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Longing: The Lived Experience of Spirituality in Adolescents with Duchenne Muscular Dystrophy

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1. 1 Introduction

Despite the increase in nursing knowledge of adult spirituality and mandates to provide spiritual care to promote healing, few researchers have addressed the lived experience of spirituality for children or adolescents experiencing chronic, debilitating or life-threatening condition. Healing does not mean “cure” in the common use of the word, but instead a sense of health and well-being as experienced by hope, love, control, relatedness with others, finding meaning and purpose in life and disease, and a awareness that there is something greater than the self (Fryback, 1993; Mytko & Knight, 1999; Reed, 1992; Tanyi, 2002). It is not known whether adolescents, like adults, need to work at creating new meaning and purpose in life despite their condition. Although teens have the ability to describe their spirituality according to developmental and systems perspective theories (Erikson, 1963; J.Fowler, 1981; J. W. Fowler & Dell, 2004; Lerner, 2002; Piaget, 1976), very few researchers have explored the phenomenon of spirituality in teens. Before developing effective spiritual assessment and intervention strategies that can promote healing, researchers need to describe an adolescent’s lived experience of spirituality in a chronic, debilitating or life-threatening illness (Benner, 1985; Wright, 2005).

In order to capture this phenomenon, adolescents 12–17 years of age, who have the chronic, debilitating and life-threatening illness of Duchenne Muscular Dystrophy (DMD) were chosen for the study. Duchenne Muscular Dystrophy (DMD) is a sex-linked inherited, chronic and debilitating condition in which the progression of the disease gradually weakens the skeletal or voluntary muscles. The natural course of DMD finds these adolescents’ dependence increasing as they are confined to wheelchairs with progressive muscle weakness (Chance, Ashizawa, Hoffman, & Crawford, 1998; Lashley, 1998). During their middle to later adolescent years, most have severe respiratory system compromise requiring ventilatory

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support (Lashley, 1998). Although advancements in the treatment have increased the longevity and aims to improve the quality of life for children and adolescents who have DMD, there is still no cure. This chronic and debilitating disease takes the lives of many of these adolescents during their early adulthood. With the ongoing regressive physiological changes and chronic debilitating nature of DMD during this age span in the adolescent's life, an increased spiritual awareness is suspected, increasing the possibility for the phenomenon of interest to be elicited in this sample. Past research has examined spirituality as a protective factor in risk-taking behaviors, to promote thriving indicators, and to provide support during illness (Christian & Barbarin, 2001; Clarke, 2001; Cotton, Larkin, Hoopes, Cromer, & Rosenthal, 2005; DeForge, Zehnder, Minick, & Carmon, 2001; Grey, Lipman, Cameron, & Thurber, 1997; Hendricks-Ferguson, 2006; Holder et al., 2000; Houskamp, Fisher, & Stuber, 2003; Langille & Curtis, 2002; Lindsey, Kurtz, Jarvis, Williams, & Nackerud, 2000; Pearce, Little, & Perez, 2003; Pendleton, Cavalli, Pargament, & Nasr, 2002; Pizer, 2000; Regnerus & Elder Jr, 2003; Wong, Rew, & Slaikau, 2006). The tools used in the measurement of the constructs have at times only used a single dimension of spirituality, usually that of church attendance. Because the focus of past research has been limited to risk reduction and spiritual support using research tools with a single dimension of spirituality, there is a need to broaden spirituality research. This need includes the description the lived experience of spirituality when an adolescent is experiencing a chronic, debilitating or life-threatening disease. The purpose of this descriptive phenomenological study is to describe the lived experience of spirituality in adolescents 12–17 years of age with Duchenne Muscular Dystrophy (DMD) using van Manen's Phenomenological method.

Definitions

Spirituality—Reed (1992, p. 350) defines spirituality as “the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual” (p. 350). These related dimensions provide connectedness through intrapersonal, interpersonal, and transpersonal relationships (Burkhart & Solari-Twadell, 2001; Reed, 1992). Reed (2003) further articulates that transcendence is “found in everyday practices in reaching deeper within the self and reaching out to others and to one's God” (p. 146). There is a developmental component to a person's spirituality, based on that person's individual characteristics; cognitive and emotional development; and interpretations of life experiences, events and questions (Baldacchino & Draper, 2001; Margaret A. Burkhardt, 1989; Farran, Fitchett, Quiring-Emblen, & Burck, 1989; J. Fowler, 1981; Goldberg, 1998; Nagai-Jacobson & Burkhardt, 1989; Pehler, 1997; Reed, 1992). Spiritual responses to a life-changing or life-threatening event can give meaning to that event and influence individual responses (Baldacchino & Draper, 2001; Hermann, 2001; Kendrick & Robinson, 2000).

Religion—Religion is the beliefs, values, practices and rituals that are an observable aspect of a person's spirituality and help a person express his or her connectedness to what they experience as the sacred (Baldacchino & Draper, 2001; Emblen, 1992; Farran et al., 1989; Goldberg, 1998; Hay, 1985; Taylor, 2001). Religiosity is more closely related to a faith community or a social institution (Burkhart & Solari-Twadell, 2001). While religion can be one way an individual expresses his or her spirituality; it is not the only way. Manifestations of music, art and nature have also been linked to spiritual expression and serve as a means of connecting with an individual's higher power or energy force (Baldacchino & Draper, 2001; Taylor, 2001).

