

# Spirituality Experiences in Hemophilia Patients: A Phenomenological Study

Masoume Rambod<sup>1</sup> · Farkhondeh Sharif<sup>2</sup> · Zahra Molazem<sup>1</sup> ·  
Kate Khair<sup>3,4</sup>

Published online: 17 April 2018

© Springer Science+Business Media, LLC, part of Springer Nature 2018

**Abstract** Spirituality plays an important role in coping with chronic diseases. However, the meaning of spirituality is not known in hemophilia, as a chronic disease. This study aimed to explore the essence of spirituality in hemophilia patients. This qualitative study with a hermeneutic phenomenological approach was conducted on twelve Muslim adult hemophilia patients. The participants were selected using purposeful sampling. The data were gathered through interview. Then, the data were analyzed using thematic analysis and van Manen’s methodological framework. MAX.QDA qualitative software package 2010 was used to import the transcripts and analyze the data. Four themes were identified: “relationship with God,” “God as the fulcrum,” “strong religious beliefs,” and “spiritual satisfaction.” “Relationship with God” meant “to ask God for help” and “praying for oneself and others.” “God as the fulcrum” consisted of two subthemes, i.e., “hope in God” and “Trust in God.” “Strong religious beliefs” also included “belief in openness of God’s mercy,” “belief in God and the omnipotence of God,” and “belief in creation by God.” Finally, “spiritual satisfaction” consisted of two subthemes, namely “accepting the

---

✉ Farkhondeh Sharif  
farkhondeh\_sharif@yahoo.com

Masoume Rambod  
rambodma@yahoo.com; rambodm@sums.ac.ir

Zahra Molazem  
molazem@sums.ac.ir; molazemzah@yahoo.com

Kate Khair  
Kate.Khair@gosh.nhs.uk

<sup>1</sup> Community Based Psychiatric Care Research Center, Department of Medical Surgical Nursing, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Shiraz, Iran

<sup>2</sup> Community Based Psychiatric Care Research Center, Department of Mental Health and Psychiatric Nursing, School of Nursing and Midwifery, Shiraz University of Medical Sciences, Zand St., Nemazee Sq., Shiraz 7193613119, Iran

<sup>3</sup> Great Ormond Street Hospital for Children NHS Foundation Trust, London WC1N 3JH, UK

<sup>4</sup> London South Bank University, London, UK

providence” and “thanking the divine blessings.” Spirituality in hemophilia patients meant having relationship with God who was considered as the fulcrum, strong religious beliefs, and spiritual satisfaction. By understanding the hemophilia patients’ spirituality experiences, the nurses and healthcare workers could provide holistic care focused on spirituality. Yet, more studies are recommended to be conducted on hemophilia patients to explore spirituality in other religions.

**Keywords** Hemophilia · Hermeneutic · Qualitative research · Spirituality

## Introduction

Hemophilia is an inherited genetic disorder that leads to spontaneous and trauma-related bleeding as a result of clotting factors VIII and XI insufficiency. This impairment leads to joint damage and consequently arthropathy (Hochenberry and Wilson 2015). It also affects the physical, social, and psychological domains of quality of life (Dolatkhah et al. 2014) and results in many stresses in life (Binnema et al. 2014). Therefore, patients have to develop coping strategies for continuing their lives (Binnema et al. 2014). Higher coping capacity was associated with less psychological distress (Gaston-Johansson et al. 2013). Spirituality, as a coping strategy, has been employed to cope with diseases (Targ and Levine 2002) and stress (Cotton et al. 2009) in various religious traditions for a long time (Targ and Levine 2002).

Spirituality was defined as “personal search to understand the final questions about life, its meaning, and its relationship with sacredness or transcendence that may or may not lead to the development of religious practices or formation of religious communities” (Lucchetti 2014).

