood chronic illness can impact spiritual development. This theorizing has gone in both directions: either the difficulty of the illness has stunted development (as it can for physical or psychosocial

development) (Neuman 2011; Weaver and Wratchford 2017) or it facilitates faster spiritual growth [witness the experiences of Saint Thérèse of Lisieux (Gaucher 1993), Saint Bonaventure (“Saint Bonaventure” n.d.), and Saint Padre Pio (Catholic Online n.d.) who were all ill as children].

In addition, a child’s experience with religious authority figures can contribute to their perceptions of religion later in life. Sixty percent of those who left their childhood religion say that they no longer believe in the teachings of the religion, and 62% left their childhood religion before the age of 18 (Jones et al. 2016). Based on these statistics, aside from the individual dimension of overall health, it seems that organized religion has the most to lose if spiritual development in youth is not well-assessed.

A chronically ill parishioner is often the recipient of pastoral care and counseling within a religious community. The response an ill child or adolescent receives to their spiritual questions can impact their sense of belonging and relationship within that community. Future research provided to the pastoral team on any developmental differences within the chronic illness community could be impactful. The care provider would be better equipped for a conversation matched to the child’s level of development, whether stunted or advanced. This, in turn, would provide space for a more positive interaction, potentially leading to greater retention within the membership of the community. The converse of this could also be argued. If spiritually precocious youth are dismissed, they could disaffiliate in higher numbers. In this case, the organization risks the spiritual equivalent of “brain-drain:” the highly spiritual youth get pushed out, and the ones that remain are those that are spiritually developmentally stagnant. This would lead to the spiritually stagnant leading the organization and teaching the younger generations, exponentially increasing this effect.

Further research is needed to evaluate the spirituality of youth with chronic illness in comparison with their healthy peers. Validation of spiritual assessment measures in adolescents is critical; asking adolescents to evaluate measures used for their own age group will improve confidence in the results. Scales which use broad terms of spirituality to be applicable across cultures are encouraged. Combining the use of qualitative and quantitative assessment scales (the SDF and FACIT-Sp, for example) in the same study would be helpful both for cross-validation and depth of information. A national or international study using a broad range of healthy and chronically ill participants with a variety of medical conditions, balanced demographics (race, gender, socioeconomic status, etc), and variable spiritual and religious background and affiliations could be extremely valuable for exploring the nuances in this field.

Conclusion

There is limited and nuanced data to suggest that youth with chronic illness are more spiritual than their healthy peers. More research is needed to confirm this connection. Using spiritual assessment tools that are externally validated for use with adolescent populations, including by young people, will be critical for reliability and confidence in future research. Accurate measurement of comparisons of spirituality in chronically ill youth can lead to improved overall health and well-being and has implications for their involvement with organized religion.

References

- “About Chronic Diseases.” 2021. April 28, 2021.
<https://www.cdc.gov/chronicdisease/about/index.htm>.
- Agli, Océane, Nathalie Bailly, and Claude Ferrand. 2017. “Validation of the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT-Sp12) on French