Often the terms spirituality and religion are used interchangeably. It is hard for adolescents to differentiate their spiritual versus religious definitions due to their cognitive and spiritual development stage (Scott, 2006). A number of researchers recommend that these concepts be understood as highly related, with blurred boundaries since youth cannot readily distinguish

religion from spirituality (Barnes, Plotnikoff, Fox, & Pendleton, 2000; Davies, Brenner, Orloff, Sumner, & Worden, 2002; Houskamp et al., 2003; Sexson, 2003). Therefore, the term spirituality will be used in this document except when referring to a specific religious institution.

Literature Review

Adolescents and Spirituality—A developmental approach was the framework used in the earliest empirical studies that explored spirituality in children and adolescents. Most of these early studies found a stage-like progression in a child and adolescent's spiritual development. The research built upon Piaget's Stages of Cognitive Development and Erickson's Eight Ages of Man, which interacted with physical and psychosocial growth and development (J. Fowler, 1981; Goldman, 1964; Harms, 1944; Heller, 1986; Klingberg, 1959; Pierce & Cox, 1995). Later research has shown spirituality to be influential in promoting healthy behaviors. Spirituality has been found to promote physical and mental well-being (Davis, Keer, & Robinson Kurpius, 2003; Pearce et al., 2003), encourage school achievement (Regnerus & Elder Jr, 2003), support resiliency (Francis & Evans, 1996; Lindsey et al., 2000) and increase the adolescent's intake of fruits and vegetables (Lytle et al., 2003).

Studies have also found spirituality in adolescents to be a protective factor against tobacco, alcohol and illegal drug use (Christian & Barbarin, 2001; Hodge, Cardenas, & Montoya, 2001; Miller, Davies, & Greenwald, 2000; Ritt-Olson et al., 2004; Sutherland & Shepherd, 2001). Additional studies have shown church attendance and an adolescent's religious beliefs as protective against voluntary sexual activity (Holder et al., 2000; Langille & Curtis, 2002; Levin et al., 2001; McCree, Wingood, DiClemente, Davies, & Harrington, 2003), and other high-risk behaviors such as school absenteeism, delinquency, poor body image, disordered eating, antisocial behavior and suicidal involvement (Hyde, 1990; Resnick, Harris, & Blum, 1993; Weaver et al., 2000).

III Adolescents and Spirituality—Few studies about spirituality in children or adolescents with chronic conditions have been published. Of the studies published, spirituality was found to contribute to a positive cognitive appraisal of negative life events through finding meaning and feeling of decreased levels of anxiety in at risk youth (Davis et al., 2003). Spirituality has also been reported as a coping strategy during an exacerbation of CF (Pendleton et al., 2002), and as a resource for siblings after the death of their brother or sister (Batten & Oltjenbrauns, 1999). For some children and adolescents, spirituality was seen as a resource during the time of illness, while others question God as to why this illness occurred to them (Coles, 1990). Cole felt the question "Why me?" was seen as a spiritual question of trying to find meaning despite disease. In another study, one avenue by which adolescents asked these questions 'Why' was through personal prayer (Francis & Evans, 1996). In groups who did and did not attend church, adolescents who prayed more frequently were able to express an increased meaning to their lives. Studies describing the lived spiritual experience of teens with Duchenne Muscular Dystrophy could not be found.

Methods

Participants and Data Collection—The Phenomenology research method of van Manen (1990) was used to frame and organize this study. A purposive sample of male adolescents with Duchenne Muscular Dystrophy who were 12–17 years of age, in the 5th–12th grade was the research participants. Eight of nine identified themselves within the Judeo-Christian tradition and six of the eight Christians identified specific church affiliations. Based on observation, all participants used wheelchairs. Some participants could easily transfer from wheelchair to sofa, other participants needed parental assistance to reposition, but no formal measurement of disability was done. Potential parents and teens were initially contacted by the

clinical nurse specialist at a neuromuscular clinic in a Midwest referral clinic. If the parent(s) approved, and if the adolescent was interested in participating in the study, he returned a form to the researcher that provided the contact information for the researcher to call the participant. The researcher then contacted the parent(s) and adolescent to describe the study, answer any questions, and if both the parent and adolescent gave consent, arrange the date, time and location of the interview. Interviews took place in the adolescent's home and were audiotaped and conducted using the Interview Guide.

The Interview Guide was developed based on van Manen's approach of staying as close to the experience as lived (van Manen, 1990) by using broad open-ended questions (Table 1). By using the spirituality framework proposed by Reed (1992), the researcher took the broad concept of spirituality and identified questions so that the participants were asked to describe their intrapersonal, interpersonal and transpersonal connectedness experiences. Specific questions were developed for the probes, based on recommendations for interviewing adolescents of potentially varying developmental and cognitive abilities (Eder & Fingerson, 2003). A demographic questionnaire was developed for the parents to complete, which included any religious affiliation and religious participation of the teen. Obtaining data on the religious affiliations and activities were used to provide context for the teens' answers. A second phone interview following one to two weeks after the first interview was designed to clarify any questions of the researcher and the participant. Data was collected until saturation was achieved.

