



St. Jude Global



Adapted Resource and Implementation Application (ARIA)

Clinical Practice Recommendations (CPR) for Spirituality and Existential Crisis



ARIA Guide

A Global Childhood Cancer **Palliative Care** Collaboration

Version 1.0
August 2023

The content (including text, graphics, images, links to third-party resources, and other material) provided within this ARIA (Adapted Resource and Implementation Application) Clinical Practice Recommendation (CPR) was compiled and developed through a global representative panel utilizing both an evidence-based and consensus-based review process. The source material in this CPR supersedes any discordant information presented through the ARIA Guide portal. We also remind users of this guideline that they are not to use this information in isolation, nor is information contained here to replace or direct the treating healthcare provider's judgment. Appropriate, timely clinical judgment is required when using information and should never be used in time-limited decision-making situations.

Preface

Comprehensive Management Guidelines for Childhood Cancer; Developing a Global Platform for Resource Adapted Child Cancer Treatment and Care.

The **Adapted Resource and Implementation Application (ARIA)** Guide collaboration between St. Jude Global and International Society of Paediatric Oncology (SIOP) began in early 2020 and arose from a shared goal of closing the global child cancer survival gap by providing trustworthy, safe, and effective guidance for the management of cancer in children, wherever they may live.

SIOP's Global Health Network (formerly Pediatric Oncology in Developing Countries, PODC) previously developed and published a series of "resource-adapted treatment regimens" for use in resource-limited settings. Still, these publications did not include the practical guidance, or the implementation tools needed to support day-to-day cancer care for children. The ARIA Guide initiative addresses this need by developing practical and comprehensive childhood cancer management guidelines hosted on a free, intuitive platform (ARIAguide.org).

In partnership with the leadership of the Paediatric Radiation Oncology Society (PROS), Childhood Cancer International (CCI), and the International Society of Paediatric Surgical Oncology (IPSO), the ARIA team is now working with representatives from many international collaborative groups to develop detailed resource-adapted management guidelines for all major childhood cancers. Each guideline includes narrative details, disease stage, and risk stratification tools through the ARIA Guide portal (website) treatment roadmaps and checklists to support healthcare teams in safely providing chemotherapy, radiation therapy, surgery, nursing, palliative care, supportive care, and survivorship care. With the shared interest of St. Jude, SIOP, CCI, IPSO, and PROS in closing the global childhood cancer survival gap and meeting the goals of the World Health Organization (WHO), Global Initiative for Childhood Cancer (GICC), the ARIA collaboration represents a major new global commitment to support the decision making and cancer care of health care providers worldwide.

About the ARIA Guide

The ARIA Guide is both a global evidence-based guideline collaboration and a web-based clinical tool. Using an innovative methodology, each CPR integrates the evidence-base with structured expert consensus to address knowledge gaps. When used appropriately, the ARIA Guide will provide the best available care for any child with cancer, based on the diagnosis, disease stage, and risk stratification, adapted to the available resources in each treatment setting.

As each guideline is launched, starting in 2023, the ARIA Guide team is simultaneously working to support the needs of individual patients, with a novel, web-based decision-aid tool (ARIAguide.org) that will provide recommendations applicable to any setting worldwide.

Disclaimer: The clinical practice recommendations contained within are synthesized from existing guidelines and have been reviewed for content accuracy. Recommendations do not yet reflect adaptation for variously resourced settings. Context adaptation is in progress and will be incorporated as soon as adaptations are available.

About this Childhood Cancer Palliative Care Clinical Practice Recommendation (CPR)

This clinical practice recommendation (CPR) has been developed to guide the diagnosis and treatment of *spirituality and existential crisis* in children across all resource settings. This CPR has been developed by a multidisciplinary panel of healthcare professionals with diverse perspectives, technical expertise, and a passion for pediatric oncology. ARIA Guide development follows the processes and procedures established by the ARIA Guide team and the ARIA Steering Committee, which represent the global partners: St. Jude Children’s Research Hospital, the International Society of Paediatric Oncology (SIOP), the Paediatric Radiation Oncology Society (PROS), Childhood Cancer International (CCI), and the International Society of Paediatric Surgical Oncology (IPSO). This CPR was generated following a systematic search and appraisal of existing guidelines. Results were synthesized and conflicts in addition to gaps were resolved by an expert panel incorporating pediatric oncology, nursing, pharmacy and topic-specific multidisciplinary expertise.