Spirituality and religious coping present a framework for determining the experience of serious diseases and even death (Daaleman and Vandecreek 2000). Spirituality has been reported to improve psychological well-being, such as lower levels of depression, anxiety, and hopelessness (Pargament et al. 1988), thus affecting physical health indirectly (Karekla and Constantinou 2010). Moreover, greater positive religious coping leads to fewer admissions in hospitals (Bediako et al. 2011) and more happiness (Lewis et al. 2005). Pargament recommended that religion might provide faith and hope in human beings (Pargament et al. 1988). It also increased pain management, affected the use of healthcare, and improved the quality of life (Clayton-Jones and Haglund 2015). Furthermore, religious coping increased the individuals’ psychological resources, such as sense of mastery and self-esteem, and helped them make an interpretive framework or cognitive schema, such as searching for and finding meaning (Siegel et al. 2001). Religious resources may also increase emotional comfort and hope and provide a sense of meaning and purpose (Jenkins and Pargament 1995).

Review of the literature revealed that a limited number of qualitative studies were published on spirituality in chronic conditions, such as cancer (Lagman et al. 2014; Rahnama et al. 2012) and sickle cell disease (Cotton et al. 2009; Cotton et al. 2012), as well as in the patients who survived hematopoietic stem cell transplantation (Alaloul et al. 2015) and adults receiving blood and marrow transplants (Ragsdale et al. 2014). In a study on Iranian cancer patients’ perception of spirituality, the three following themes emerged: “God as the spiritual truth (relationship with God and trust in God), moralities as a spiritual sign (considering personal and social moral codes), and spiritual resources as the source of hope (religious, personal, and social resources)” (Rahnama et al. 2012). Moreover,

adolescents with sickle cell disease described their spirituality and religiosity experiences as “spirituality and religiosity are sources for coping,” “influence of spirituality and religiosity beliefs on health and illness,” and “sharing spirituality and religiosity with healthcare providers” (Clayton-Jones et al. 2016).

The results of the previous qualitative studies indicated that the meaning of spirituality and its essence seemed to be different in chronic diseases and in various backgrounds and cultures. Moreover, although the positive effects of spirituality on health were reported in some chronic conditions (Pargament et al. 1988; Karekla and Constantinou 2010; Lewis et al. 2005), no studies have evaluated spirituality in hemophilia patients using qualitative or quantitative approaches. Therefore, the meaning of spirituality in hemophilia patients is unclear. As the meaning of spirituality in adult hemophilia patients is not known, a study has to be performed to describe and interpret the experiences of spirituality in this group of patients. This would be possible through a qualitative study and hermeneutic phenomenological approach. Hermeneutic phenomenology is a method of reflection on the fundamental structures of the lived experience of human existence. In other words, it is the way to access the world as it is experienced reflectively. According to van Manen, experiences seem to have their routes in the flow of every day existence. Additionally, experiences are identified in the sense that we can recall, name, describe, and reflect on them. In fact, experiences are recognized as experiences since they can be named and described (Van Manen 2014). Therefore, by using lived experiences, this hermeneutic phenomenological study aimed to explore the essence of spirituality in hemophilia patients.

## Materials and Methods

This qualitative study with a hermeneutic phenomenological approach was conducted in a hemophilia center in Dastgheib hospital affiliated to Shiraz University of Medical Sciences, Shiraz, Iran. The inclusion criteria of the study were being Muslim, aging 18 years and above, speaking Persian, and being alert and oriented. On the other hand, the patients with cognitive impairment, untreated mental illnesses, and other genetic diseases were excluded from the study. The study participants included twelve adult hemophilia patients with deficiency of factors VIII and IX selected through purposeful sampling. In order to gain rich, deep, oriented, and strong information, the hemophilia patients described their spirituality stories and the data were set as they reflected the sound of the patients and revealed the spirituality experiences.

The hemophilia patients' spirituality experiences were elicited through semi-structured interviews. The interviews were conducted by the first author of this article in a conference room in the hemophilia center. The interviews were focused on spirituality experiences. The interviews started with “What are your spirituality experiences in living with hemophilia,” “What is the meaning of spirituality in hemophilia patients' lives,” and “How did you feel about spirituality in hemophilia patients' lives.” The interviews were continued according to the patients' answers. Exploratory questions, such as “Can you explain more,” “What do you mean,” and “Could you give me an example” were asked, as well. The participants' descriptions were audiotaped and transcribed immediately after being listened to repeatedly and analyzed simultaneously with the process of data collection. MAX.QDA qualitative software package 2010 was used to import the transcripts

and analyze the data. It should be mentioned that each participant took part in one interview lasting for 30–90 min.