Minimizing Risks—Although minimal risks included the participant's feeling embarrassment or pressure that there were right or wrong answers to the questions, the researcher monitored and observed the participant closely for any signs of distress or increased anxiety. Except for one participant with cognitive involvement from DMD, no participant stated he was, or was observed to be anxious. In the lone instance, the researcher stopped that interview and the data were not included in the final data analysis (final sample N=9). Participants were also given the names of a chaplain from the Spirituality Department and a psychologist affiliated with the study site to contact should they have any untold effects after participating in the research project. Six months after the final interview, neither the Chaplain nor the psychologist had received any phone calls from the participants asking for assistance. Confidentiality was maintained through each participant's receiving of a code that could not be linked to him, and all data was kept in a locked file drawer, or as in the case of electronic data, password protected. IRB approval was obtained prior to data collection.

Data Analysis—Analysis of the data followed van Manen's method. The four essential steps of van Manen's Phenomenological Research method include: a) turning to the phenomenon, b) investigating the experience as lived, c) reflecting on the essential themes, and d) describing the phenomenon through writing. Differing from other phenomenological research methods, van Manen calls researchers to trace the etymological sources and idiomatic phrases of the phenomenon and essential themes, and explore instances of the phenomenon in art, music and literature. The researcher consulted dictionaries, art, music, published phenomenological and other research studies before and after the data collection. By exposing herself to various expressions of spirituality through these various mediums, the researcher was able to broaden her own understanding of spirituality, keeping herself open to the varied expressions the participants might share. NVivo (QSR NVivo 2, 2002) was used to assist with the data analysis and organization of the data summaries. Use of Sandelowski's (1986) criteria for scientific rigor addressed the credibility, fittingness, auditability, and confirmability of the findings. The researcher increased the credibility of the findings by bracketing prior held knowledge and beliefs on the phenomenon of interest, and using field notes after each interview to describe her own feelings and experiences. These reflections were often reviewed to ensure that the researcher's personal ideas and themes were not embedded in the analysis. Members of the

researcher's dissertation committee were experts in the phenomenological research method, adolescent development, and genetic disease. These experts provided guidance and oversight to be sure that the findings were well-grounded in life experiences of the participants. All data and field notes were transcribed by the researcher and verified by an independent reviewer. The data, field notes, and final analysis were audited by Dr. Howard Butcher, an experienced researcher and methodological expert in phenomenological research. Confirmability was enhanced through member checks, as the second phone interview was an opportunity for the researcher to clarify any questions from the initial interview and allowed the adolescents to share further thoughts. A pilot study was conducted with two participants prior to the start of data collection to test all procedures, documents and Interview Guide.

1. 2 Results

Lived Experience of Spirituality: Longing

The essential and central theme of the lived experience of spirituality the participants shared was that of longing. Longing is "that which longs; characterized by yearning desire" (Oxford English Dictionary Online, 2006). Webster further identifies longing as "a strong desire especially for something unattainable" (Merriam-Webster Online Dictionary, 2006). The concept of longing was not found in the nursing literature. In an analysis of longing from the psychology literature, Holm(1999) (1999)(1999; Holm, 1999) defined longing as "a need for something—a thing, a state, a relationship--without which one's life does not feel complete" (p. 625). This need for completeness was evident through the participants' longing of missed activities and longing in relationships, as seen in their descriptions of having DMD, their reports of the progression of the disease, and their accounts of instances when they were teased by others.

Longing for missed activities—The most prevalent component of the adolescents' longing was for missed activities. Although longing is often for something in the future, the longing expressed by all of the participants was that of yearning for something that they could no longer do. John* described his experience of having Duchenne's as:

I just wish I could do stuff that my friends could do...When I'm watching TV, when I'm watching them ride bikes and I wish I could do that stuff. It sucks to have it... and sometimes it makes me mad, 'cause when I see my friends like ride bikes off of jumps and stuff...It's hard to watch them do that.

Ryan expressed his longing in "watching other kids playing on the playground, and that's hard to watch them. I wish I could be with them, running around." Fred also shared the difficulty to get to places: "I just can't walk, walk around like other people. And it's hard for me to get in houses, and that is what bothers me the most in a wheelchair, like I would go up a ramp and get stuck."

Participants also expressed longing when they described their disease progression. This longing was a strong desire for the disease to slow down in its progression to preserve remaining abilities. Ryan had a cousin who also has DMD. His description of how his cousin was affected and how he tried to decrease the effects of the disease exemplifies the longing to avoid the further loss of abilities:

MD [Muscular Dystrophy] it could make your bones get weaker, but I do stretches and stuff so it makes it stronger. Yeh if you don't stretch, if you don't curve in like this, you ... curve in, hunched over like this [participant curves back and leans forward in his chair] my cousin is like that.

* All names have been changed to protect confidentiality.