This resource was developed through a collaborative effort by the ARIA Coordinating Center, the ARIA Palliative Care Team, and the CPR-specific panel, under the guidance of the ARIA Steering Committee, to provide the most up-to-date information available while striving to meet the needs of the standard of care for specific childhood cancers in any setting.

We thank all who participated in this global effort to benefit children worldwide.

On behalf of the ARIA Guide Steering Committee and Palliative Care Team:

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With the approval of the ARIA Guide Program Co-Directors

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How to Get Involved

If you are interested in getting involved as a writer on a working group or as a reviewer please contact your regional SIOP structures or your organization’s management structure.

Visit us at: ARIAguide.org

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Background and Definition(s)

Although spirituality is recognized as a key component of palliative care, it is often an area that is inadequately examined by clinicians.¹⁻³ Both the WHO (World Health Organization) and American Academy of Pediatrics acknowledge the benefits of taking a spiritual history by clinicians and recommend general and subspecialty pediatricians to become familiar and comfortable with faith, existential, and spiritual aspects of life and illness of pediatric patients and their families.^{4,5}

Religion and spirituality are often mentioned in the same breath, but they are different concepts. A person's religion and/or spirituality are often the main source of their ethical and moral beliefs, however not all individuals who are religious are spiritual and vice versa. Religion is rooted in faith or worship and can determine a person's world view. Spirituality is a dynamic process by which humans seek meaning, purpose, and transcendence through relationships, nature and the sacred.^{6,7}

Spirituality and religion are means by which patients and their families can make meaning of their disease and may be a means of providing hope and inner peace. Despite this, up to 60-80% of families have unmet spiritual needs in hospital settings.⁸ An unaddressed spiritual and existential crisis can amplify a patient's experience with symptoms such as pain, anxiety, and depression.⁹ Questions around the spiritual meaning behind illness can arise during a patient's or a family's illness journey. Questions such as the "Why is this happening?" or "Is my child's illness a punishment?" are questions that are often asked by families.¹⁰ Hence stressing the importance for all health care professionals to be familiar with assessing a patient's spiritual needs. In fact, patients have expressed desires to build trusting relationships with their physicians that allow space for sharing fears and concerns.¹¹ Studies have shown that patients would like their clinical teams to recognize and address their spiritual needs.¹² Children and adolescents similarly have demonstrated a search for deeper meaning during challenging or traumatic events (e.g. hospitalizations, illness, abuse) in their life through religion or spirituality.¹³⁻¹⁵ It is important to note that patients posing questions in the realm of spirituality does not necessarily demonstrate crisis but if not addressed appropriately may lead to challenges with coping.⁹

General Approach

When physicians have inquired about a patient's spiritual well-being it has led to stronger and deeper relationships between them.¹⁶ Regardless of our own personal belief systems, palliative care providers should be equipped to ascertain a spiritual history and provide spiritual support or refer to a chaplain or spiritual leader. Healthcare providers are in a unique position to be able to have these serious conversations due to the intimate nature of the patient/clinician relationship.

The biopsychosocial-spiritual model and the patient care model are both used as frameworks for providing sound spiritual care. The biopsychosocial-spiritual model describes the totality of a patient's experience in the context of their disease which stresses the importance of an interdisciplinary approach to address all dimensions of care. While the patient-centered model recognizes the role shared decision has in leading to improved outcomes in patient care.^{6,7}

Do keep mind, a clinician's role in a patient's spiritual journey is to explore spiritual needs as a *spiritual generalist* and avoid proselytization, "fix" spiritual distress or respond to theological questions beyond one's scope of practice. Instead, spiritual *experts or specialists* (chaplain, community leaders, etc.) should be included in the spiritual plan to offer in depth spiritual assessment and provide interventions and further guidance.

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Key Take-aways

1. Pediatric palliative care addresses the whole child including biopsychosocial-spiritual aspects therefore clinicians should explore a patient's spiritual journey with them when they are faced with a life-threatening illness.
2. A person's religion and/or spirituality are often the main source of their ethical and moral beliefs, however not all individuals who are religious are spiritual and vice versa.
3. Spiritual care is a partnership between the person and their health care provider and is an integral component of holistic care.¹² Exploring needs as a spiritual generalist is the responsibility of all members of the interdisciplinary team (doctors, nurses, advanced practice providers, social work, chaplain, ancillary staff).
4. Spiritual development has stages much like psychosocial development.
5. A chaplain or spiritual faith leader should take a good spiritual assessment and create a plan with the interdisciplinary team.
6. Healthcare providers should respect spiritual needs in the setting of unique religious/cultural practices even if they differ from your own.

