

8-1-2019

# Use of the Spiritual Development Framework in Conducting Spirituality and Health Research with Adolescents

Dora L. Clayton-Jones  
*Marquette University, dora.clayton-jones@marquette.edu*

Kristin Haglund  
*Marquette University, kristin.haglund@marquette.edu*

Jame Schaefer  
*Marquette University, jame.schaefer@marquette.edu*

Harold C. Koenig  
*Duke University Medical Center*

Safiya George Dalmida  
*University of Alabama - Tuscaloosa*

Marquette University

e-Publications@Marquette

## ***Nursing Faculty Research and Publications/College of Nursing***

***This paper is NOT THE PUBLISHED VERSION; but the author's final, peer-reviewed manuscript.*** The published version may be accessed by following the link in the citation below.

*Journal of Religion and Health*, Vol. 58, No. 4 (August 2019): 1259-1271. [DOI](#). This article is © Springer and permission has been granted for this version to appear in [e-Publications@Marquette](#). Springer does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from Springer.

# Use of the Spiritual Development Framework in Conducting Spirituality and Health Research with Adolescents

Dora Clayton-Jones

Marquette University College of Nursing, Milwaukee, USA  
Medical College of Wisconsin, Milwaukee, USA

Kristin A. Haglund

Marquette University College of Nursing Milwaukee USA

Jame Schaefer

Department of Theology, Marquette University, Milwaukee, USA

Harold G. Koenig

Department of Psychiatry, Duke University Medical Center, Durham, USA  
Department of Medicine, Duke University Medical Center, Durham, USA  
Department of Medicine, King Abdulaziz University, Jeddah, Saudi Arabia

Safiya George Dalmida

Capstone College of Nursing, The University of Alabama, Tuscaloosa, USA

## Abstract

Spirituality is considered a universal phenomenon, but research addressing the spiritual needs of adolescents in the context of health and illness is limited. The aim of this article is to provide a description of how the spiritual development framework (SDF) was used in conducting research with adolescents. An exemplar of a qualitative descriptive study is provided to demonstrate applicability of the SDF. The SDF was used as a guiding theoretical framework in conducting research with adolescents living with sickle cell disease. The SDF is culturally applicable and methodologically appropriate. Additional research applying the SDF is warranted.