Data collection was performed from March 2013 to July 2015. Data collection and analysis were conducted until achieving rich information and the point where analysis disclosed nothing new or different regarding the phenomenon (Van Manen 2014).

van Manen's (1990) six-step methodological framework was used for data analysis. First of all, we turned to the nature of lived experiences of spirituality in hemophilia patients. Second, we investigated the experience as the patients live it. In this step, deep interview was done with 12 Muslim hemophilia patients. The third stage consisted of hermeneutic phenomenological reflection on the essential themes characterizing the spirituality experiences. In this step, thematic analysis with holistic or sententious, selective or highlighting, and detailed or line-by-line approaches was performed and reflection on transcripts was done. The fourth step was hermeneutic phenomenological writing. In this step, writing and rewriting were done. The fifth stage was maintaining a strong and oriented relation to the spirituality experiences. In this step, focus was on research questions. The sixth and last stage consisted of balancing the research context by considering the parts as well as the whole. In this part, the researchers always focused on research question and assessed the part and whole of the experiences (van Manen 1990).

This study was approved by the Ethics Committee of Shiraz University of Medical Sciences. Besides, informed consent was obtained for digital audiotaping of the interviews. In doing so, the study objectives and the interviewing process were explained to the participants. They were also informed that they could withdraw from the study at any time. In addition, they were reassured about their anonymity.

The validity and reliability of this study were examined using van Manen's explanations. According to van Manen, the researchers determined if the phenomenological interpretation of the spirituality meaning structure was valid and the phenomenological themes emerging from the descriptions were appropriate and original. Based on van Manen's explanations, phenomenological study of the same phenomenon can be diverse in different studies (Van Manen 2014). Therefore, our study, like other phenomenological studies, was not reliable.

## Results

This study was conducted on twelve Muslim hemophilia patients. The patients' ages ranged from 19 to 76 years, with the mean age of 36.25 years. Among the 12 patients participating in this study, eleven were male and one was female. Besides, 66.67% of the patients were married. Additionally, half of the participants had primary and secondary school degrees. Most of the participants had hemophilia A (83.33%), and the disease was severe in 50% of the cases (Table 1).

Spirituality experiences in hemophilia patients consisted of four themes, including: "relationship with God," "God as the fulcrum," "strong religious beliefs," and "spiritual satisfaction" (Table 2).

### Relationship with God

"Relationship with God" in the lived experiences of the hemophilia patients meant "to ask God for help" and "praying for oneself and others" (Table 2). The adult hemophilia

**Table 1** Frequency and percentage of the hemophilia patients participated in the study

Variables	Number (percentage)
Sex	
Male	11 (91.67)
Female	1 (8.33)
Education levels	
Primary school	4 (33.33)
Secondary school	2 (16.67)
High school and diploma	4 (33.33)
Academic	2 (16.67)
Marital status	
Single	4 (33.33)
Married	8 (66.67)
Type of hemophilia	
A	10 (83.33)
B	2 (16.67)
Severity of disease	
Mild	2 (16.67)
Moderate	4 (33.33)
Severe	6 (50.0)

**Table 2** Themes and subthemes of the spirituality experiences in the hemophilia patients

Themes	Subthemes
Relationship with God	To ask God for help Praying for oneself and others
God as the fulcrum	Hope in God Trust in God
Strong religious beliefs	Belief in openness of God's mercy Belief in God and the omnipotence of God Belief in creation by God
Spiritual satisfaction	Accepting the providence Thanking divine blessings

patients had a relationship with God and asked God for help at the time of physical limitations for joints recovery. They also asked God for help for being healthy and not having bleeding and disease complications. In addition, the patients asked God for help for healing of themselves and other patients and meeting the financial needs.