Aaron described his experience of disease progress as a separate entity, almost as if it had its own personality: “It means the muscles in my legs are weak and deteriorating, it also causing for some reason, [Contractures]. Yeh, that’s what happening to those, and it progresses whenever it wants to, it [disease] progresses fast if it wants to or as slow as possible.”

There was hesitancy and pausing as this participant described his disease progression. He loved to draw, and the sense of longing was expressed not only when he shared the physical changes that had occurred, but also through his inability to take caps off of markers or draw circles or straight lines due to the disease progression.

Longing for relationship—The sense of longing was also evident when the teens talked of their relationships with others. For some of these teens, it was difficult for them to have friends, either due to their dependence on others to take them places or because of their inability to participate in activities. Ben described, “It is kind of hard to get friends because they run and play and other stuff, and you can’t run around, and you have to sit down and do other stuff.” Andrew described a more specific time when this occurred. “When friends are going to do something that I can’t do... They wanted to go play basketball, and I couldn’t.” This participant further expressed his desire for missed relationships, not only through missed activities, but also missed time being spent together. “When friends are going out of town, they...can take friends and I can’t [go].”

1.2.1.1 Longing to be seen as a person

Finally, a number of the participants expressed a longing to be seen as a person, and not to be made a target for jest due to the disease. The teens shared specific examples of not only their peers calling them names or making fun of them, but also adults. “What makes me sad; is when people talk to me and call me a cripple, that makes me feel sad, it is mean and I don’t know why they do that... ‘Hey cripple,’ I don’t like that word.”

Amelioration of Longing—The teens expressed longing through their desires of wanting to be able to do activities that they no longer could participate in, through missed relationships with others, and the longing to be seen for who they were. Overwhelming longing can lead to despair and loss of self (Holm, 1999). The teens in this study attempted to ameliorate the lived spiritual experience of their longing through connecting with self, others and beyond self. Connecting is defined as “to place or establish in relationship” (Merriam-Webster Online Dictionary, 2006). The Oxford English Dictionary Online (Oxford English Dictionary Online, 2006) defines connecting as “related by ties of family, intimacy, common aims.”

Connecting with self—Under the essential theme of connecting with self, all of the participants attempted to establish a relationship with self in the midst of their longing. Some of the teens used strategies that could be found in the coping literature, such as avoidance, diversion, physical activity, and looking to others for examples. The transactional theory of coping proposes that during emotional-focused coping, a person uses strategies such as avoidance, minimization, distancing, selective attention, and positive comparisons to attempt to lessen emotional distress (Lazarus & Folkman, 1984). During emotional-focused coping, a person also diminishes a threat by changing the meaning of the situation, especially when they are unable to change the reality of the situation. Teens may also transcend longing by focusing on the positive and by identifying their purpose in life in an attempt to reappraise their situation.

Most often, participants used diversion to fill the longing. When feeling the longing of not being able to participate in the same activities with friends, the teens often played video games, watched TV, drew or listened to music as means of filling the longing. “It [TV] gets me off

the subject [of feeling sad].” The participants frequently used avoidance when they had to deal with being picked on. They would try to ignore the person teasing them, try to forget about it, or move away from that person: “People who make fun are just losers; I get away.” Ryan used avoidance as a strategy after experiencing seizures that often left him scared. “I take a deep breath till the scary goes away. I just try [to] shake it off; I just shake it off; I don’t know why....but it just goes away.”

Andrew used physical activity in the form of taking things apart or tearing down walls. “That’s fun sometimes [punching holes in a wall]. When you are mad, it’s better than taking it out on something else.” Aaron filled his fear of an upcoming surgery by connecting with his own inner strength after hearing other people’s stories: “Probably just being in the hospital and seeing, hearing about some people taking a turn for the worse, and coming out of it and stuff like that.”

Despite the physical limitations of the participants, they still found positive approaches to their experiences. As an MDA ambassador, Fred saw the positives of being able to go to different activities: “I get to go to different games, like hockey games. I am the state MDA for basketball, and I get to go to camp, summer camp.”

Ryan found a positive aspect of being in the wheelchair: “But sometimes it’s [being in a wheelchair] fun. Like when my cousin and I race around and stuff. So it’s actually kind of fun and stuff.” Aaron even saw the necessary adaptations in a positive light: “But I take adaptive PE and that is really nice because it doesn’t make you focus on the things that you can’t do, it focuses on the things you can do.” The same teen also transcended longing through connecting with self by looking at the abilities he still has:

But I think it [living with DMD] also a couple of good things about it, I can draw better than a lot of people, because I don’t have anything else to do during the winter and I can just sit there for hours and draw and get better...I am also able to see technical things in my head...It took a while but I can see in my head how an engine works, how everything is moving, and I have a really good imagination.

In addition to focusing on the positives, the teens transcended longing through identifying their purposes in life. For Andrew, it was “to help other people, other children in wheelchairs, to design wheelchairs, design one that works better, because some people who aren’t in wheelchairs are making them and they don’t understand.” Luke felt his purpose was related to his skills in working with computers: “I feel I know what a computer needs and how to fix it... I’ve guided them [others] through their [computer] problems. I show them things.” Aaron saw not only his purpose in life as what he could do for others, but also how his disease might help others find their purpose.