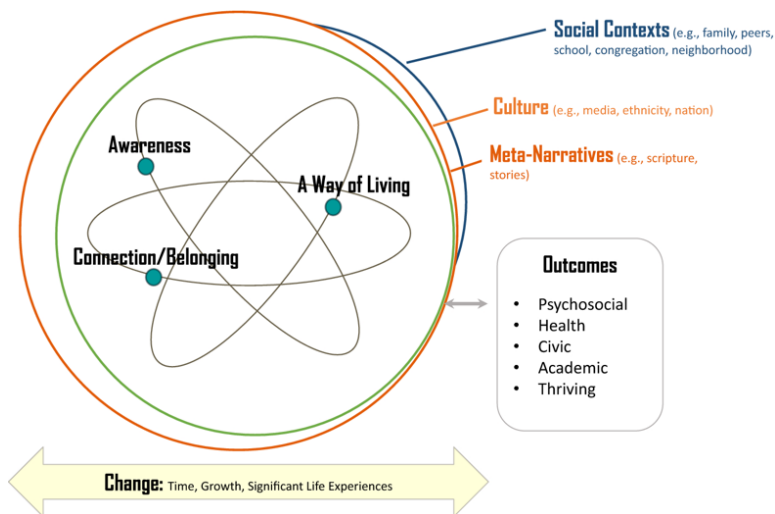
## Keywords

Spirituality Theory Adolescents Chronic illness

## Introduction

Although limited in scope, previous research has revealed the significance of spirituality in the lives of children and teens living with chronic illnesses such as cancer, cystic fibrosis, diabetes, HIV, end-stage renal disease, muscular dystrophy, and sickle cell disease (SCD) (Clayton-Jones et al. [2016](#); Haase and Phillips [2004](#); Pendleton et al. [2002](#); Pehler and Craft-Rosenberg [2008](#); Reynolds et al. [2014](#); Snethen et al. [2004](#)). Their spirituality helped them to cope with their illnesses and life. Spirituality has been shown to alleviate stress and correlate with positive health outcomes in research conducted with children and adolescents (Cotton et al. [2006](#); George et al. [2000](#); Jackson et al. [2010](#); Wong et al. [2006](#)). Spirituality may be especially relevant during adolescence and contributes to adolescents' overall well-being and healthy development (Benson and Roehlkepartain [2008](#)). Spirituality is defined here as the innate capacity of persons to transcend themselves to discern and experience meaning and purpose in life beyond their material, temporal existence through contemplation and action aimed ultimately toward the sacred (Benson et al. [2003](#); Miller and Thoresen [2003](#); Pargament [1997](#)). Sacred refers to a divine being, or ultimate reality or ultimate truth as perceived by the person (Larson et al. [1998](#)). People can gain a sense of meaning and purpose through their relationships and personal experiences (North American Nursing Diagnosis Association [2001](#); Reed [1992](#)). Religiosity is defined as a commitment to an organized way of knowing and orienting one's self to the religious community's subject of worship (Benner-Carson and Koenig [2004](#); Roehlkepartain et al. [2006](#); Taylor [2002](#)). For adolescents living with SCD, their spirituality may serve as a protective factor that promotes positive health outcomes.

Spirituality is considered a universal phenomenon, but research addressing the spirituality of adolescents and the role it has in their health and lives has not been studied extensively. In addition, there is little literature addressing methods for conducting research in spirituality, religion, and health with adolescents. The spiritual development framework (SDF) was developed by Benson and Roehlkepartain ([2008](#)) to provide a foundation for conceptualizing the spiritual element of human development (see Fig. [1](#)). The SDF may be used by researchers to investigate spiritual development and the role of spirituality among adolescents.



**Fig. 1.** Spiritual development framework. This figure illustrates the relationship of three core developmental processes and other dimensions of development (Benson and Roehlkepartain [2008](#))

Within the SDF, spiritual development is defined as the process of growing the innate human capacity for self-transcendence leading the person to discern and experience meaning and purpose in life (Benson et al. [2003](#); Miller and Thoresen [2003](#); Pargament [1997](#)). The SDF offers a flexible approach to understanding spiritual development. Rather than being hierarchical, the SDF allows for interpretations of spiritual development to remain open to differences in life experiences and the processes that evolve with those experiences. The SDF is focused on the period of adolescence. Data used to develop the SDF were gathered in focus groups conducted in 13 countries with adolescents, young adults, parents, and youth workers rendering the SDF applicable across cultures and religious traditions, and inherently relevant to adolescents (Benson and Roehlkepartain [2008](#)). In addition, international experts participated in a method of consensus that guided development of the SDF.

According to the framework, three central developmental processes underpin spiritual development. Each process varies in how it occurs for different people. The processes are (a) awareness or awakening, (b) interconnecting and belonging, and (c) a way of living (Benson and Roehlkepartain [2008](#)). The authors posit that the processes are vital for healthy development. Further, these processes are of interest to those engaged in spiritual and religious traditions around the world. Each process is embedded in and interacts with (d) other dimensions of development (physical, cognitive, social, emotional, and moral), as well as (e) social contexts, (f) culture, (g) meta-narratives, and (h) change: time/growth/life experiences) (Benson and Roehlkepartain [2008](#)). The processes lead to (i) outcomes that may be harmful or healthy. Outcomes may be physical, cognitive, affective, or social. Further description of the core developmental processes will be provided to give greater insight on the applicability of the SDF.