Risk Factors

Patient Considerations

Studies have demonstrated correlation between positive spiritual and religious views with better mental health, quality of life, and coping in the setting of illness.^{17,18} However it is important to be aware of those who are experiencing negative religious coping and be prepared to provide support. Those who have had high levels of religiosity and view illness as a punishment are experiencing negative religious coping which could lead to poor mental health outcomes. Some may even turn to religion or spirituality when faced with illness to find meaning through these avenues – some of whom may experience negative spiritual coping.^{19,20} Individuals who have not incorporated spiritual or religious views prior to their illness may still ponder worthiness, meaning of life and the afterlife without ascribing to any particular faith.

Another consideration is the cultural and spiritual diversity that lies within one cultural, religious, or spiritual tradition. Healthcare providers should observe cultural and spiritual humility by asking families about their beliefs and rituals to understand each family's and patient's unique spiritual needs and give them the opportunity to explore their spiritual beliefs and ask questions. Avoid assumptions and stereotypes because members of the same religious or spiritual tradition may not observe all the same teachings. In addition, children and teens can have divergent beliefs from their parents/caregivers.

Pediatrics is unique when assessing spiritual and existential needs. Children, adolescents, and adults have varying understanding and expression of their beliefs based on their spiritual development which can be correlated with their psychosocial development. These six stages of faith development offer a perspective on understanding the development of faith in humans from the time they are born to when they are adults.²¹ Of note, children can vary in how they progress through the stages of faith, and it may not occur as a linear progression.

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Source: Neuman ME. Addressing children's beliefs through Fowler's stages of faith. *J Pediatr Nurs.* 2011;26(1):44-50. doi:10.1016/j.pedn.2009.09.002

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Assessment & Monitoring

It is important to remember that as a clinician, most of us are not trained experts on giving spiritual guidance or advice. If you have found yourself in a situation where there is extreme spiritual distress, continue to explore with open-ended questions and remain non-judgmental. Do not try to fix the problem or answer unanswerable questions (e.g., Why me?) Provide a safe space for the patient and let them lead the conversation. Always involve a trained spiritual care expert when it is possible. Ensure spiritual needs have been identified successfully and met by checking in regularly and reassessing.

Interventions

Evaluation and Interventions

Clinicians should be able to take a sound spiritual history regardless of whether they share the same beliefs as their patients and families or not. Over 90% of the world is involved in spiritual or religious practices and it is well known that many families turn to spirituality when faced with illness and dying to gain strength and meaning.²²

The interdisciplinary team including physicians, advanced practice providers, nurses, social workers, chaplain etc. should be part of assessing a patient's spiritual well-being and be prepared to offer support in order to care for their whole patient: body, mind, and spirit.²³ A successful interaction requires the clinicians to have a compassionate presence, demonstrate active listening and empathetic communication.⁹ It is equally critical for a clinician to self-reflect on one's own beliefs which can lead to increased empathy when interacting with patients and families who are grappling with their beliefs. It is also just as important to be alert to the complexity of each child and families lived experience with serious illness and the factors that contribute to it. Individual (e.g., developmental level), family (e.g., communication style, religion) and environmental factors (e.g., place of care, resources) all play a role in coping.¹

Several tools have been created for non-spiritual care experts to take spiritual histories (FICA, SPIRIT, HOPE).²⁴⁻²⁶ Most tools were designed to take a history in adult patients and are used commonly for parents, but a few have been used that are specific to children. The FICA tool has an adolescent version, while an interview guide has been proposed for children ages 6-17.²⁷ For those children too young to interview, one can employ other strategies such as art, stories, and play.²⁸

Tools used in obtaining a spiritual history

FICA

F: Faith and beliefs: Is there a particular faith that you and your family are members of?

I: Importance of spirituality in a patient's or family's life

C: Spiritual community of support

A: How can the healthcare team support your child and family in your faith and spirituality at this time?

SPIRIT

S: Spiritual belief system: Do you have a faith or sense of spirituality as part of your life?

P: Personal spirituality: How do you express your spiritual connection to something greater?

