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Research Article

Caregiver Spirituality for Children Receiving Occupational Therapy

Linda R Barnett*

5500 Southwestern Medical Center Blvd, Dallas, Texas 75235, USA

Abstract

Occupational therapy provides a holistic approach to healthcare, addressing children's and their families' physical, emotional, and spiritual needs. Spirituality is an experience of meaning that occurs when one engages in occupations involving the culmination of client factors, including personal values and beliefs. This study aimed to identify the importance of the spirituality of caregivers whose children receive early intervention occupational therapy. The researcher used a secure online survey software tool to measure caregivers' perceptions of occupational therapists addressing their spiritual needs. The survey participants were caregivers whose children aged 0-36 months received occupational therapy services. Research supports the importance of incorporating spiritual care into a child's plan of care to attain optimal health and positive outcomes when resolving crises. Caregivers found spiritual needs essential and relevant to their child's care, although most caregivers indicated their spiritual needs were not discussed with their occupational therapist. The Occupational Therapy Practice Framework states that spirituality is in the scope of practice. OT practitioners would benefit from incorporating spirituality into didactic and experiential learning to ensure an understanding of appropriate assessment tools, intervention strategies, and the development of client-centered goals to facilitate engagement in desired occupations.

More Information

***Address for correspondence:** Linda R Barnett, 5500 Southwestern Medical Center Blvd, Dallas, Texas 75235, USA, Email: lindabarnett@twu.edu

https://orcid.org/0000-0002-2863-043X

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Introduction

One of the most challenging events that families face is coping with serious problems related to their children. During these life-changing events, families turn to spirituality for comfort, hope, and relief from stress [1]. Parents may be overwhelmed and uncertain about the present and the future. Occupational therapists face challenges in providing quality care that addresses the physical, emotional, and spiritual needs of children and their families. Healthcare practitioners across varied disciplines have increasingly paid attention to spirituality, which has proven helpful for actively embracing the pursuit of philosophical holism—integrating body, mind, and spirit. The existing occupational therapy literature lacks consistency in academic preparation for occupational therapy assistants and students to address clients' spirituality [2]. Despite efforts to determine a clear definition of spirituality, scholars conclude that spirituality is seemingly undefinable and continue to grapple with making clear distinctions between spirituality and religion [3]. It is essential to recognize spirituality "as dynamic and often evolving" [4]. Although the concept of mind, body, and spirit is not new, occupational therapists often do not consistently address these components simultaneously, leading to missed opportunities in client practice [5].

People have described the difference between faith and spirituality as faith being the "religion piece" that's lived out in community, such as places of worship, whereas spirituality is more of an individual journey, an opportunity to deepen one's sense of containment, wholeness and ability to find peace and purpose, especially when it comes to caregiving [6].

Systems thinking offers a useful theoretical lens for examining caregiver experiences within pediatric rehabilitation because it highlights the interdependence of biological, psychological, sociocultural, policy, financial, and spiritual systems [7]. Within pediatric occupational therapy, a systems orientation recognizes that caregiver meaning-making, coping, and stress responses are co-produced across multiple relational and contextual levels [8]. Thus, caregiver

spirituality is not simply an individual belief variable—it is shaped by, and contributes to, the ongoing dynamics among the child, the therapist, the family, and the wider healthcare ecology. Systems thinking, therefore, offers conceptual legitimacy for addressing spirituality not as an ancillary "topic," but as one of the relational variables embedded in how families engage in the child's rehabilitation trajectory.

Health has also been widely defined as more than the absence of disease. Global and interdisciplinary health scholarship conceptualizes well-being as integrating physical, mental, social, and spiritual dimensions [9]. Within pediatric rehabilitation, emerging literature shows that spirituality functions as a meaningful resource for family-centered coping, resilience, and hope [10]. The occupational therapy profession itself formally includes spirituality as a client factor fundamental to participation and meaning [11]. Therefore, investigating caregiver spirituality is not outside the scope of occupational therapy; it is consistent with contemporary and profession-specific health frameworks that conceptualize health as whole-person and spiritually inclusive.

Occupational therapists determined several barriers to addressing spirituality. The perceived barriers included the lack of a universal definition or understanding of spirituality, lack of empirical data or evidence to validate spirituality as a component of human performance, lack of assessment tools to measure spirituality, role ambiguity regarding the inclusion of spirituality within the scope of practice, and whether incorporating spirituality in treatments is within the scope of licensure and a therapist's training [12]. Decreased knowledge of the theoretical basis of spirituality and concerns with being accused of proselytizing while incorporating spirituality in treatment sessions were also concerns of occupational therapy practitioners. Published in 2020, The Occupational Therapy Practice Framework: Domain and Process identifies spirituality as an aspect of occupational therapy's client factor domain supporting engagement, participation, and health [11].