The three core processes of awareness, interconnecting, and a way of living interact with each other and with varying levels of intensity. Awareness is the process of being, or becoming aware of, or awakening to one's self, others, and the universe (which may be understood as including the sacred or divine) in ways that cultivate identity, meaning, and purpose (Roehlkepartain et al. [2008](#)). An example of awareness is discovering one's capacity to make a difference in their community. Another example is being conscious of one's thoughts and feelings regarding self, relationships, world events, nature, and other entities or activities. Interconnecting is the process of seeking, accepting, or experiencing meaning in one's relationship with others, the world, or the transcendent (often including an understanding of God or a higher power). These connections are linked to beliefs that give meaning to human experiences across time (Roehlkepartain et al. [2008](#)). Beliefs are expressions of faith, and faith is profound confidence in a subject or being (Borgman [2006](#); Fowler [1981](#)). Examples of the process of interconnecting include valuing one's relationships with family members and advocating for connectedness and stability in all families. A way of living is the process of conveying one's individuality and

beliefs through relationships and activities that shape connections with oneself, others, and the transcendent (Roehlkepartain et al. [2008](#)). An example of this process is considering how one may have been guided or influenced by their belief system in making daily choices. The three core processes of the SDF are significant in understanding the interplay between life experiences and one's spirituality. The purpose of this paper is to present the SDF as a useful framework for the investigation of spirituality among adolescents. A description of how the SDF was used to develop and conduct a qualitative descriptive study with adolescents living with SCD is provided. An exemplar of the way the SDF informed the development of the interview guides and managing data during the process of data analysis will be presented.

## Methods

### Exemplar Study

A qualitative descriptive design was used to explore the spirituality of adolescents living with sickle cell disease. Participants aged 15–19 years were recruited from a sickle cell comprehensive clinic and a support group organization. Data collection continued until saturation was reached. A total of nine participants completed two semi-structured, one-on-one interviews. One semi-structured interview was conducted during the first scheduled interview session, and one semi-structured interview was conducted during the second scheduled interview session. Interviews lasted approximately 1 h each and were digitally recorded and transcribed verbatim. Results of this study have been reported elsewhere (Clayton-Jones et al. [2016](#)). Next, a description of how the SDF informed the development of the interview guide, data collection, and data analysis is provided.

### An Exemplary Use of the Spiritual Development Framework

The SDF was chosen as the theoretical framework for the exemplar study because it is not a stage-driven theory and allows interpretations of spiritual development to remain open to differences in life experiences and in more than one context (Benson and Roehlkepartain [2008](#)). The SDF offered an approach to understanding the spiritual development of adolescents prior to conducting research and throughout the research process.

The SDF provided both a philosophical framework and a methodology for the current study. Concepts and terminology were refined after reflecting on the SDF. Through purposeful reflection, terminology and concepts were designed to reflect the sacred and non-sacred ways spirituality may be expressed. The definition of spirituality was presented previously. A definition of religiosity was developed to provide a distinction between the two concepts. In addition, the depth of the interview questions and prompts were broadened to encompass the adolescents' spirituality.

### SDF and Interview Guides

The SDF was especially valuable as a reference to the researcher during the development of the interview guides. Originally, the researcher developed one version for the interview guide, but in order to gather data on the non-sacred aspects of the adolescents' spirituality such as social relationships, creative arts, or nature, a second version of the interview guide was developed (version 2). Use of the SDF facilitated refining of concepts and terminology used in questions on the interview guides. Each guide consisted of 24 open-ended questions that were accompanied by additional probes. The first version of the interview guide was used for participants who indicated on their demographic forms as having religious beliefs. The second version of the interview guide was used for participants who indicated not having religious beliefs. Use of the SDF allowed further development of the depth of the interview questions and the prompts for each question and incorporation of content that may not have been contemplated.

Use of the two versions of the interview guide allowed the researcher to appreciate that spirituality exists without religion and to capture the spirituality of adolescents regardless of their religious preference. It also

allowed for greater diversity and less restriction in their responses. In applying the process of *Interconnectedness*, the researcher was prompted to ensure that the beginning of the interview guides consisted of questions to lessen anxiety and convey that the researcher was interested in what the adolescents had to say. Examples include, “What kinds of things are you interested in?” and “What kinds of things do you like to do?” In applying the process of *awareness*, adolescents were queried about their self-awareness. Examples include “Tell me about some of your proudest moments or biggest source of happiness.” “How has this influenced your life?”