One of the participants who was a 28-year-old man paralyzed for 15 years because of the hip and both knees arthropathy talked about his request from God during this period:

sometimes, I nag to my God. I felt angry or became aggressive when I saw my legs are paralyzed. I told my God if you liked me, I would never have these problems. However, on those moments I became regretful because of this kind of communication with God. Then, I apologized God and I wanted God to help me. . . I always wanted God to help me. I said, my God help me. From the bottom of my heart, I said my God, I need help (P 6).

One of the participants talked about the time of hospitalization in childhood:

I said, “God heal me so that I do not have to deal with these problems when I am playing, falling down . . .” . I said, “my God, discharge me form hospital so that I can go home. . . When I see children with hemophilia, I say God heals you . . . heals all, and heals me. God, you as the uniqueness, heal all people, heal me (P 8).

The participants had relationships with God by “praying for themselves and others.” They talked with God by praying for healthcare providers and their own family members. Moreover, they linked with God by saying peace be upon Mohammad and his holy family and requesting for improvement of their paralyzed legs. One of the participants who was a 53-year-old man prayed for himself and said:

I hope that if God gives a disease, honoring Imam Hussein Ibn Ali (as), He himself heals us. . . OK, I said to God, God! Heal all of us so that the disease doesn’t affect us (the patient raised his hands during the prayer), that we will not have problems, that we will not need others (P8).

### **God as the Fulcrum**

The second theme of spirituality in the lived experiences of the patients with hemophilia was “God as the fulcrum.” This theme consisted of two subthemes, namely “hope in God” and “trust in God” (Table 2).

The patients’ expressions were full of “hope in God” for removing physical limitations, achieving goals, ability to perform daily tasks, having a healthy child, and nonrecurrence of hepatitis. One of the participants who had recently got married said:

I like to have a healthy boy. I always trusted in God. In general, when I am doing anything, I always trust God. I start with hope, I remember Allah, and then I will do the job (P 6).

The hemophilia patients had “trust in God” about healing from the disease, control of hepatitis B, and not having hemophilia children. In this regard, one of the participants said:

We just have to trust in God. God will hopefully solve all people’s problems (P 8).

### **Strong Religious Beliefs**

The third theme of this study was “strong religious beliefs.” This theme meant “belief in openness of God’s mercy,” “belief in God and the omnipotence of God,” and “belief in creation by God” (Table 2). The participants believed in a supernatural power (God) that controls human destiny. Moreover, they had a strong belief in God. They believed that the universe is made by God. One of the participants about his belief in God stated:

This means that God is merciful and compassionate. If He closes a door, He opens thousands of other doors. I believe it. I always pray (Namaz). I believe that He can do anything. Only God has the absolute power (P 8).

### **Spiritual Satisfaction**

The fourth theme of this study was “spiritual satisfaction,” which consisted of two sub-themes; i.e., “accepting the providence” and “thanking divine blessings” (Table 2). The hemophilia patients’ descriptions of “accepting the providence” revealed hemophilia and

hepatitis as a divine destiny. This implies that there was a philosophy behind suffering from hemophilia. In fact, the patients were satisfied with God's will for having this disease.

One of the participants who was a 76-year-old man said:

I mean I'm satisfied with God's will. . . Everything coming from God is good. . . It is a part of our destiny. It was God's will that I have hemophilia. A leaf does not fall from a tree unless with God's order. This was also God's will.

"Thanking divine blessings" in living with hemophilia involved sense of gratitude to God because of competency in self-management, not having AIDS, other diseases, and complications in critical moments of life, and having appropriate socioeconomic status.

The hemophilia patients appreciated God because of having the ability to control bleeding in their complications, efficacy of infusion of the factor, having the ability to work and walk, and having mobility and self-management capabilities. One of the participants who suffered from severe arthropathy in one's right knee and used crutches to move mentioned:

Thank God. Thank God again. I can move and do my tasks, thank God. . . I always say thank God (P 5).