Spirituality in the literature covers a spectrum of thought, from general concepts of meaning and purpose in life to definitions that include a belief in a higher being or God. Occupational therapists define spirituality in various ways, often from their experiences, beliefs, and values. However, occupational therapists frequently report consistent barriers to the inclusion of spirituality into practice [13]. These include (1) a lack of training in taking a spiritual history; (2) a concern that therapists would project their own beliefs onto clients; (3) a lack of ability or experience to handle spiritual issues raised by clients; (4) a lack of time needed to address spiritual needs; (5) a lack of certainty regarding the place of spirituality within the occupational therapy practice domain, and (6) a lack of academic preparation for addressing clients' spiritual needs [12].

Literature indicates the need to clarify these concerns for occupational therapists. However, there is limited research regarding the caregiver's perception of occupational therapists addressing their spiritual needs. By examining the caregivers' perceptions more closely, this study sought to identify the relevance and need of spirituality for caregivers whose children currently receive occupational therapy. The research question posed in this study was, "How do caregivers of children receiving occupational therapy perceive that their spiritual needs have been addressed?"

When individuals cope with significant life events and transitions, questioning and searching provide reassurance regarding life views and purpose. For others, critical thoughts and questions may lead to acceptance of mystery. In any case, the meaning gained, or the ongoing wrestling with ideas, motivates people to move forward in the spiritual experience and engage in avenues to and through spirituality [14]. Although people frequently link spirituality to religion and use the terms interchangeably, spirituality refers to an individual's beliefs, experiences, and ideals. In contrast, religion is an organized method of sharing beliefs and practicing worship.

Spiritual expression may include affirmations, imagery, storytelling, and other means of releasing fears and worries. Religion may serve as a channel of expression that enhances one's spirituality [1]. Children may express distress through crying, withdrawal from interaction, inability to sleep, or display resistant behavior. These behaviors may affect the caregiver's ability to nurture and effectively meet the child's needs. However, incorporating spiritual care into the child's care plan can lead to positive outcomes for caregivers, offering hope, comfort, and strength while serving as a coping mechanism.

Occupational therapists researched perceptions toward addressing spiritual care and spirituality, and results indicated that therapists were apprehensive about addressing spirituality due to poor academic preparation and a lack of understanding of the relevance of spirituality in the scope of practice. Therapists in settings that are accredited by either the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) or the Commission on Accreditation of Rehabilitation Facilities (CARF) may not comply with the written accreditation standards for spiritual care if they do not acknowledge the spiritual needs of their patients and make appropriate accommodations for assessment, treatment, and spiritual care. As members of multidisciplinary treatment teams, occupational therapists are required, under JCAHO and CARF standards, to be alert to the spiritual needs of their patients and to make appropriate referrals to clinical chaplains or other team members as necessary [15].

There are minimal occupation-based spirituality assessments, which affect the therapist's ability to measure client or caregiver needs to achieve the occupational potential

of individuals, families, and communities. If occupational therapy is to be practiced holistically, incorporating spirituality into client treatment must become a priority [15]. Although assessment tools are becoming more available, they are still limited. The ability to conceptualize spirituality in practice is a universal concern among students and practitioners. When occupational therapists are cognizant of cues signaling a need for spiritual care and can differentiate between religion and spirituality, they will have an enhanced awareness of ways to incorporate spirituality into healthcare plans and establish appropriate outcomes for children and families.

Spiritual context is important when addressing spirituality. Spiritual context is considered a person's internal world and external practices. It is a state of being, not necessarily a "place," that inspires and motivates individuals. It may include actions, beliefs, or ideas. In contrast, a spiritual environment is a place where an individual attempts to accept, make sense of, or find meaning in strengths, resolve loss and grief issues, understand or relate to oneself, or face fears. One's spiritual environment may help them solve problems, make life decisions, cope with struggles, adjust to change, embrace joys, become vulnerable, and dedicate themselves to something or someone beyond themselves [16].