The questions in the interview guides were divided into three main areas of inquiry, including: (a) general information about the participant, (b) spiritual and religious beliefs, and (c) how the participants’ spiritual and religious beliefs influenced their lives and health. While the principal investigator (PI) considered having adult experts review the content of the interview guides for feedback, consideration of the SDF also directed the author to solicit the thoughts and reflections of adolescents around spirituality. This prompted the inclusion of adolescent content reviewers to provide feedback on the material contained within the interview guides and on the actual interview process. The interview guides were revised and established for use based on responses from the adolescent content reviewers. For example, when reflecting on the question an adolescent content reviewer reflected on the question “What do you feel is the purpose of your life?” “What do you feel gives your life meaning?” one adolescent reviewer indicated “For the second part of that question, why don’t you just ask “What gives your life meaning? I already know the question is based on my point of view.” The question “What do you feel gives your life meaning” was revised as suggested. The adolescent content reviewers indicated that both questions were necessary as they felt purpose and meaning were related but could mean different things to different people. Both questions were included as part of the interview guides as suggested.

## SDF and Data Collection

The principal investigator (PI) used the SDF for reflection and preparation before the one-on-one interviews. This preparation allowed the PI to be keenly aware of the significance of establishing rapport with adolescents, to be sensitive to verbal and nonverbal communication, and to be open to the adolescents’ descriptions of their spirituality and life experiences. This process also prompted the PI to have an increased awareness of personal beliefs and experiences regarding spirituality and how this may impact the course of the research. This awareness continued during the interview process.

One of the teen content reviewers suggested adding an activity to promote comfort during the interview process in the event the teen exhibited signs of being nervous. This activity consisted of a stress ball that was made available prior to the beginning of the interview for the teen to use as needed during the interview. Two different participants used the stress ball during their first individual interview session by handling it for the first 10–15 min of the interview. As the interviews progressed, the participants set the ball down and no longer expressed an interest in the stress ball. The PI also worked to conduct the interviews in a space with a window. Participants often looked outside the window during the interviews, and most were engaged in the interview process up until it was time to end (after 1 h).

Field notes were recorded after each interview to include thoughts of the PI. The PI’s pediatric background and experience include conceptual and operational knowledge of developmental stage theories. Review of the SDF concepts prompted the researcher to consider the manner in which spiritual development occurs rather than focusing solely on stage-driven concepts. Field notes consisted of reflections on stage theory concepts as well as concepts and occurrences that may influence spiritual development.

## SDF and Data Analysis

An integrated approach consisting of inductive and deductive methods for analysis was used. Data were analyzed using a template analysis style and a concurrent process of content analysis. A coding template was

created (Miller and Crabtree [1992](#)). The initial template included coding labels corresponding to the three core developmental processes of spiritual development as described in the SDF, including: (a) awareness or awakening, (b) interconnecting and belonging, and (c) a way of living.

The initial template was used to code the first interview transcript. New codes were generated, and the coding template included 14 codes. This template was applied to the second transcript. A second researcher independently coded the same two transcripts using the coding template of 14 labels. Again, new labels were generated. A fourth construct from the SDF, Meta-narratives, was added as a code. This construct described some of the historical and influential moments as shared by the adolescents. While the remaining constructs from the SDF were not included in the final coding template, obvious intersection does exist between the final codes and the remaining SDF constructs. Upon comparison, coding between the two researchers was approximately 80% matched and the template was revised to include 21 labels. This 21-label template was used for the next transcripts. At the end of each coding session, the PI reviewed codes, checked for redundancy, and combined codes to reduce data describing similar information and reorganized previous codes as needed. This resulted in a final coding template of 25 codes (20 top-level codes and five sub-codes) (see [Table 1](#)). The three core concepts of the SDF were robust codes capturing passages from across participants. The SDF coding labels were used to code passages within all of the participants' interviews. Thus, the SDF coding labels stayed on the final coding template. Use of the SDF allowed the researcher to remain open to interpretations of spirituality as described by the adolescents and enhanced interpretation of findings.