- Old People.” *Journal of Religion and Health*. <https://doi.org/10.1007/s10943-016-0220-0>.
- Alijani Renani, Houshang, Fatemeh Hajinejad, Esmaeil Idani, and Maryam Ravanipour. 2014. “Children with Asthma and Their Families’ Viewpoints on Spiritual and Psychological Resources in Adaptation with the Disease.” *Journal of Religion and Health* 53 (4): 1176–89.
- Alvarenga, Willyane Andrade de, Lucila Castanheira Nascimento, Claudia Benedita Dos Santos, Ana Carolina Andrade Biaggi Leite, Holger Mühlhan, Silke Schmidt, Monika Bullinger, et al. 2019. “Measuring Spiritual Well-Being in Brazilian Adolescents with Chronic Illness Using the FACIT-Sp-12: Age Adaptation of the Self-Report Version, Development of the Parental-Report Version, and Validation.” *Journal of Religion and Health* 58 (6): 2219–40.
- Alvarenga, Willyane de Andrade, Júlia Rezende Machado, Ana Carolina Andrade Biaggi Leite, Sílvia Caldeira, Margarida Vieira, Silvana Santiago da Rocha, and Lucila Castanheira Nascimento. 2021. “Spiritual Needs of Brazilian Children and Adolescents with Chronic Illnesses: A Thematic Analysis.” *Journal of Pediatric Nursing* 60 (September): e39–45.
- Atobrah, D. 2012. “When Darkness Falls at Mid-Day: Young Patients’ Perceptions and Meanings of Chronic Illness and Their Implications for Medical Care.” *Ghana Medical Journal* 46 (2 Suppl): 46–53.
- Bakker, A. Damsma, R. R. van Leeuwen, and P. F. Roodbol. 2018. “The Spirituality of Children with Chronic Conditions: A Qualitative Meta-Synthesis☆.” *Journal of Pediatric Nursing* 43: e106–13.
- Barnes, Patricia M., Barbara Bloom, and Richard L. Nahin. 2008. “Complementary and Alternative Medicine Use among Adults and Children: United States, 2007.” *National Health Statistics Reports*, no. 12 (December): 1–23.
- Bernstein, Karen, Lawrence J. D’Angelo, and Maureen E. Lyon. 2013. “An Exploratory Study of HIV+ Adolescents’ Spirituality: Will You Pray with Me?” *Journal of Religion and Health* 52 (4): 1253–66.
- Catholic Online. n.d. “St. Padre Pio - Saints & Angels - Catholic Online.” Accessed November 19, 2021. https://www.catholic.org/saints/saint.php?saint_id=311.
- Clayton-Jones, Dora, Kristin A. Haglund, Jame Schaefer, Harold G. Koenig, and Safiya George Dalmida. 2019. “Use of the Spiritual Development Framework in Conducting Spirituality and Health Research with Adolescents.” *Journal of Religion and Health* 58 (4): 1259–71.
- Clayton-Jones, Dora, Kristin Haglund, Ruth Ann Belknap, Jame Schaefer, and Alexis A. Thompson. 2016. “Spirituality and Religiosity in Adolescents Living With Sickle Cell Disease.” *Western Journal of Nursing Research* 38 (6): 686–703.
- Cotton, Sian, Ian Kudel, Yvonne Humenay Roberts, Harini Pallerla, Joel Tsevat, Paul Succop, and Michael S. Yi. 2009. “Spiritual Well-Being and Mental Health Outcomes in Adolescents with or without Inflammatory Bowel Disease.” *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine* 44 (5): 485–92.
- Cotton, Sian, Jerren C. Weekes, Meghan E. McGrady, Susan L. Rosenthal, Michael S. Yi, Kenneth Pargament, Paul Succop, Yvonne Humenay Roberts, and Joel Tsevat. 2012. “Spirituality and Religiosity in Urban Adolescents with Asthma.” *Journal of Religion and Health* 51 (1): 118–31.
- Fernandez, C. V., C. A. Stutzer, L. MacWilliam, and C. Fryer. 1998. “Alternative and Complementary Therapy Use in Pediatric Oncology Patients in British Columbia: Prevalence and Reasons for Use and Nonuse.” *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology* 16 (4): 1279–86.

- Fradelos, Evangelos, Foteini Tzavella, Evmorfia Koukia, Konstantinos Tsaras, Ioanna Papathanasiou, Adamantia Aroni, Victoria Alikari, Maria Ralli, Jason Bredle, and And Zyga. 2016. "The Translation, Validation and Cultural Adaptation of Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being 12 (facit-sp12) Scale in Greek Language." *Materia Socio Medica*. <https://doi.org/10.5455/msm.2016.28.229-234>.
- Gaucher, Guy. 1993. *Story of a Life: St. Therese of Lisieux*. Harper Collins.
- Grossoehme, Daniel H., Rhonda VanDyke, and Michael Seid. 2008. "Spirituality's Role in Chronic Disease Self-Management: Sanctification of the Body in Families Dealing with Cystic Fibrosis." *Journal of Health Care Chaplaincy* 15 (2): 149–58.
- Hatch, Robert L., Mary Ann Burg, Debra S. Naberhaus, and Linda K. Hellmich. 1998. "The Spiritual Involvement and Beliefs Scale." *The Journal of Family Practice* 46 (6): 476–86.
- Jafari, Najmeh, Ahmadreza Zamani, Mark Lazenby, Ziba Farajzadegan, Hamid Emami, and Amir Loghmani. 2013. "Translation and Validation of the Persian Version of the Functional Assessment of Chronic Illness therapy—Spiritual Well-Being Scale (FACIT-Sp) among Muslim Iranians in Treatment for Cancer." *Palliative and Supportive Care*. <https://doi.org/10.1017/s1478951512000727>.
- Jager Meezenbroek, Eltica de, Bert Garssen, Machteld van den Berg, Dirk van Dierendonck, Adriaan Visser, and Wilmar B. Schaufeli. 2012. "Measuring Spirituality as a Universal Human Experience: A Review of Spirituality Questionnaires." *Journal of Religion and Health* 51 (2): 336–54.
- Jones, Robert P., Daniel Cox, Betsy Cooper, and Rachel Lienesch. 2016. "EXODUS: Why Americans Are Leaving Religion - and Why They're Unlikely to Come Back." Public Religion Research Institute (PRRI).
- Juškienė, Vaineta. 2016. "Spiritual Health as an Integral Component of Human Wellbeing." *Applied Research In Health And Social Sciences: Interface And Interaction* 13 (1): 3–13.
- Kark, J. D., G. Shemi, Y. Friedlander, O. Martin, O. Manor, and S. H. Blondheim. 1996. "Does Religious Observance Promote Health? Mortality in Secular vs Religious Kibbutzim in Israel." *American Journal of Public Health* 86 (3): 341–46.
- Lazenby, Mark, Jamal Khatib, Feda' Al-Khair, and Majdoleen Neamat. 2013. "Psychometric Properties of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being (FACIT-Sp) in an Arabic-Speaking, Predominantly Muslim Population." *Psycho-Oncology*. <https://doi.org/10.1002/pon.2062>.
- Losier, Andrea, Brett Taylor, and Conrad Vincent Fernandez. 2005. "Use of Alternative Therapies by Patients Presenting to a Pediatric Emergency Department." *The Journal of Emergency Medicine* 28 (3): 267–71.
- Martin, Carmel M. 2007. "Chronic Disease and Illness Care: Adding Principles of Family Medicine to Address Ongoing Health System Redesign." *Canadian Family Physician Medecin de Famille Canadien* 53 (12): 2086–91.
- Miller, William R., and Carl E. Thoresen. 2003. "Spirituality, Religion, and Health. An Emerging Research Field." *The American Psychologist* 58 (1): 24–35.
- Morita, Satoshi, Okihiko Aihara, Hirohiko Tsujii, Kojiro Shimozuma, Eisuke Matsushima, Wataru Noguchi, and Tatsuya Ohno. 2004. "Reliability and Validity of the Functional Assessment of Chronic Illness Therapy?Spiritual (FACIT?Sp) for Japanese Patients with Cancer." *Supportive Care in Cancer*. <https://doi.org/10.1007/s00520-003-0582-1>.
- Mueller, P. S., D. J. Plevak, and T. A. Rummans. 2001. "Religious Involvement, Spirituality, and Medicine: Implications for Clinical Practice." *Mayo Clinic Proceedings*. *Mayo Clinic* 76