The participants appreciated God due to the efficacy of infusion of the factor and not having other diseases. One of the participants maintained:

Thank God because there were no self-injection factors in the past, but you can do that these days. Thank God. You can stop bleeding easier and faster . . . Thank God. When I compare the disease to other diseases . . . I thank God for thousand times (P 3).

A participant who was 21-year-old also explained his spiritual satisfaction in this way:

Thank God. Now that I've grown up, my life is better, the severity of my disease has decreased . . . I thank God that I don't have HIV. . . Thank God nothing happened to me while I was on a trip. Thank God, God gave me both the pain and the treatment (P 9).

## Discussion

Spirituality in living with hemophilia meant "relationship with God," "God as the fulcrum," "strong religious beliefs," and "spiritual satisfaction." In every moment of life, the hemophilia patients lived with remembrance of Allah, requesting God to help them, praying for themselves and others, hope and trust in God, and strong religious beliefs. However, review of the literature revealed no studies on spirituality in patients with hemophilia; therefore, the findings were compared to those of similar articles. Spirituality and religiosity, as coping mechanisms, in adolescents living with sickle cell disease involved "interconnecting with God, interconnecting with others, interconnecting with creative arts, scriptural metanarratives, transcendent experiences, and accepting and finding meaning" (Clayton-Jones et al. 2016). In a study on sickle cell disease, the participants reported high rates of religious attendance and belief in God, prayed often, and had high levels of spirituality (finding meaning/peace in their lives and deriving comfort from faith). Moreover, spirituality played an important role in coping with chronic diseases (Cotton et al. 2009).

The results of the present study showed that the hemophilia patients had a "relationship with God" in their lives. One of the meanings of spirituality is "relationship with God"

(Rahnama et al. 2012). In this regard (e.g., guidance and conversation with God), one of the patients in the research by Walton and Sullivan maintained that “He’s my friend, because I talk to Him like we’re really pals, although I know He’s God, He’s a pal-God. He’s like the closest pal I know that I can talk to about the hardest things that I have to think about” (Walton and Sullivan 2004). It was also reported that “God in a supportive or emotional role helped patients, comforted them, and was there for and with them in times of need” (Cotton et al. 2012). Overall, God’s support is a religious coping strategy in which God assists, benefits, protects, and comforts (Pendleton et al. 2002).

Spirituality in the lived experiences of the patients with hemophilia also meant “God as the fulcrum.” This theme consisted of two subthemes; i.e., “hope in God” and “trust in God.” Spirituality / religion led to maintenance of hope and a sense of meaning and purpose of life (Thune-Boyle et al. 2006). Religious beliefs might also mean days of illness and hope for a better life and a desire to boost survival (Bussing et al. 2016). “Hope in God” has also been often used in the holy Quran. In 18 Al-Kahf: 24, it has been stated that “And remember your Lord when you forget [it] and say, perhaps my Lord will guide me to what is nearer than this to the right conduct.” Moreover, in various verses, Allah wants His servants to have trust (3 Ali ‘Imran: 122, 160; 11 Hud: 123; 4 An-Nisa: 81; 33 Al-Ahzab: 3, and 5 Al-Ma’idah: 5, 11). In 5 Al-Ma’idah: 11, it has been mentioned that “And upon Allah let the believers rely” (2016). In these verses, God wants His servants to trust him. This helps them endure difficulties and God will help them. By these verses, the hemophilia patients always trusted in God through their difficulties.

In the current study, the hemophilia patients always asked God for help. In Quran, Allah speaks about helping His servants and reminds them about the participants of the battle of Badr “[Remember] when you asked your Lord for help and He answered you” (8 Al-Anfal: 9) (2016). This verse indicates that if servants ask God, God helps them if He wants.