**Table 1.** Final coding template

Name	Description	Hierarchical name
1. A way of living	Expression of one's identity through action and relationships with self, others, the universe, and the sacred (Benson and Roehlkepartain, <a href="#">2008</a> ) Beliefs, values, and commitments expressed and lived out daily and life is grounded in a sense of hope and belief. Experiences of hope, meaning, or resilience in midst of hardship, conflict, and suffering. Person contemplates spiritual challenges and questions and identifies ways to live a life of strength.	A way of living
2. Awareness	Act of being aware of one's self, others, and the universe in ways that nurture and develop meaning and a sense of identity (Benson and Roehlkepartain <a href="#">2008</a> ) Consists of finding accepting, seeking, creating, or experiencing a reason for being or a sense of meaning and purpose (Benson and Roehlkepartain <a href="#">2008</a> )	Awareness
3. Beliefs (General)	Expressions of faith	Beliefs (General)
Beliefs and decision making	How one's beliefs do or do not influence how decisions are made	Beliefs (General)
Beliefs and illness or health	Participants thoughts on beliefs and impact during illness or influence on health outcomes	Beliefs (General)
Beliefs on purpose	Individual's beliefs on whether people are here for a reason	Beliefs (General)
4. Coping	Ways participants cope with problems, change	Coping
5. Expectations for healthcare providers	Adolescents' perceptions on the role of healthcare providers conducting a spiritual assessment	Expectations for healthcare providers
6. Faith	Profound confidence in a subject or being	Faith
7. Friend	One the participants identifies as a friend	Friend
8. Health perception	The individual's perception of their health and may include physical or mental health as described by the individual	Health perception

9. History of spiritual care	When participants indicate receiving spiritual care while ill, in the hospital, or in need	History of spiritual care
10. Identity perception	Characteristics the individual identifies as belonging to himself or herself based on their perception	Identity perception
11. Interconnecting	Finding, accepting, or creating profound significance and meaning in everyday experiences and relationships (Benson and Roehlkepartain 2008). The person may experience a sense of love or responsibility for others and the world and becomes connected to certain beliefs, traditions, mentors, communities, and narratives; these remain significant over time and may create sense of belonging	Interconnecting
Interconnecting God or a higher power, transpersonal	Seeking, accepting, or experiencing significance in one's sense of the transcendent to include God or a higher power	Interconnecting
Interconnecting-others, or creative intrapersonal, or creative arts	Seeking, accepting, or experiencing significance in one's relationships with others	Interconnecting
12. Life satisfaction	Periods in life that the individual has proud memories of	Life satisfaction
13. Meta-narratives	Stories, scriptures, historical moments shared	Meta-narratives
14. Perceived challenges	The individual's perception of experiences in life that may test their ability and call for support and/or resources within and possibly outside of the individual in order to cope	Perceived challenges
15. Religiosity	Expression of an individual's commitment to an organized way of knowing and orientating oneself to the religious community's subject of worship	Religiosity
16. Relationship is personal	Relationship with God or a higher power is personal, between the person and God and the relationship is private, communal as the person is a part of an organized religious community	Religiosity
17. Religion and meaning	Individual's thoughts on the meaning of religion	Religiosity
18. Sickle cell experiences	A description of the individual's pain crisis experiences or other experiences related to their sickle cell disease	Sickle cell experiences
19. Support	Sources of social support	Support
20. Transcendence	To go beyond oneself and perhaps beyond human experience and understanding	Transcendence

Use of the SDF assisted the researcher in understanding the process of spiritual development in an age-specific population with diverse experiences. For adolescents who indicated having religious beliefs and adolescents who indicated not having religious beliefs, processes from the SDF were consistently applicable throughout data analysis (see Table 2). The researcher was able to make comparisons between adolescents with different religious views. Greater insight was gained on the manner in which these processes of spiritual development and other SDF concepts intersect health and illness among adolescents living with a chronic condition. As adolescents shared their stories and described their experiences, the researcher gained sensitivity to their unique encounters that can be applied when working with this population.