Well I think, I don’t think I got this disease out of spite, I think it might just be to make me think of something that can help people or make me see things different and help the world...And like this might help me see...just for people like me, that ... like make things for us or do things for us.

1.3 Connecting with others

The essential theme of connecting with others took on a deeper dimension than was initially revealed. As explained earlier, DMD is a progressive, neuromuscular disease in which teens become more dependent, losing their ability to walk, dress or eat by themselves. This loss creates a growing dependence on others for their basic activities of daily living, especially at a time when developmentally most teens should become more independent. All participants, for example, used a wheel chair to move around. There were varying degrees of upper body strength, with some being able to lift themselves out of the wheel chairs to move to other chairs,

and other teens needing to throw their body weight forward in the chair just to change body positions. Because of the growing dependence on others, the essential theme of connecting with others moved beyond the emotional connection, with teens sharing how their connections with others were also physical connections. Of ten the researcher observed a symbiotic relationship between the teen and parent, as the parent was able to reposition or anticipate the teen's needs, often without the teen saying a word. Even if the parent was in another room, the teen easily called to the parent to verify a date or the name of something they were trying to describe. It was against this backdrop that the theme "connecting with others" took on an added dimension, that of a symbiotic physical connection as well.

Almost all teens identified this connection with one or both parents. For John it was the physical presence of the parent that was very important: "Yeh, like watch my dad. He works on cars." This teen described later in the interview what was important to him: "Being with my dad. There's... I don't know...like spending time with my mom... and my friends and a lot of people." For Ryan, it was to "talk to my mom." Similarly, Luke said: "My mom, I can talk about things that bother me." Ben had a number of connections to others: "My mom, my sister, my friends. My pets, my dad when he is around, sometimes...my dog and my guinea pig." Aaron was able to describe how his parents provided every opportunity for him to fill this longing, no matter how long (or short) the timeframe would be:

I don't know, I think it's just, if you have someone to talk to, or family of any kind, just know that there is still joy and still be happy, just knowing that there is some things you can't do but there are some things you can still say you can do or say you've done that other people can't. Like even though someday I wouldn't be able to ride my 4-wheeler, my dad still got me one and the couple years I could ride, the 4 years I could, it was worth it. Even though it is sad to know I can't go back and do it, at least I did it, and I knew it was fun. My dad and my mom like, ...like they'll do anything so I can do something just a little bit longer.

Besides parents, friends also provided this connection. Although some teens had friends to whom they could talk, most teens identified the mere presence of their friends as most helpful. When asked if his friends were people he could talk to when he was feeling sad, Ben said, "No, I just play with them and that helps me feel better." Andrew identified the connection with friends due to their physical assistance, "...opening doors and such. If I drop something they [friends] help me; they pick it up for me." Later in the interview, Andrew identified how his friends stick up for him when teased by others: "They're nice to me; not too many people make fun of me. My friends yell at the people who are making fun of me; it helps." But this participant was also able to describe how his friends and he did the normal teenage things: "[I] drive around outside, go to the shelter house. It is a place where everyone hangs out at a park. We just talk, hang out together." Aaron echoed this sense of normalcy that friends can provide for the teens:

Like when we're at his house, he'll kind of help me because he can, ...we'll hangout with his little cousins, play video games, watch TV, play with Lego's. Well, Eric, and Bruce, there're really my three real friends, besides my friend Robby; they just make me feel normal and help me with things too, and they're just good friends.

Participants also shared their connections with professionals at school and in the hospital. Fred spoke of a couple of the professionals he had as resources: "I talk to other people, guidance counselor." Later in the interview he shared: "I work with this adult, and I do stuff with him, homework; he helps me with homework, play, shoot baskets." Luke found his personal assistant helpful when things weren't going well: "Especially at school when I'm mad or stressed out about something, my associate will talk about things at school." The relationship that these professionals and participants shared helped to maintain normalcy for the participants, filling the longing for missed activities.

Animals also provide this connection. A number of the participants had dogs, while a few had guinea pigs or cats. Some of the participants connected to their pets by talking to them. John said, "I usually talk to my dog." For Adam and Ben, it was the presence of the pet that created the connection. When asked if he could talk to his dog when he was sad, Ben said, "No, I pet him." Adam related that one of the things he liked to do was draw pictures of dogs. When asked what types of dogs he drew pictures of, he said, "Just my dog." With reflection he was able to describe how his dog helped him: "I don't know....her presence."

Connecting beyond self

The essential theme of connecting beyond self helped the participant transcend longing. Participants were able to describe connecting beyond self in two dimensions. One dimension related to a religious connection, in which the participant transcended longing through a higher power. This connecting beyond self was seen in the way they described attributes of the higher power, the relationship with the higher power, prayer requests to the higher power, and participation in religious activities. The second dimension helped participants transcend through spirituality in a way that empowered them to fill their longings.

