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# SPIRITUALITY AND SPIRITUAL CARE OF ADOLESCENTS AND YOUNG ADULTS WITH CANCER

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**OBJECTIVES:** *To review research on spiritual perspectives and spiritual care of adolescents and young adults (AYA) living with cancer.*

**DATA SOURCES:** *Peer-reviewed publications, book chapters, and websites of professional organizations.*

**CONCLUSION:** *There is a paucity of research specifically investigating AYA spirituality and lack of AYA-sensitive instruments to measure spirituality. Research that applies robust scientific methods to the study of AYA spirituality is needed. Research that provides evidence on which to base best practices for spiritual care that supports AYA spiritual well-being is likewise necessary.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Nurses can influence AYA health-related outcomes and experiences by providing ethical and evidence-based spiritual nurture.*

**KEY WORDS:** *Adolescents, young adults, cancer, spirituality, religion*

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0749-2081/3103-836.00/0.

<http://dx.doi.org/10.1016/j.soncn.2015.06.002>

When adolescents and young adults (AYA) receive a diagnosis of cancer and face the possibility of untimely death, they often have an increased focus on spirituality that continues throughout the disease trajectory, regardless of whether the outcome is remission and cure or relapse and the end of life.<sup>1,2</sup> During this time, AYA with cancer have unique spiritual needs, and these spiritual needs, paired with their precarious health status, place AYA at great risk for spiritual distress.<sup>3</sup>

In the context of illness, spirituality has the potential to influence AYA well-being by: (1) providing hope-derived meaning and purpose in life, death, and suffering; (2) fostering strong relationships with others and with the divine; and (3) providing positive religious coping strategies as

alternatives to feelings of loss and fear.<sup>4-6</sup> The American Nurses Association,<sup>7</sup> International Council of Nurses,<sup>8</sup> and The Joint Commission<sup>9</sup> all identify spirituality as a domain that must be respected in the provision of health care. The National Consensus Project for Quality Palliative Care<sup>10</sup> has issued a call to action, including specific guidelines regarding what needs to be done regarding provision of spiritual care as a component of palliative care.<sup>11</sup>

Findings from studies of adult cancer patients indicate that significant relationships exist between spiritual well-being and various indicators of psychological well-being, such as adaptive coping, as well as decreased levels of stress, depression, and anxiety.<sup>12,13</sup> Unfortunately, relatively little research has investigated the effects of spirituality in AYA cancer. In addition, there are few evidence-based guidelines for providing spiritual care to AYA and pediatric patients.<sup>14</sup>

The purposes of this article are to review what is known about AYA spirituality, discuss ways it has been studied, and make research and clinical recommendations to address gaps. Specifically, the article: (1) defines and differentiates the multiple terms related to spirituality and related concepts; (2) describes AYA spiritual development in general and in the United States; (3) reviews measurement and empirical evidence regarding the spirituality of AYA living with cancer; (4) suggests therapeutic approaches nurses can use to support patients' spiritual perspectives; and (5) discusses research implications for investigating the spiritual perspective of AYA.

### WHAT IS SPIRITUALITY?

Many terms in the literature relevant to spirituality are elusive, ill-defined, or used interchangeably. To have a consistent conceptual foundation for this review of AYA spirituality and spiritual care, Table 1 provides working definitions of key terms. Based on these definitions, *spirituality* serves as the foundation for and is antecedent to the development of one's *spiritual perspective*, a term that conveys each person's unique forms of spiritual awareness, beliefs, practices, and experiences, beginning in childhood and extending over time.<sup>19</sup> Positive outcomes of spiritual perspective in AYA with cancer can significantly foster AYA hope-derived meaning, courageous coping, and self-transcendence.<sup>6</sup> *Religion* is a term often

used interchangeably with spirituality. For some, spiritual perspective may include *religion*, a specific set of *beliefs* and principles that are enacted through practices (*religiosity*).<sup>20,21</sup> Because *religious and spiritual coping*, like other ways of coping with stress, can be detrimental or positive, assessment of AYA's ways of seeking and expressing meaning through their religious beliefs and practices is critical to providing appropriate spiritual care.

### AYA SPIRITUAL PERSPECTIVES IN THE UNITED STATES

Spirituality is expressed in widely differing ways based on culture and religion, and it is important to consider the shifting context of AYA spirituality in the United States. Data from three large, longitudinal national surveys of adolescents and teens in the mid 1990s showed that the majority of AYA identified themselves as religious (83% vs 13% who were non-religious); about half participated regularly in youth groups or attended religious services (38% weekly); and, although participation in religious activities declined somewhat for both sexes over time, it was greater among girls than boys.<sup>22</sup>

During the past decade, large national surveys of American young adults (ages 18 to 29) verify this trend towards declining religiosity.<sup>23</sup> For example, about one fifth of young adults attended religious services nearly every week or more often, whereas one third of young adults never or rarely attended. Nearly half of the AYAs (46%) indicated that they prayed at least once every day, whereas 20% never prayed. Few individuals (13%) reported reading a sacred text several times a week or more often, and 52% read such materials only several times a year or less often. In response to an item stating, "I have no doubts that God exists," 55% of participants agreed; less than the 62% to 70% reported by older adults.<sup>23</sup> Indeed, Smith and Snell<sup>24</sup> characterized almost half of "emerging adults" as *sporadic* (18%) or *disengaged* (26%) with religion, while the remaining were *devoted* (8%), *regular* (13%), or a mix of these categories (35%). Whereas these findings portray diminished religiosity, they nevertheless still show that AYA often have religious identity and sentiments. These data also do not describe the shift from institutional religiosity towards the personalized spirituality that others have observed.<sup>25-27</sup>

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