

# Spirituality in young adults with end-stage cancer: a review of the literature and a call for research

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**Abstract:** Existing research finds that spiritual wellness may enhance quality of life in those with end-stage cancer. Unfortunately, much of the literature is focused on the spirituality of those in middle and older adulthood, leaving questions about the spirituality of young adults facing life-threatening illness. This article reviews the current landscape of spirituality in young adults with cancer. In addition, this paper serves as a call for research to consider the development of spirituality in this unique population. The literature shows that young adults with cancer are less likely to use mental health services compared to other age groups with cancer. Research tends to be restricted to early young adulthood with a focus on spiritual or religious practices and less about the meaning of spirituality in the context of their illness. A review of the development of spirituality in healthy young adults helps to build the framework to ask questions about what may be occurring for those with life-threatening illness.

**Keywords:** Spirituality; young adult; life-threatening illness; spiritual development

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Cancer is one of the top five leading causes of death for young adults ages 18 to 34 (1). Around 80% of young adults with cancer will survive, but 20% will not (2). Patients with cancer experience depressive symptoms at a significantly higher rate than healthy individuals, which may be compounded with the additional threat of imminent death (3,4). As patients attempt to cope with a diagnosis of a life-threatening illness, it is common to encounter thoughts, questions, and fears related to death (5). Some questions posed by patients include: “When will I die?”, “What does death feel like?”, and “Does my life have meaning?” (5). One way that has been shown to reduce distress in patients with life-limiting illness is deriving meaning and purpose from life (6). Spirituality is an avenue through which meaning and purpose can be attributed through a higher power or inter/intrapersonal connections (7). Research in palliative care settings suggest that while not all people are religious, everyone is spiritual, particularly those nearing the end of life (5). Palliative care physicians position that to neglect spirituality is to neglect an essential component of patient care (8). This assertion has sparked growing interest

in the way spirituality can help patients adjust to the reality of death (9).

Studies in palliative care settings find that spiritual wellness can aid in psychological, social, and physical healing (10-12). While adults with cancer express a desire for additional attention to spiritual wellness (8,13), little is known about whether young adults with cancer have these same requests. Spiritual coping in young adulthood, especially young adults nearing the end of life, has been underrepresented in the literature. The investigative nature of this research may be aided by developmental theory, which can be a helpful framework when examining developmental variations. Understanding spiritual development in healthy young adulthood will yield insights into future research and intervention of young adults with end-stage cancer.

## Spiritual development theory

To begin, young adulthood represents a time of identity exploration, deepening of relationships, and

experimentation with what the world has to offer (14). There may exist a tension within families and in a young adult's sense of identity formation as they struggle to deal with issues of dependence and independence (15). For those dealing with cancer, the element of uncertainty and role confusion is heightened (16). In addition to these experiences, young adults are moving through spiritual development milestones.

The topic of spiritual development has been a difficult construct to study (17). Fowler's stage of faith development was one of the first empirical investigations into this topic (18). Before presenting these stages, a definition of terms is in order. Spiritual development represents the way that people move to a place of self-transcendence, meaning that they become connected to something bigger than themselves (17). Religion refers to the way people observe the beliefs and rituals of a religious group (19). Religion can be considered as one part of spirituality, but at its foundation, spirituality is far more encompassing (20). Fowler's use of the word faith does not refer to following a set of beliefs, but to how all humans from different backgrounds construct meaning to the self and the world (18,21).

Beginning with adolescence, according to Fowler's faith development theory (18,22), the time of adolescence signifies synthetic-conventional faith. Fowler (18) asserted that adolescents are adamant about establishing their identity, beliefs, and values. Even though adolescents have developed the ability to think logically and abstractly, they tend to find difficulty in relating to those that live according to different values, since they tend to consider their own beliefs to be universal truths (23,24).

After adolescence, however, faith development is dependent on one's ability to move beyond his or her own cultural assumptions (23). Should people progress, as not all do, they may experience various stages of faith development: the individual-reflective stage, characterized by an ability to think critically about one's previously held values and how they may or may not inform one's current individual beliefs; the conjunctive stage, marked by the capacity to acknowledge the multiplicity of belief systems and an understanding that a paradox exists in these multiple truths; or the universalizing stage, an exceptional stage where one is committed to the inclusiveness of all beings (18,22).