Spirituality assessments are currently utilized in various healthcare disciplines. The B-E-L-I-E-F assessment tool helps the nurse evaluate the spiritual and religious needs of the child and family. The acronym B-E-L-I-E-F stands for B-Belief Systems, E-Ethics or Values, L-Lifestyles, I-Involvement in a Spiritual Community, E-Education, and F-Future Events [1]. Developed to help healthcare professionals address spiritual issues with patients, FICA serves as a guide for conversations in the clinical setting. Since 2000, JACHO has required a spiritual history for hospital patients. F—Faith and belief (What gives the patient's life meaning?), I—Importance (How important is this to the patient's life situation?), C—Community (Does the patient have a place in any social or religious group?), A—Address in care (How would the patient prefer their beliefs to be addressed in health care?

In 2001, Anandarajah and Hight designed the HOPE Questionnaire. This assessment helps to increase understanding of the client's values and beliefs, helps the occupational therapist choose appropriate intervention, and helps the OT respect the client's background and culture. After completing this questionnaire, the client and practitioner set relevant, meaningful goals [17]. See Table 1, which outlines the HOPE Questionnaire.

Table 1: HOPE Questionnaire.

Letter	Representation	Sample Questions
H	Sources of hope	What are your sources of hope, strength, comfort, and peace?
O	Organized religion	Do you consider yourself part of an organized religion?
P	Personal spirituality and/or practice	What aspects of spirituality or spiritual practices do you find most helpful?
E	Effects on medical care and/or end-of-life issues	Has your current condition affected your ability to do the things that usually help you spiritually? Has it affected your relationship with God? Are there any specific practices or restrictions I should know about in providing you with care or services?

Method

Survey design

Following Institutional Review Board approval and consent from all participants to participate in the study, the researcher measured caregivers' perceptions of addressing spiritual needs in occupational therapy using data from Psych Data, a secure online survey software tool (https://www.psychdata.com). The researcher designed the questions in this instrument to identify caregivers' perceptions of how early intervention occupational therapists address their spiritual needs and assess how these perceptions affect occupational therapy practice.

Participants

The sample size included thirteen English-speaking caregivers whose children received occupational therapy services, living within the thirteen counties of North Texas served by the early intervention agency, ranging from birth to three years old. The researcher invited one hundred fifty English-speaking participants, aged eighteen years or older, whose children currently receive occupational therapy services and whose email addresses are provided in the agency's electronic health record, to participate in the survey via email, including a link to access the survey on Psych Data. A six-question survey assessed caregivers' perceptions of how their spiritual needs have been addressed in early intervention. At the time of the study, approximately 150 emails were provided in the agency's electronic health record. After two weeks, the researcher sent a follow-up email to participants to increase the response rate.

The questionnaire included the following statement at the top: "The return of your complete questionnaire constitutes your informed consent to act as a participant in this research." Participants were informed that the survey was voluntary and that respondents would remain anonymous. Data collected from the survey responses were gathered for 30 days. The survey consisted of the following questions: How do you define spirituality? What is your understanding of spiritual needs? What role does spirituality play when caring for your child? Have you talked about your spiritual needs to the occupational therapist providing care to your child? How have you expressed your spiritual needs to your occupational therapist? What were your experiences discussing your spiritual needs with your occupational therapist? The survey ended if caregivers answered "no" when asked, "Have you talked about your spiritual needs to the occupational therapist providing care to your child?"

Results

Information was uploaded from Psych Data using NVivo

12 Qualitative Research Software (QSR International Pty Ltd.), a computer-assisted qualitative data analysis software. Thirteen participants were English-speaking caregivers, eighteen or older, whose children were zero to three years of age and who were currently receiving occupational therapy. From the demographic data, the two primary diagnosis categories identified were neurological concerns and speech delays. Six participants' children had neurological diagnoses, including cerebral palsy, agenesis of the corpus callosum, and hydrocephalus. Three children were diagnosed with speech delays: one was visually impaired, one was diagnosed with Down Syndrome, one was diagnosed with brachial plexus injury, and one child was premature (Table 2).

A word query was conducted to determine word frequency and identify common perceptions of spirituality. A high frequency of words indicates a more significant response to the particular perception, whereas a lower frequency conveys a minimal reaction to the specific perception.

Once the 50 most commonly used words among the survey responses were identified, coding was established using NVivo coding to gather data regarding particular themes into a node for further exploration. Words most frequently used were analyzed in context and based on their relation to the research question, with synonyms used in coding. Next, six codes were developed using the two demographic categories previously mentioned. The codes were refined by exploring relationships and patterns using a contextual format from participant responses. The six codes identified based on the participant responses and word frequency were "Definition of Spirituality," "Advantages of Spirituality," "Personal Choice," "Spiritual Practice," "Communication," and "No Communication with Occupational Therapists."