- (12): 1225–35.
- Neuman, Michelle E. 2011. “Addressing Children’s Beliefs through Fowler’s Stages of Faith.” *Journal of Pediatric Nursing* 26 (1): 44–50.
- Parsons, William Barclay. 2018. *Being Spiritual But Not Religious: Past, Present, Future(s)*. Routledge.
- Peterman, Amy H., George Fitchett, Marianne J. Brady, Lesbia Hernandez, and David Cella. 2002. “Measuring Spiritual Well-Being in People with Cancer: The Functional Assessment of Chronic Illness Therapy—spiritual Well-Being Scale (FACIT-Sp).” *Annals of Behavioral Medicine: A Publication of the Society of Behavioral Medicine* 24 (1): 49–58.
- Puchalski, Christina M., Robert Vitting, Sharon K. Hull, and Nancy Reller. 2014. “Improving the Spiritual Dimension of Whole Person Care: Reaching National and International Consensus.” *Journal of Palliative Medicine* 17 (6): 642–56.
- Reynolds, Nina, Sylvie Mrug, and Kimberly Guion. 2013. “Spiritual Coping and Psychosocial Adjustment of Adolescents with Chronic Illness: The Role of Cognitive Attributions, Age, and Disease Group.” *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine* 52 (5): 559–65.
- Reynolds, Nina, Sylvie Mrug, Molly Hensler, Kimberly Guion, and Avi Madan-Swain. 2014. “Spiritual Coping and Adjustment in Adolescents with Chronic Illness: A 2-Year Prospective Study.” *Journal of Pediatric Psychology* 39 (5): 542–51.
- Reynolds, Nina, Sylvie Mrug, Kelly Wolfe, David Schwebel, and Jan Wallander. 2016. “Spiritual Coping, Psychosocial Adjustment, and Physical Health in Youth with Chronic Illness: A Meta-Analytic Review.” *Health Psychology Review* 10 (2): 226–43.
- Rubin, Daniel, Melissa Dodd, Neelam Desai, Bradley Pollock, and John Graham-Pole. 2009. “Spirituality in Well and Ill Adolescents and Their Parents: The Use of Two Assessment Scales.” *Pediatric Nursing* 35 (1): 37–42.
- “Saint Bonaventure.” n.d. Newman Connection. Accessed November 16, 2021. <http://www.newmanconnection.com/faith/saint/saint-bonaventure>.
- “Tackling the Burden of Chronic Diseases in the USA.” 2009. *The Lancet* 373 (9659): 185.
- Wang, Claudia, Kaigang Li, and Susan Gaylord. 2019. “Prevalence, Patterns, and Predictors of Meditation Use among U.S. Children: Results from the National Health Interview Survey.” *Complementary Therapies in Medicine*. <https://doi.org/10.1016/j.ctim.2019.02.004>.
- Weaver, Meaghann S., and Dale Wratchford. 2017. “Spirituality in Adolescent Patients.” *Annals of Palliative Medicine* 6 (3): 270–78.