Faith development theory asserts that spirituality is indeed a process of development and that spiritual development beyond adolescence is not absolute (23,25). Thus, the question arises of whether young adults with terminal cancer would seek spiritual exploration. Research

suggests that this may be the case, since spirituality confers many benefits even for healthy young adults (26-29). The experiences of young adult cancer survivors, while not facing the reality of death in the immediate moment, may help to gain insights into the spiritual development of those with end-stage cancer.

### **The effects of cancer on psychosocial and spiritual functioning in young adult cancer survivors**

Research shows that the diagnosis of cancer in young adulthood can arrest normal development (30). Young adults with cancer face a relinquishing of independence in adopting a sick role, fewer platonic and romantic relationships with peers, isolation, and a delay in education (16). They also report less personal, role, and cognitive growth, and deficits in social functioning (30). The detriments to psychosocial and spiritual functioning are well documented, but other studies have found positive changes (31).

One study sought to identify changes in the spiritual perspectives of young adults undergoing blood and bone marrow transplants (32). Through interviews with 12 patients, they found themes centered around questions such as, "why me" and "what will happen to me" prior to their transplant procedure. One year after the transplant, the six remaining participants indicated a shift in their perspective. The interviews suggested themes of life having a purpose, having a renewed strength in their faith, and believing that they were chosen to experience this for a reason. However, researchers did not ask participants what they believed contributed to these changes in spiritual perspectives. Therefore, the precipitants of these changes cannot be determined. They may be due to increased spiritual support or knowing they had a better prognosis of recovery. Research finds that young adults with cancer begin by having deficits in well-being compared to health young adults, but report an enhanced state of well-being as the time since diagnosis increases (33). Since those with end-stage cancer will not have the chance to experience a life post-illness, it is unknown whether they too report an enhanced state of well-being.

A review of nine studies examining spirituality and religion in adolescents and young adults with cancer does not help to fill this gap (34). Even though spirituality was found to be important for adolescents with cancer, there appeared to be conflicting findings about whether spirituality differed with age, gender, and length of time since diagnosis, with some research noting that there are differences

(35,36) and other research finding no differences (37). Conclusions from this review are diminutive. Among the nine studies reviewed, none sampled young adults above the age of 22 and the mean age of participants in all studies was below 18. Considering that children under 18 are still under the guidance of their parents, it would be difficult to compare these findings to those of young adults, many of whom are in a more mature stage of cognitive development and may lead more independent lives. A deeper understanding of the meaning of spirituality in the context of their illness and lived experience was only reviewed in one case study using diary data (38). Finally, previous samples are limited to a Christian perspective, leaving questions about the importance of spirituality for people of other religious or non-religious traditions, unanswered.

Studies state that adverse circumstances can initiate an awareness of spirituality (23,39). Fowler himself stated that unexpected life events and adversity can initiate the development of faith (18). Longitudinal research supports this claim by finding that negative life events at an early age promote greater spiritual development (40). Young adults with terminal cancer have a greater likelihood of developing depression (4) and are less likely to use mental health services compared to their older and younger counterparts with cancer (41). These findings suggest that a diagnosis of cancer could initiate spiritual development in young adults. These studies also indicate that while spirituality could serve as a protective factor, the increased likelihood of depressive symptoms and lack of adequate support could inhibit their psychosocial spiritual well-being.

### The need for further research

Small, homogeneous samples have limited the extent to which conclusions can be drawn about spiritual development in young adults with life-threatening cancer. Yet, this information could have great influence in clinical practice, theory, and future interventions with this population. Palliative studies of adolescents and adults tend to exclude the experiences of young adults in their mid to late twenties (42). Knowledge of the spiritual landscape of young adults with cancer may impact the way physicians and nurses approach the dying process with young adults. Providing developmentally appropriate psychosocial spiritual care to young adults, instead of subsuming them under the classification of adolescents or adults, may help them to feel seen and heard (43). Additionally, few studies have researched spirituality in the context of spiritual

development theory (23), especially in relation to the unique experiences of those facing an early death. Further research could provide preliminary evidence for how the various faith stages cope with adverse circumstances. Finally, identifying whether young adults experience spiritual/existential distress may spark interventions involving existential therapies, which have shown initial success in alleviating psychopathology and increasing self-efficacy in physically ill populations (44).

The developmental period of young adulthood is fraught with uncertainty and characterized by attempts to solidify their identity apart from parental figures and embark on their own journey through life (15). Young adults with cancer must resolve these conflicts while facing a shortened lifespan and unfortunately there is a paucity of research focusing on this issue. Thus, examining the spiritual experiences of young adults facing death from cancer would be a fruitful area of study.

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### Footnote

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