**Table 2.** Examples of application of SDF coding labels

SDF concept	Participant	Example of coded data passage
-------------	-------------	-------------------------------



Awareness	16-year-old female	<i>Self-awareness:</i> "I plan to attend college and major in nursing"; "I consider myself a people person"; "I was naïve when I first entered high school and later I became more aware about the diversity of other people" <i>World Awareness (people, nature, God):</i> "I feel that I am very aware of the diversity of my friends and others and I respect them all"; "I believe there is a God"
	16-year-old male	<i>Self-awareness:</i> "I do plan to go to college and become a marine biologist"; "I am usually only interested in 3-4 classes at a time and I just want to get school over with" <i>World Awareness (people, nature, God):</i> "My friends don't necessarily share the same beliefs that I do, but that's OK. It doesn't stop them from being my friends or interfere with who they are."; "I like animals and I am interested in protecting and helping them"; "I'm an atheist, but if there is a God, I think I would be alright since I'm not a bad person"
Interconnecting	16-year-old female	<i>Interconnecting:</i> "My mom, stepdad, friends, cousin, God-mother, and God-sisters are important in my life" "Being at the right church to meet my needs and faith are important"; "I look forward to participating in the gospel choir, volunteering in the community, participating in drama, and being an athletic trainer"; "I have a relationship with God, a bond"
	16 year-old male	<i>Interconnecting:</i> "My mom, maternal grandparents, younger brother, cousins, and paternal grandmother are important to me"; "I participate in rugby and wrestling and I like baseball, but I am not a fanatic"
A way of living	16-year-old female	<i>A Way of Living:</i> "I try to closely pattern and live my life based on the Bible, on how virtuous women live their lives in the Bible"; "I try to pattern my life after my mom, and see that she's strong. She's successful because she trusts—faith and trust go hand-in-hand, so she has faith in God."; "If you're just solely waiting on God to do something, He's waiting on you to put in the effort."; "I think if, oh, this is so cliché, like the WWJD, like what would Jesus do, it's kind of like, literally, would Jesus really be out here"
	16-year-old male	<i>A Way of Living:</i> "Overall having good morals is important"; "...but I think we all cheat"

Data were distributed fairly evenly among the three core developmental processes of the SDF and indicated that adolescence is a period where awareness, interconnecting, and a way of living are significant. Without use of the SDF, consistency in remaining open to individual descriptions may have been interrupted or reduced. In addition, being familiar with the SDF encouraged the researcher to have an awareness of developmental frameworks that are stage driven and how prior knowledge of such frameworks could impact data analysis.

An iterative data analysis process led to identification of themes that captured the descriptions and experiences of spirituality and health of the participants. Four major themes emerged to include spirituality and religiosity as coping mechanisms, shaping of identity, influence of beliefs on health and illness, and expectations of healthcare providers. The theme spirituality and religiosity as coping mechanisms included six threads to include: interconnecting with God, interconnecting with others, interconnecting with creative arts, scriptural meta-narratives, transcendent experiences, and acceptance and finding meaning. The theme expectations for healthcare providers included two threads: religiosity is private/personal and sharing spiritual and religious beliefs can be risky.

### Participants' Experiences in the Study

After the interviews were completed, a follow-up telephone call was made to participants to ask the following: "Describe your experience with participating in this study." Five of the nine adolescents who participated in this

study were available and provided responses (Table 3). Overall, participants verbalized satisfaction. They reported that the experience was “enjoyable,” provided an opportunity to “reflect” and “express” themselves, and that they would participate in a similar study again. The integration of spirituality as a concept for research development may be fundamental for research with adolescents living with sickle cell disease (SCD).

**Table 3.** Participant responses to the statement: “describe your experience with participating in this study.”

Participant One:	“I enjoyed it because I was able to reflect on my life. I was able to reflect on not only the bad things but also the good things that I’ve been through....so it helped me to really learn from what I’ve gone through and help me grow from that. I found it challenging in a way when putting my thoughts together about certain things but I would participate again.”
Participant Two:	“Just normal I guess, it was just an interview....I didn’t really think too much of it”
Participant Three:	“I thought it was very professional and it allowed me to express myself and look at my life differently...and be able to have a good casual and informative kind of conversation. It was very thorough and kind of let me dig deep....I enjoyed it. It wasn’t a typical interview it was different and I liked it. I would absolutely do this again.”
Participant Four:	“It was pretty relaxing, while it was a long questionnaire....it wasn’t bad at all. It was like a regular interview. Going through the process I wasn’t nervous about anything....I just felt comfortable.
Participant Five:	“I had fun and the interviews were great. It was great and I would do it again.”