Connecting beyond self through a higher power

Whenever the participants discussed a higher power, they referred to the higher power as God in the Judeo-Christian tradition, which coincided with the information provided by the parents on the demographic survey. Some of the attributes relate to the physical appearance and activities of God. Ben pictured God as "someone like sitting on a throne...looking down on us playing." Some of the participants provided attributes of what God is like. James described God's actions: "He likes us...He is kind."

For Ryan, the attributes of God could be seen in a get-well card he made for his cousin, who also has DMD. This cousin had recently fallen and broken his arm. The card had a picture of a fire truck and Mickey Mouse on the front, to represent the cousin's recent trip to Disney World and the vehicle that comes to help people. On the inside of the card, in the upper left hand corner was the picture of an angel, in the center of the card a picture of a cross, and below the cross another figure. He described his drawing this way:

I'm drawing that there is hope that he [cousin] is going to be okay. [That an] angel [is] watching over him. And this cross that shows that God is watching over him and there is hope that I will see him soon. That is me and I hope that... hope I will see him soon and hope that he will get better.

Besides the feeling that God was watching over them, their relationship with God was evident in how they described how God helps them. Ryan stated: "He's [God] is important to me, because he helps me out a lot. He is someone I can talk to, like pray to him." Andrew, who was stuck for two hours in a park because his electric wheelchair had broken down, described how God sent people to help him: "Once in a while I pray when I get stuck somewhere; that works to get help usually." God was helpful for Ben when he was angry or at school: "At school, to get my work done, I ask him to help me...when I get mad I just pray to Him and I feel better." For Luke, who was struggling to learn how to sleep with a bipap machine and who had concerns with a brother who was getting into trouble at school, God was there to help him:

I just pray if I feel like I need it or if there is no hope or no help. I just pray and it makes me feel better with the problems that are going on....helping me feel better if I'm crying, just to help me relax so I can go to sleep.

Besides praying to God when they were mad or needed help, one of the prayers described was to find a cure for DMD. John prayed "that they will find a cure or something...Like if I could walk and stuff." Aaron not only prayed for himself, but also for others. "[I pray] that I'll get

better or that something good will happen to someone I know, or just anything like that.” Ryan said his prayers were for “good dreams at night, that people will have safe travel.” This participant also prayed for “stuff that makes me sad, Grandma [who had died]; I pray for my sister because she is in college.”

Some of the teens shared their experiences of when prayers were answered, affirming their belief in prayer. Ryan shared one experience: “It’s like things I ask Him [God] for come true. It’s like I asked to see my dad, and I got to see my dad the next day.” Aaron said:

I believe in God because, you know, like when I was little and my grandma got really sick, and she took a turn for the worse one night and I prayed for her and the next morning she walked out of the hospital.

Connecting beyond self through a higher power is also evident in the participants’ descriptions of religious activities in which they participate, despite some of the difficulties. Andrew almost apologetically stated, “Going to church, reading the Bible, and praying. I go to church once in a while; it is hard to get up that early to go to church; that’s the main thing.” Fred described what he does at church: “I go to church...Sunday School, learn about the Bible and get to do fun things, like at Bible school...[Bible school] gives kids hope.” Ben stated, “I read about Him [God] in the Bible. I do my devotions, I believe I do that every day...I think about Him.”

Descriptions of the connecting beyond self to alleviate longing through a higher power provided insight into the religious understanding of the participants and their relationship to God. This connecting to God was filled with descriptions of hope, requests for help, prayers for a cure, as well as prayers for others.

Connecting beyond self through spirituality

Most of the participants did not know what spirituality was when asked a general question from the Interview Guide. First by sharing the probe from the Interview Guide in how some people define spirituality, then asking the participants to describe a picture they would draw about spirituality, participants described rich insights into their spirituality.

For most of the participants, religious descriptions of the Judeo-Christian God were how they defined spirituality. Ryan stated, “It’s talking to God and going to church and praying.” Andrew described a picture of heaven similar to that of the Judeo-Christian belief of God having “a long beard, tall” and “He made all of the animals, that the animals are there in the picture” with “people praying, singing.”

Luke, who was aware of the term spirituality, had a definition from the religious perspective, but his picture of spirituality transcended the religious aspect. For this participant, spirituality was “what you believe in; like if you believe in God or a reason to live.” For him personally, he tried “following the Bible, living by God’s terms, living a way that you follow the 10 Commandments.” A little later in the interview his picture of spirituality had “people that look different on the globe that hold hands together...peace like they get along, like holding hands together all over the globe.” Adam had also heard of the term spirituality and defined it as, “What you believe in.” He, however, could not describe those beliefs. “I don’t know, I don’t really have a religion; I don’t have a certain one.” His picture of spirituality was of things that were in his everyday life. “My dog and my mom, stuff I do, like drawing or playing or stuff.” In Ben’s picture of spirituality, he did not have any physical limitations, “Like big giant trees, & waterfalls, and me running around and I’d be playing with other kids.” Fred’s picture of spirituality, however, pictured him as still needing a wheelchair: “People helping me, like opening doors.”