I: Integration with a spiritual community: Is there a spiritual community you are part of?

R: Ritualized practices and rituals: Are there any specific rituals/practices or laws that you follow?

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I: Implication of medical care: Can you see a role of spirituality in what you are facing with your child now?

T: Terminal events planning: In the event that someone dies, what are any rules or beliefs that should be carried out?

HOPE

H: Source of hope

O: Role of organized religion

P: Personal spirituality and practices

E: Effects on care and decision making

Spirituality quality of life interview questions (ages 6-17)²⁷

1. What makes you feel good or happy?
2. What makes you feel bad or unhappy?
3. When you feel bad or unhappy, what helps you feel better?
4. Some children while they are sick do things to feel close to God (or a higher power). Have you done anything like that? If so, what did you do?
5. Some children pray (meditate) when they do not feel good or are unhappy. Do you pray? If so, what do you pray for? Does it [prayer] help?
6. Is there anything you do to help people in your family feel good or happy? If so, what do you do?
7. What do you like to do for fun?
8. What have you done this week for fun?

Proposed interventions will be individualized to be culturally and family specific. Some studies have indicated that parents find empathetic listening, prayer with children/families, silent communication, performing religious rites and access to clergy are important when coping with their child's illness.^{8,10} Once it has been determined what is valued by the patient and family a spiritual plan should be created which can include appropriate referrals to chaplain if available, providing religious texts, or community supports can be sought.²⁹

Action's clinicians should take when assessing spiritual and existential needs²⁹

1. Listen to the patient/family story
2. Learn about the patients' religious or spiritual beliefs and how they play a role in goals of care
3. Listen with empathy
4. Acknowledge with humility the universal mystery of spirituality and death as well as patient and families hope for miracles³⁰
5. A clinician's role in a patient's spiritual journey is to explore spiritual needs as a *spiritual generalist* and avoid proselytization, "fix" spiritual distress or respond to theological questions beyond one's scope of practice. Spiritual *experts or specialists* (chaplain, community leaders, etc.) should be included in the spiritual plan to offer in-depth spiritual assessment and provide interventions and further guidance.
6. Involve other team members such as psychology, social work in plan
7. Integrative therapies: music or pet therapy, aromatherapy
8. Honor the patient/family religious or cultural practices: holy days, diet restrictions, need for daily prayers/meditations, hygiene, modesty are a few examples
9. Help with arranging religious books/music, clergy members.

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Goals of Care

How spiritual views align with goals of care

Religion and spiritual views can inform goals of care discussions with patients and their families. Religious and spiritual views can influence everything from when and if to redirect care such as withdrawal of life sustaining treatments, ceasing nutrition, burial and bereavement beliefs and rituals. It is not within the scope of this work to describe each unique situation however it is important to recognize that there are many. It is important to practice shared decision making while setting aside our bias and practice spiritual and cultural humility in these situations. Respecting another's views does not mean we have compromised our own values.

Considerations if spiritual and religious views between clinician-patient dyad do not align

There is always the possibility that clinicians and patients are not aligned with their spiritual beliefs due to the highly nuanced nature of personal spiritual beliefs. Often times as clinicians we are also grappling with our own spiritual beliefs and existential distress leading to tension in these scenarios which may also lead to tension. Regardless of the misalignment, the clinician should be aware patients/families may have different views spiritual beliefs and explore the belief system of their patient's family by engaging in an open unbiased communication.⁷

Some patients/families may ask you to pray with them. If this does not align with your beliefs, it still may be beneficial to the patient and family to engage in this meaningful act with them. In situations where you do not feel appropriate participating, ask if you can silently observe.

Bereavement

Bereavement is an expected state of mourning when one has experienced the death of a loved one. Bereavement impacts every aspect of a person from the physical, to psychological, spiritual, and social areas of personhood.³¹ If not attended to, long term impacts such as complicated grief, difficulty sleeping, and adverse health outcomes can result.^{32,33} Few structured bereavement programs exist worldwide, especially those specific to pediatrics. The benefit of having such a program is to help parents heal and process as well as early identification of those at risk for complicated bereavement.³⁴ Some successful bereavement programs have empowered bereaved parents to be integral in the growth and development of the institutional grief and bereavement programs.³⁵

Every family will have different needs during their bereavement depending on their culture, religious, or spiritual needs. It is important to use good communication to ask what each family needs and work with the chaplain or local community religious leaders.