Further investigation is needed on whether participation in a study encompassing spirituality or using a qualitative design has any impact on the level of satisfaction with the interview experience. Additional factors such as characteristics of the researcher, antecedents to the participants’ spirituality, or the interview environment should also be considered. Additional insight can contribute to further theory development and usefulness of the theory when conducting research with chronic illness populations.

## Discussion and Conclusions

Spirituality may be particularly meaningful for adolescents living with sickle cell disease (SCD) in comparison with other age groups or those who do not live with a chronic illness. This population deals with the transitions that occur during adolescence to include the shaping of their identity, preparing for their future, and their evolving relationships. Living with a chronic illness coupled with health disparities that exist for persons of color in general often leads to unique and challenging experiences (Jenerette and Brewer 2010; Ezenwa et al. 2015; Smith et al. 2006). Spirituality, a universal phenomenon innate in each person is worth exploring when developing an approach to conduct research with adolescents living with SCD. Providing adolescents with opportunities to make meaning out of their experiences, including their participation in research, may benefit both the participants and researchers.

There are currently no published studies (known to the principal investigator of the current study) on use of the SDF in conducting spirituality and health research, or when working with vulnerable chronic illness populations. The exemplar was provided in order to demonstrate the significance of the SDF when conducting research with adolescents living with SCD. The SDF was valuable and used as a guide to develop conceptual definitions and language, the interview guides, and throughout the process of data analysis. Based on the findings from this study, the researchers identified ways adolescents relied on their spirituality to cope with life and specifically their SCD. The SDF was a fit for exploring how adolescents living with SCD used their spirituality and the manner in which spiritual development occurred. Use of the SDF may provide a foundation and systematic method for developing and conducting more robust studies with adolescents in the context of spirituality and health. Understanding how spirituality impacts health and illness will support researchers in research development and analysis. This knowledge may be used by adults working with young people to identify spiritual strengths and

appropriate resources adolescents can use to cope with challenges, illness, or other life events. Identifying best practices to evaluate spiritual needs of adolescents will assist clinicians in providing developmentally appropriate holistic care that is essential for adolescents' quality of care and quality of life.

## Notes

### Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## References

- Benner-Carson, V., & Koenig, H. G. (2004). *Spiritual caregiving: Healthcare as a ministry*. Philadelphia: Templeton Foundation Press.
- Benson, P. L., & Roehlkepartain, E. C. (2008). Spiritual development: A missing priority in youth development. *New Directions for Youth Development*, 118, 13–28. <https://doi.org/10.1002/yd.253>.
- Benson, P. L., Roehlkepartain, E. C., & Rude, S. P. (2003). Spiritual development in childhood and adolescence: Toward a field of inquiry. *Applied Developmental Science*, 7(3), 204–212. [https://doi.org/10.1207/S1532480XADS0703\\_12](https://doi.org/10.1207/S1532480XADS0703_12).
- Borgman, D. (2006). Bridging the gap: From social science to congregations, researchers to practitioners. In E. C. Roehlkepartain, P. E. King, L. Wagener, & P. L. Benson (Eds.), *The handbook of spiritual development in childhood and adolescence*. Thousand Oaks: Sage.
- Clayton-Jones, D., Haglund, K., Belknap, Ruth Ann, Schaefer, J., & Thompson, A. A. (2016). Spirituality and religiosity in adolescents living with sickle cell disease. *Western Journal of Nursing Research*, 38(6), 686–703.
- Cotton, S., Zebracki, K., Rosenthal, S. L., Tsevat, J., & Drotar, D. (2006). Religion/spirituality and adolescent health outcomes: A review. *Journal of Adolescent Health*, 38, 472–480.
- Ezenwa, M. O., Molokie, R. E., Wilkie, D. J., Suarez, M., & Yingwei, Y. (2015). Perceived injustice predicts stress and pain in adults with sickle cell disease. *Pain Management Nursing*, 16(3), 294–306.
- Fowler, J. W. (1981). *Stages of faith*. New York: Harper Collins
- George, L. K., Larson, D. B., Koenig, H. G., & McCullough, M. E. (2000). Spirituality and Health: What we know, what we need to know. *Journal of Social and Clinical Psychology*, 19(1), 102–116. <https://doi.org/10.1521/jscp.2000.19.1.102>.
- Haase, J. E., & Phillips, C. R. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*, 21, 145–149.
- Jackson, L., Roller-White, C., O'Brien, K., DiLorenzo, P., Cathcart, E., Wolf, M., et al. (2010). Exploring spirituality among youth in foster care: Findings from the Casey field office mental health study. *Child and Family Social Work*, 15, 107–117. <https://doi.org/10.1111/j.1365-2206.2009.00649.x>.
- Jenerette, C. M., & Brewer, C. (2010). Health-related stigma in young adults with sickle cell disease. *Journal of the American Medical Association*, 302(11), 1050–1055.
- Larson, D. B., Swyers, J. P., & McCullough, M. E. (1998). *Scientific research on spirituality and health: A consensus report*. Rockville: National Institute for Healthcare Research.
- Miller, W. L., & Crabtree, B. F. (1992). Primary care research: A multimethod typology and qualitative road map. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research*. Newbury Park: Sage.
- Miller, W. R., & Thoresen, C. E. (2003). Spirituality, religion, and health: An emerging research field. *American Psychologist*, 58, 24–35. <https://doi.org/10.1037/0003-066x.58.1.24>.
- North American Nursing Diagnosis Association. (2001). *NANDA nursing diagnoses: Definitions and classification 2001–2002*. Philadelphia: North America Nursing Diagnosis Association.
- Name and title deleted to maintain the integrity of the review process.
- Pargament, K. I. (1997). *The psychology of religion and coping: Theory, research and practice*. New York: The Guilford Press.