Data about participants' definitions of spirituality indicated responses related to one's belief in God and an attempt to reconcile one's soul with the spirit world. One respondent defined spirituality as "A belief or set of beliefs that guides one's lifestyle. It brings comfort to the person." When asked how respondents define spirituality, a minimal response was related to personal choice, indicating spirituality is associated with a personal relationship with God, identifying one's moral code or guidance, and one's need to feel there is something other than this life. Respondents indicated the need to address spiritual needs and spiritual practice. One respondent stated, "My understanding of spiritual needs is prayers, going to mass, and following the commandments." In contrast, another respondent stated, "My understanding is spirituality is a must to maintain a balance without allowing the influences of negative thinking and acting to invade your life." The terms spirituality and spiritual needs were used synonymously in respondent perceptions.

Table 2: Participant Characteristics.

Participant Characteristics	N
Caregiver gender	
Male	1
Female	12
Language	
English	13
Other	0
Diagnoses	
Neurological	6
Speech delayed	3
Visually impaired	1
Brachial plexus injury	1
Down syndrome	1
Prematurity	1
Client age	
Birth to three years	13

n = 13 Participants receiving occupational therapy.

Most respondents shared concerns related to spiritual practice and the advantages of spirituality. Regarding the advantages of spirituality, a respondent mentioned, "Spiritual need is important when caring for my child because it allows me to have a hope and belief that my child will be able to accomplish developmental milestones." Significantly, few respondents indicated they discussed spiritual needs with their occupational therapist, and one elaborated by stating, "No, I do not feel it is her obligation to meet those needs. I also do not feel it is acceptable to discuss spirituality with someone not specifically trained or desiring to address these needs. I think it would put our OT in a difficult situation, which she may not be prepared for. In addition, as a government employee, I would not want her to feel anxiety over the legality of her replies. My reaction to our current societal culture has caused me to avoid these discussions with individuals I have a professional relationship with."

The researcher found that few respondents indicated they had discussed their spiritual needs with their occupational therapist and were asked to answer follow-up questions. The respondents indicated they did not initiate the conversation with their therapist. When asked the follow-up question, "What have been your experiences when discussing your spiritual needs with your occupational therapist?" the respondent indicated their child was placed in hospice care, the occupational therapist referred them to a chaplain, and her spiritual needs were discussed at that time.

Discussion

Caregiving is more than a relational responsibility; it is an occupation that organizes time, identity, energy, behavior, habits, and meaning. Within occupational therapy, occupation refers to the everyday activities people need and want to do, and those through which they express who they are (Canadian Association of Occupational Therapists, 2014). Caregiving fits directly within this definition. It involves complex task demands (monitoring, coordinating, advocating, comforting, managing crises) as well as interpretive and moral dimensions (discernment, sacrifice, hope, commitment). Caregiving reorganizes daily routines and life trajectories, creates new

habit patterns, constrains or expands life participation, and reshapes the caregiver's sense of self.

When caregiving roles intensify, the caregiver's own person–environment–occupation configuration shifts. Occupational adaptation theory suggests that identity and performance are directly influenced by the meaning a person makes from their occupational challenges. Thus, when caregivers draw upon spirituality, faith, and sacred belief systems to interpret what caregiving means, they are actually leveraging an internal resource that transforms the occupation itself.

Spirituality has been described as the search for meaning, purpose, transcendence, and connection to something greater than oneself. In caregiving, spirituality often becomes the interpretive lens through which suffering, sacrifice, daily demands, and moral obligations are understood. Spiritual coping involves efforts to conserve or transform what is sacred when life circumstances threaten core beliefs [18]. For caregivers, this may include perceiving their work as ministry, expressing faith through service, or trusting God amid uncertainty [19]. Spirituality, therefore, functions as a meaning-making mechanism that helps caregivers integrate the emotional, physical, and moral labor of care into a coherent identity narrative [20].

Parents and communities have a strong influence on a child's spirituality, and parents use their spirituality to make sense of and cope with their child's illness or death [21]. This study sought to identify the importance of caregiver spirituality whose children who receive early intervention occupational therapy. The research question posed in this study was, "How do caregivers of children receiving occupational therapy perceive that their spiritual needs have been addressed?" Literature states that although spirituality is frequently linked to religion and the terms are often used interchangeably, spirituality refers to one's beliefs, experiences, and ideals.