Aaron shared his understanding of spirituality which he said came after he had a major surgical procedure. Prior to this procedure, he stated he had been very afraid of dying. His spiritual experience of making it through surgery provided these insights to him, which helped him transcend his longing:

It [surgery] also made me realize that even though, people can have any religion, still nobody judges them. Knowing that everyone is the same, it doesn't matter if you are Hindu or Christian or Jewish, spirituality is different than religion if you're spiritual it's believing in something...It's believing in something to keep you going...It's knowing that there's a better place, where everyone gets to see everybody again and, ...and knowing that there just, that it be perfect, that's basically it...There'd be like no war, no crime, stuff like that.

Later in the interview, the participant described his picture of spirituality and, in the process, gained an additional insight.

Probably just enjoying life...something about that.... And just believing in something, likelike even though people see cars as inanimate objects, I still think, things like that can still have character. Just imperfections can make things different, because if everything would be perfect it wouldn't be a nice world. Things that have imperfections...like there are a lot of things that can give things character, like...My hobbies and my friends and my beliefs. Well, I believe that that everyone has something good in them,and deep down everyone is a nice person...and I also believe there are things that can cloud that and can make people go a different way, but like everybody starts out innocent, and the things that they do can kind of make them guilty or more innocent, that, and it's the choices they make...Sometimes that's the thing, why I'm here, why now, or ... why could anything like this happen to anybody, things like that, but sometimes that leads me to realize that even though you have a little troubles, it still really doesn't matter in the long run...Yeh, that's it!

1. 4 Discussion

The finding that most of the teens in this study did not describe their experiences with DMD as crises supports conclusions from other literature of adolescents with chronic illness that they view themselves as adolescents who just happen to also have chronic diseases (Knafl & Deatrick, 2002; Madden, Hastings, & V'ant Hoff, 2002; Snethen, Broome, Bartels, & Warady, 2001). As in this study, the teens did not see having DMD as the crisis. The teens' stories of longing for missed activities, relationships and being seen as self is seen within the context of their everyday, experienced lives.

The central and essential theme of the lived experience of spirituality shared by the participants was interpreted to be that of longing. Holm (2001), felt that longing was a secondary emotion, made up of the primary emotions of love and sadness, while acknowledging that other emotions, such as fear, anger, depression and satisfaction or happiness might also be involved. Although the psychological literature does not acknowledge this sense of longing as a spiritual experience, Holms does acknowledge that if the type and level of longing is maligned, it can be detrimental to an individual's psychological development and relationships. An individual's striving to resolve or alleviate longing can induce feelings of helplessness. This sense of helplessness and powerlessness may lead to an increased awareness of one's spirituality and increase the potential for spiritual distress (Collins & Kuehn, 2004; Ferrell, Ervin, Smith, Marek, & Melancon, 2002; Lin & Bauer-Wu, 2003). With only one teen describing an increased spiritual awareness in which he came to a new understanding of his purpose and meaning to life when faced with major surgery; spiritual distress in teens with chronic and progressive diseases is an avenue that needs further exploration.

Despite the lack of a life-changing crisis that could precipitate an increased spiritual awareness, the teens described connectedness as their spiritual need to alleviate the spiritual experience of longing. This spiritual need for connectedness is seen in relationship to self, others and beyond self. This mirrors how nursing has described spirituality in the literature: that which infuses the person and is evidenced through connectedness.

Because it [spirituality] is practical and relevant to daily life, people experience spirituality in the mundane as well as in the profound, the secular as well as the sacred. Spirituality is active and expressive. It is how we experience and live, in the present moment, our connectedness with our body-mind-spirit Self, with others, with nature or the cosmos, and with the Sacred Source, however we image or name this Source. Spirituality is the search for right relationships more than it is the search for right answers. (M.A. Burkhardt & Nagai-Jacobson, 2002, p. 21).

It is the search for relationships, the connectedness with others that was most often described by the teens and used to ameliorate their longing.

1.4.1.1 Implications for Practice and Research

A significant implication stemming from this study is that teens with DMD describe a spiritual experience of longing. Pediatric nurses must be alert for cues and use their communication and listening skills to create healing relationships with patients as they describe their disease experience and brings meaning to their experience through spiritual connectedness (Benner & Wrubel, 1989). How a teen understands the disease, and brings meaning to their life despite disease can be a source of interventions for nurses. In order for this to be done, the education of nurses must go beyond the sociologic review of the major religions and their tenets and into the new spiritual paradigm of a person's search for meaning in existence and the meaning of reality (Barnum, 2003).

This study has pointed out that much work needs to be done related to spirituality and self-transcendence in adolescents. Longitudinal studies are needed to follow participants with DMD and other chronic diseases to determine the changes of their spirituality over time and across crisis situations. The impact of parental spiritual responses on the teens' spiritual responses is also an area for future research. Intervention research needs to be done to find the most effective activities to support the spiritual dimension in teens.