- Pehler, S. R., & Craft-Rosenberg, M. (2008). Longing: The lived experience of spirituality in adolescents with Duchenne muscular dystrophy. *Journal of Pediatric Nursing, 24*(6), 481–494.
- Pendleton, S. M., Cavalli, K. S., Kenneth, B. A., Pargament, K. I., & Nasr, S. Z. (2002). Religious/spiritual coping in childhood cystic fibrosis: A qualitative study. *Pediatrics, 109*, 1–11.
- Reed, P. G. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing and Health, 15*, 349–357. <https://doi.org/10.1002/nur.4770150505>.
- Reynolds, N., Mrug, S., Hensler, M., Guion, K., & Madan-Swain, A. (2014). Spiritual coping and adjustment in adolescents with chronic illness: a 2-year prospective study. *Journal of Pediatric Psychology, 39*(5), 51–542.
- Roehlkepartain, E. C., Benson, P. L., King, P. E., & Wagener, L. M. (2006). Spiritual development in childhood and adolescence: Moving to the scientific mainstream. In E. C. Roehlkepartain, P. E. King, L. Wagener, & P. L. Benson (Eds.), *The handbook of spiritual development in childhood and adolescence*. Thousand Oaks: Sage.
- Roehlkepartain, E. C., Benson, P. L., Scales, P. C., Kimball, L., & King, P. E. (2008). *With their own voices: A global exploration of how today's young people experience and think about spiritual development*. Minneapolis: Search Institute.
- Smith, L. A., Oyeku, S. O., Homer, C., & Zuckerman, B. (2006). Sickle cell disease: A question of equity and quality. *Pediatrics, 117*(1), 1763–1770.
- Snethen, J. A., Broome, M. E., Kelber, S., & Warady, B. (2004). Coping strategies utilized by adolescents with end stage renal disease. *Nephrology Nursing Journal, 31*, 41–49.
- Taylor, E. J. (2002). *Spiritual care: Nursing care: Nursing theory, research, and practice*. Upper Saddle River: Prentice Hall.
- Wong, Y. J., Rew, L., & Slaikeu, K. D. (2006). A systematic review of recent research on adolescent religiosity/spirituality and mental health. *Issues in Mental Health Nursing, 27*(2), 161–183. <https://doi.org/10.1080/0161284050>.