In contrast, religion is defined as an organized way of sharing beliefs and practicing worship. Respondents indicated spiritual practice was necessary, and many stated there were advantages to spirituality to assist in coping with their child's illness. Emerging evidence demonstrates a consistent relationship between spirituality and caregiver burden. Using a nationally representative U.S. dataset, Young, et al. [22] found that higher spirituality was associated with lower caregiver burden and greater quality of life in older adult informal caregivers.

While some respondents indicated prayer and worship were coping mechanisms for stress, one indicated she regularly visits with her chaplain. The respondents' comments support Elkins and Cavendish as they suggest, "Spirituality, however, intrinsically supports a sense of hope, comfort, and strength and serves as a coping mechanism. Incorporating spiritual care into the child's care plan is essential for positive outcomes when resolving crises and optimal health [1]."

Spirituality is in the scope of practice for occupational therapists to address spiritual needs and provide opportunities for caregivers to address concerns for spiritual or religious routines in early intervention. Research supports the importance of incorporating spiritual care into the child's plan of care to attain positive outcomes when resolving crises and optimal health [23]. Occupational therapists with clinical experience and confidence in justifying spirituality as part of their role helped address client spirituality. Courage and the competence to justify addressing spirituality contributed to a deeper understanding of how spirituality can manifest for clients, including being expressed non-verbally [24].

The evidence suggests that spirituality is both a resource and a modifiable practice for caregivers, but occupational therapists addressing spirituality in practice consistently is not identified [19]. This synthesis advances an interprofessional understanding of caregiver support by explicitly naming spirituality as a domain that holds clinical, pastoral, and occupational relevance.

Potential study limitations

While the studies reviewed demonstrate consistent spiritual effects on caregivers' existential outcomes, this study was limited by small samples and the representation of limited geographic regions. The study was non-generalized and consisted of a small population. Limited caregivers' email addresses were available in the electronic health record; many were not contacted to participate in the study. Some children were listed as active clients in the health record. However, two respondents indicated that although they were interested in participating in the survey, their child was discharged from occupational therapy.

Recommendations for future research

Future research recommendations include using a larger population of children receiving occupational therapy in early intervention and a phenomenological study among practitioners to determine the current use of spirituality assessments. Expanding the sample size or replicating the study across additional counties could strengthen the generalizability and robustness of the findings. Participants may consist of caregivers of children up to age eight and occupational therapy practitioners working in early intervention. Future studies may also be conducted following the COVID-19 pandemic to determine occupational therapists' perceptions of spirituality in early intervention and identify any influences on their perceptions regarding spirituality in occupational therapy practice. Additionally, further research will be conducted on incorporating spirituality curriculum into occupational therapy education. Focus groups will be designed to gather responses from occupational therapy graduate students regarding their perceptions of the need for spirituality in the occupational therapy curriculum to expand their knowledge in addressing spirituality with clients.

Conclusion

Results from this study revealed that although most caregivers indicated they did not discuss their spiritual needs with their occupational therapist, they found these needs essential and relevant to the care of their child. As members of multidisciplinary treatment teams, occupational therapists, under JCAHO and CARF standards, must be alert to their patients' spiritual needs and make appropriate referrals to clinical chaplains or other team members as necessary [15]. Incorporating spirituality with appropriate academic training will be essential for occupational therapy practitioners who aim to provide holistic, occupation-based interventions.

Spirituality is not ancillary to caregiving; it is an active meaning-making resource that shapes how caregivers interpret role demands, engage in daily routines, make sacrifices, and sustain hope. Spirituality is a vital aspect of human experience and gives meaning to occupations. The Occupational Therapy Practice Framework includes spirituality as a dynamic client factor that evolves as individuals search for purpose and meaning in life. Addressing the spiritual needs of caregivers allows them to cope in times of distress and manage crises. In an approach to spirituality in practice, occupational therapists would benefit from spirituality resources and training. In academia, occupational therapy students could gain greater insight and practical application of spirituality by understanding appropriate assessment tools, intervention strategies, and practicing implementing client-centered goals that facilitate engagement in desired occupations. Providing students with didactic and experiential learning opportunities to address spirituality may increase occupational therapy practitioners' confidence in addressing the spiritual needs of caregivers and clients.

Educational training or resources and a supportive workplace facilitate addressing spirituality in practice. Spirituality training and resources, including culturally sensitive approaches and diverse learning platforms, may impact a therapist's ability to address spirituality. Increased educational opportunities that provide methods to address spirituality from a cultural perspective, such as webinars, virtual platforms, or podcasts, are suggested strategies for responding to spirituality in occupational therapy [24]. The profession can address these challenges through continued research, training, and resources to increase comfort and efficiency in addressing spirituality in occupational therapy.

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