1.4.1.2 Limitations

This study's limitations include use of Reed's paradigm to construct the Interview Guide, cognitive developmental issues in the participants, and a population that only reflected the Judeo-Christian perspective. The consistency of the participants' connectedness with self, others and beyond self with Reed's (1992) framework of intrapersonal, interpersonal and transpersonal connectedness emerged during data analysis. Although Reed's framework was not used a priori in analyzing the data, developing the Interview Guide using Reed's paradigm to investigate spirituality may have led the participants to share experiences of connectedness. While this potential bias could be reflected in how the teens described how they ameliorate their longings, it did not influence what the participants shared as their lived experiences of spirituality, that of longing.

The cognitive development of the teens participating in this study and the social and cultural constraints on young men may also have contributed to the data collected (Hoffman, 1998; Seiffge-Krenke, 1993). Compounding the normal developmental stage of these teens was the effect of DMD on cognitive and emotional abilities. Cognitive impairment is felt to be related to the lack of dystrophin in the brain tissues leading to cerebral and cerebellar hypometabolism (Bresolin et al., 1994; Moizard et al., 1998; Polakoff, Morton, Koch, & Rios, 1998), resulting

in expressive language difficulties, in which the teen is able to process information but is unable to verbally share his thoughts. The inability to describe in more detail their lived religious and/or spiritual experiences may also reflect the findings from the National Study of Youth and Religion (Smith & Denton, 2005). Although the majority of teens in the United States identify with a religion, the religious and spiritual understanding of those religions are weak based on telephone and personal interviews of 3,370 youth across the nation (National Study of Youth & Religion, 2006). Most had a difficult time explaining what they believed in, and others could only share tangential beliefs.

Another limitation of this study was a lack of religious affiliation and beliefs beyond the Judeo-Christian perspective. Eight of the nine teens were able to describe their experiences from a Judeo-Christian understanding of a higher power. This finding is consistent with the demographics of the population from which the researcher obtained the sample, but it does limit the understanding of teens' experiences from other religious and spiritual experiences. Further research is needed from a larger population to obtain data that would reflect more diverse lived experiences.

Conclusion

Despite the limitations in this research project, the lived experience of spirituality in nine teens with Duchenne's Muscular Dystrophy has been described through the essential theme of longing. Nursing is in a unique position to learn how to assess for longing and determine the appropriate interventions to assist the teen in ameliorating his longing through connectedness with self, others and beyond self. It is through the spiritual dimensions of connectedness that healing can occur. Healing is that sense of health and well-being as experienced by hope, love, sense of control, relatedness with others, finding meaning and purpose in life and disease, and a sense that there is something greater than the self (Fryback, 1993; Mytko & Knight, 1999). Nursing's origins of healing began in early religious traditions that focus on service to others (Barnum, 2003). It is from this rich tradition that nurses need to continue to provide spiritual care to promote healing.

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Table 1

Interview Guide

Broad Question	Samples of Probes
1. First, I'd like to get to know a little bit about what you like to do when you have free time?	1. Do you like to play any video or computer games? Tell me about your favorite game. a. Tell me about the TV programs like to watch? b. Tell me about the kind of music you like to listen to? Who is your favorite artist? What is your favorite song?
2. I am really interested in hearing what it is like to have Duchenne Muscular Dystrophy?	2. I'd like to hear what a normal day is like for you? a. Let's start when you first wake up in the morning. b. What happens next? c. If I knew nothing about Duchenne's, what would you tell me about it?
3. You described some good things and hard things about having DMD. I would like to ask you more questions about the hard things about having DMD. Tell me more about the _____(item identified by adolescent that is hard).	3. "Tell me more about being in a wheelchair (or whatever the difficult thing the adolescent expressed)? a. Tell me about the things that bother you most about having DMD? b. Some teens get angry that they cannot do the same things as their friends. Tell me your experience with that?
4. Who are the people to whom you feel connected?	4. When you are feeling_____ (insert the words the adolescent used above) about having Duchenne's, who or what makes you feel better? a. When things go wrong, what do you do to cope?
5. Is there anything else or anyone else who helps you feel better?	5. Who or What makes it easier when you feel this way? a. Tell me more about how special people have influenced you? b. Are there others that help you feel positive about things? c. Who or What helps you when you feel afraid or need special help?
6. Describe for me the things that are most important to you?	6. Do you have any 'rules' that you try to live by and if so what are they? a. What kinds of things do you want to be sure to do everyday? b. What do you look forward to when you get up in the morning? c. What gives your life meaning and purpose?
7. Describe what the word spirituality means to you?	7. For some, spirituality may mean their faith in a higher power or God, for others it is feeling of being a part of nature or the universe. Describe your experiences with those? a. Is religion or God* important to you? If so, can you describe how? b. Sometimes teens feel that their spirituality (religion, faith, prayer or God) helps them when they are feeling _____(again, use appropriate feeling based on past answers). Do you have any experience with any that? c. For some teens, prayer or meditation helps them. What kinds of things do you do? How do these things help you?
8. Can you describe your spiritual beliefs?	8. If you could draw a picture of spirituality, what would be in your picture?
9. Have I forgotten to ask you anything	9. I have asked you a lot of questions, what questions do you want to ask me?

Broad Question	Samples of Probes
that you wanted to tell me?	

* Name that adolescent uses for God, higher power, belief in universal force, nature, etc. as identified by the adolescent.