In our study, the hemophilia patients prayed for themselves and others. Praying, as a very valuable activity, was also seen in the lived experiences of patients with cancer (Lagman et al. 2014). Levine et al. showed that the women who prayed found positive aspects in their experience with breast cancer (Levine et al. 2009). Langman et al. also conducted a qualitative study and indicated that cancer patients prayed in their lives. They believed that prayer in a variety of ways was a source of comfort and healing. In fact, prayer, as an effective and powerful coping mechanism, helped participants to be calm, reduce their fears, and derive positive meaning and strength from their experiences of the disease (Lagman et al. 2014). In another study, patients with sickle cell disease prayed “to get well, to keep from getting sick, and to get out of the hospital” (Cotton et al. 2012). One other study on the lived experiences of sickle cell patients also demonstrated prayer and spiritual activities as the major coping strategies. In that study, the participants believed in God and prayed, particularly in case of exacerbation of their conditions. They also took part in spiritual activities, including fasting and going to church for prayer meetings (Forrester et al. 2015). Considering answers to prayers, God in Quran says “And when My servants ask you, [O Muhammad], concerning Me, indeed I am near. I respond to the invocation of the supplicant when he calls upon Me” (Al-Baqarah 2: 186) (2016). Thus, the hemophilia patients with strong beliefs in God asked for help and prayed for themselves and others.

In the present study, one of the themes of meaning of spirituality in the hemophilia patients was “strong religious beliefs.” “Believing that God chose me, affirming that my life has a purpose, receiving spiritual encouragement, and experiencing strengthened faith” were four themes emerged from the meaning of use of religion and/or spirituality in adults receiving blood and marrow transplants (Ragsdale et al. 2014). In fact, religion was



effective in coping with the disease and might act as a buffer for some disease-related stresses (Bussing et al. 2016). The hemophilia patients also believed in the omnipotence of God, representing their strong religious beliefs. In many Quran verses, it has been expressed that “He [God] is competent over all things” (11 Hud: 4, 8 Al-Anfal:41, 67 Al-Mulk:1, 35 Fatir:1). In addition, the patients with hemophilia in this study referred to the openness of divine mercy. “Say, Your Lord is the possessor of vast mercy” (6 Al-An’am:147). It was also stated in 10 Yunus: 58 that “Say, in the bounty of Allah and in His mercy, in that let them rejoice” (2016). God’s mercy has been pointed out in these verses and the hemophilia patients believed in it.

Spirituality in the hemophilia patients also meant “spiritual satisfaction.” It consisted of two subthemes, namely “accepting the providence” and “thanking divine blessings.” Thanking God for blessings in the lived experiences of the hemophilia patients referred to the sense of gratitude to God because of self-management capabilities, not having other diseases, appropriate socioeconomic status, not having complications in sensitive moments of life, and not having AIDS. The hemophilia patients also appreciated God because of having the ability to control bleeding and their complications, efficacy of infusion of the factor, having the ability to work and walk, and having mobility and self-management capabilities. In a study conducted by Levine et al. in 2009, one of the patients reported that “I praise you and I thank you and I praise you and every time thank you” (Levine et al. 2009). In addition, the patients in the research by Smith et al. stated that “when I get up, I thank God because I have another day (Smith et al. 2012). In Quran, God wants His servants to be always thankful for God’s blessings. In 31 Lugman: 12, it has been expressed that “And We had certainly given Luqman wisdom [and said], be grateful to Allah. And whoever is grateful is grateful for [the benefit of] himself. And whoever denies [His favor], indeed, Allah is free of need and praiseworthy” (2016).

The findings of this study showed that the hemophilia patients’ lives were full of spirituality. Yet, further researches are required to design a spirituality scale and evaluate its psychometric properties. Other studies are also suggested to assess the effect of themes, such as hope in God, trust in God, and religious beliefs on hemophilia patients’ health and quality of life.

## Conclusion

Spirituality in hemophilia patients meant “relationship with God,” “God as the fulcrum,” “strong religious beliefs,” and “spiritual satisfaction.” By understanding the spirituality experience of hemophilia patients, nurses can provide high-quality care focused on patients’ unique spirituality needs. Moreover, they can communicate with and care for patients based on spirituality and their belief in God. Yet, more studies are recommended to explore spirituality in other religions.