A bereavement program should include at least these 5 components:

1. Acknowledgement of the patient's death (e.g., condolence letter preferably by one who knows the child).³⁶
2. Information and education on death (e.g., seminars, bereavement guide)
3. Support services (e.g., support groups, religious community)
4. Staff support (e.g., debriefing with team, bereavement rounds)
5. Program evaluation (e.g., written evaluations)

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Who provides bereavement?

Bereavement care comes in many forms (e.g., individual psychotherapy, peer group support, and group therapy) and is offered by a range of organizations, including hospices, nonprofit community organizations, and faith-based groups, in addition to informal care offered by individual providers, such as primary care physicians and other clinic. There is great variability according to institutions and their resources. These offerings exist in person as well as virtually.

Resources

Patient Education

1. Fast Facts on Cultural Beliefs in Palliative Care, Interpreters in Palliative Care: <https://www.mypcnow.org/fast-fact/asking-about-cultural-beliefs-in-palliative-care/>
2. The Role of Chaplaincy in Caring for the Seriously ill: <https://www.mypcnow.org/fast-fact/the-role-of-chaplaincy-in-caring-for-the-seriously-ill/>
3. Intersection of Palliative Care and Spiritual Care: <https://www.mypcnow.org/fast-fact/use-of-interpreters-in-palliative-care/>
4. George Washington Institute of Spirituality in Healthcare, ISPEC (Interprofessional Spiritual care Education Curriculum): <https://gwish.smhs.gwu.edu/programs/transforming-practice-health-settings/interprofessional-spiritual-care-education-curriculum-ispecc>

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A Word About the Global Partners

Since its founding in 1962, **St. Jude Children’s Research Hospital** has been committed to finding cures and saving children with cancer and other life-threatening diseases through research and treatment. Discoveries made by St. Jude are freely shared with the global scientific community. More than 80 percent of children with cancer live in low- and middle-income countries today. In parallel with **St. Jude Global** (an initiative focused on supporting global pediatric oncology and hematology outreach), the Department of **Global Pediatric Medicine** unites doctors and scientists with expertise in international medicine, epidemiology, health economics, and health policy. These professionals work together to help speed progress against childhood cancer, blood disorders, and other life-threatening diseases. Our goal is to give children with cancer access to quality care no matter where they live.

The **Société Internationale d’Oncologie Pédiatrique/International Society of Paediatric Oncology (SIOP)** was formed on November 6, 1969, as a small group of specialists at the Institute Gustave-Roussy (IGR) in Villejuif, Paris, whose mission it was to advance the study and care of children with cancer in underdeveloped nations and societies. SIOP has transformed into a truly global, multifaceted organization and is the only global multidisciplinary society devoted to pediatric and adolescent cancer. The society has members worldwide, including doctors, nurses, other healthcare professionals, scientists, and researchers. Our members are dedicated to increasing knowledge about all aspects of childhood cancer.

The success of a 2003 SIOP congress gave rise to the **Paediatric Radiation Oncology Society (PROS)**. As pediatric radiation oncologists met regularly at the annual SIOP meetings, a formal proposal was made to form an independent pediatric radiation oncology society. Accordingly, at the 2005 SIOP meeting in Vancouver, Canada, a motion was carried on 19 September 2005 to proceed with the formation of the new organization. PROS was officially created in Lyon on 1 March 2006, when the official statutes were submitted to the Préfecture du Rhône.

Childhood Cancer International (CCI) was founded in 1994 as an umbrella organization of childhood cancer grassroots and national parent organizations. Today, CCI is the largest patient support organization for childhood cancer. It is a global, parent-driven non-profit that represents more than 170 parent organizations, childhood cancer survivor associations, childhood cancer support groups, and cancer societies in more 90 countries across five continents.

The **International Society of Paediatric Surgical Oncology (IPSO)** is an international society of surgeons who specialize in the surgical care of children with cancer. IPSO is a truly global organization, with an expanding membership in all parts of the world. At the last count, 50 countries were represented. Membership is open to all surgeons who have a demonstrable commitment to pediatric surgical oncology, and the society is always keen to attract new members.

Disclaimer: The clinical practice recommendations contained within are synthesized from existing guidelines and have been reviewed for content accuracy. Recommendations do not yet reflect adaptation for variously resourced settings. Context adaptation is in progress and will be incorporated as soon as adaptations are available.