**Acknowledgements** This article was extracted from Masoume Rambod’s PhD dissertation in Nursing (Proposal No. 93-7081), which was approved and financially supported by the Research Vice-chancellor of Shiraz University of Medical Sciences. The authors would like to thank the personnel of the hemophilia clinic in Dastgheib hospital affiliated to Shiraz University of Medical Sciences for their cooperation. They are also grateful for all the participants who kindly contributed their time to this research. The authors would like to thank Shiraz University of Medical Sciences, Shiraz, Iran, and also Center for Development of Clinical Research of Nemazee Hospital and Dr. Nasrin Shokrpour for editorial assistance.

**Author Contributions** The study was designed by MR, FS, ZM, and KK. The interviews were conducted by MR. The data were analyzed by MR and FS. The manuscript was written by MR, FS, ZM, and KK. All the authors critically reviewed the early drafts of the manuscript and agreed with the final version.

**Funding** This study was funded by Research Vice-chancellor of Shiraz University of Medical Sciences (Grant Number: 93-7081).

### Compliance with Ethical Standards

**Conflict of interest** All of the authors declare that they have not conflict of interest.

**Ethical Approval** This study was approved by the Ethics Committee of Shiraz University of Medical Sciences (EC-9371-7081, date: 9 July 2014). Moreover, all procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all the participants included in the study.

## References

- Alaloul, F., Schreiber, J.A., Al Nusairat, T. S., Andrykowski, M. A. (2015). Spirituality in Arab muslim hematopoietic stem cell transplantation survivors. *Cancer NursingTM*. Wolters Kluwer Health, Inc.
- Bediako, S. M., Lattimer, L., Haywood, C., Jr., Ratanawongsa, N., Lanzkron, S., & Beach, M. C. (2011). Religious coping and hospital admissions among adults with sickle cell disease. *Journal of Behavioral Medicine*, *34*(2), 120–127.
- Binnema, M., Schrijvers, L. H., Bos, R., Schuurmans, M. J., & Fischer, K. (2014). Coping in adult patients with severe haemophilia. *Haemophilia: The Official Journal of the World Federation of Hemophilia*, *20*(4), 513–518. (Epub 2014/01/25).
- Bussing, A., Franczak, K., & Surzykiewicz, J. (2016). Spiritual and religious attitudes in dealing with illness in polish patients with chronic diseases: Validation of the Polish version of the SpREUK questionnaire. *Journal of Religion and Health*, *55*(1), 67–84. Epub 2014/10/27.
- Clayton-Jones, D., & Haglund, K. (2015). The role of spirituality and religiosity in persons living with sickle cell disease: A review of the literature. *Journal of Holistic Nursing*, *34*(4), 351–360.
- Clayton-Jones, D., Haglund, K., Belknap, R. A., 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., Grosseohme, D., & McGrady, M. E. (2012). Religious coping and the use of prayer in children with sickle cell disease. *Pediatric Blood & Cancer*, *58*(2), 244–249.
- Cotton, S., Grosseohme, D., Rosenthal, S. L., McGrady, M. E., Roberts, Y. H., Hines, J., et al. (2009). Religious/spiritual coping in adolescents with sickle cell disease: A Pilot Study. *Journal of Pediatric Hematology/oncology*, *31*(5), 313–318.
- Daaleman, T., & Vandecreek, L. (2000). Placing religion and spirituality at end of life care. *Journal of the American Medical Association*, *284*, 2514–2517.
- Dolatkah, R., Fakhari, A., Pezeshki, M. Z., Shabanlouei, R., Tavassoli, N., & Gholchin, M. (2014). Social determinants and health-related dimensions of quality of life in adult patients with haemophilia. *Haemophilia: The Official Journal of the World Federation of Hemophilia*, *20*(3), 376–381. (Epub 2013/11/21).
- Forrester, A. B., Barton-Gooden, A., Pitter, C., & Lindo, J. L. M. (2015). The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica. *International Journal of Qualitative Study on Health and Well-being*, *10*, 28104. 10.3402/qhw.v10.28104.
- Gaston-Johansson, F., Haisfiels-Wolfe, M. E., Reddick, B., Goldstein, N., & Lawal, T. A. (2013). The relationships among coping strategies, religious coping, and spirituality in African American women with breast cancer receiving chemotherapy. *Oncology Nursing Forum*, *40*(2), 120–131.
- Hochenberry, M. J., & Wilson, D. (2015). *Wong's nursing care of infants and children: Mosby*. Amsterdam: Elsevier Inc.
- Jenkins, R. A., & Pargament, K. I. (1995). Religion and spirituality as resources for coping with cancer. *Journal of Psychosocial Oncology*, *13*, 51–74.

- Karekla, M., & Constantinou, M. (2010). Religious coping and cancer: Proposing an acceptance and commitment therapy approach. *Cognitive and Behavioral Practice, 17*, 371–381.
- Lagman, R. A., Yoo, G. J., Levine, E. G., Donnell, K. A., & Lim, H. R. (2014). Leaving it to god: Religion, spirituality and filipina American breast cancer survivors. *Journal of Religion and Health, 53*(2), 449–460.
- Levine, E. G., Aviv, C., Yoo, G., Ewing, C., & Au, A. (2009). The benefits of prayer on mood and well-being of breast cancer survivors. *Supportive Care in Cancer, 17*(3), 295–306. <https://doi.org/10.1007/s00520-008-0482-5>. (PubMed: 18633651).
- Lewis, C. A., Maltby, J., & Day, L. (2005). Religious orientation, religious coping and happiness among UK adults. *Personality and Individual Differences, 38*, 1193–1202.
- Lucchetti, G. (2014). Spirituality, religiousness and health: Implications for the field of hematology. *Rev Bras Hematol Hemoter, 36*(3), 171–172.
- Pargament, K. I., Kennell, J., Hathaway, W., Grevengoed, N., Newman, J., & Jones, W. (1988). Religion and the problem-solving process: Three styles of coping. *Journal for the Scientific Study of Religion, 27*, 90–104.
- Pendleton, S. M., Cavalli, K. S., Pargament, K. I., & Nasr, S. Z. (2002). Religious/spiritual coping in childhood cystic fibrosis: A qualitative study. *Pediatrics, 109*, 8.
- Ragsdale, J. R., Hegner, M. A., Mueller, M., & Davies, S. (2014). Identifying religious and/or spiritual perspectives of adolescents and young adults receiving blood and Marrow transplants: A prospective qualitative study. *Biology of Blood and Marrow Transplantation, 20*, 1238–1257.
- Rahnama, M., Fallahi Khoshknab, M., Maddah, S. S. B., & Ahmadi, F. (2012). Iranian cancer patients' perception of spirituality: A qualitative content analysis study. *BMC Nursing, 11*, 19.
- Siegel, K., Anderman, S. J., & Schrimshaw, E. W. (2001). Religion and coping with health related stress. *Psychology and Health, 16*, 631–653.
- Smith, A. R., DeSanto-Madeya, S., Perez, J. E., Tracy, E. F., DeCristofaro, S., Norris, R. L., et al. (2012). How women with advanced cancer pray: A report from two focus groups. *Oncology Nursing Forum, 39*(3), 310–316.
- Targ, E. F., & Levine, E. G. (2002). The efficacy of a mind–body–spirit group for women with breast cancer: A randomized controlled trial. *General Hospital Psychiatry, 24*, 238–248.
- The Noble Quran. (2016). <http://quran.com/>. Accessed 16 June 2016.
- Thune-Boyle, I. C., Stygall, J. A., Keshtgar, M. R., & Newman, S. P. (2006). Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Social Science and Medicine, 63*(1), 151–164.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. New York, NY: State University of New York Press.
- Van Manen, M. (2014). *Phenomenology of practice: Meaning- giving methods in phenomenological research and writing*. Walnut Creek, California: Left Coast Press, Inc.
- Walton, J., & Sullivan, N. (2004). Men of prayer: Spirituality of men with prostate cancer: A grounded theory study. *Journal of Holistic Nursing, 22*(2), 133–151.