Commentary

A proposed global framework for pediatric cancer communication research

Dylan E. Graetz, MD, MPH [1,2]; Ana Caceres-Serrano, PhD[3]; Venkatraman Radhakrishnan, MD, DM, MSc[4];
Carmen E. Salaverria, MS[5]; Joyce B. Kambugu, MD[6]; and Bryan A. Sisk, MD, MSCI [7,8]

The World Health Organization (WHO) has identified communication as an essential component of sustainable care for children with cancer worldwide.[1] Nevertheless, nearly all communication research has been conducted in high-income countries.[2] In these settings, high-quality pediatric cancer communication can decrease parental distress,[3-5] increase trust in the physician, and foster hope.[6,7] Meanwhile, 8 to 9 of every 10 children diagnosed with cancer live in a low- or middle-income country (LMIC).[8] Culture and setting affect cancer communication,[9-11] and foundational research in LMICs is essential to understand the communication needs and priorities of patients and families. In addition, survival rates for childhood cancer in LMICs are as low as 20% to 30%,[12] and abandonment rates may be as high as 50% to 60%.[13] Misdiagnosis, gaps in care access, and treatment refusal are partially attributable to cancer misconceptions; a lack of knowledge or awareness regarding cancer care; and cultural barriers, including distrust.[14,15] Communication research in LMICs thus has the potential to affect care quality and outcomes for children with cancer.

To improve pediatric cancer communication around the world, this field needs a shared framework or model that can facilitate comparative analysis and the adaptation of interventions from one region to another. Communication researchers in high-income countries have previously called for a broad interactional framework that not only includes the clinician or patient but also encompasses the collective interaction between families and health systems.[16] To be globally applicable, this framework should also include the cultural backgrounds of families and clinicians, including all types of social support.[17]

Here, we introduce a framework for culturally adaptive family-centered pediatric oncology care that highlights and contextualizes communication (Fig. 1). We adapted this framework from the WHO model for integrated people-centered health care[18] and modified it for pediatric cancer. The WHO framework emphasizes people and communities, rather than diseases, as the center of health care and encourages patient empowerment. In this model, the person is surrounded by his or her family, community, health sector, and, eventually, country. Our framework focuses on the cultural context of the clinical environment within the health system in addition to the cultural context of the patient and family.

Importantly, the center of our framework emphasizes interactions between the health care environment and the patient, family, and community. This interactional portion of the model has been adapted from the WHO model for health system responsiveness.[19] According to the WHO, responsiveness refers to how well a health system meets the nonhealth needs of the population it serves. The original model includes 7 domains: dignity, confidentiality, autonomy, prompt attention, social support, basic amenities, and choice of provider. We have adjusted these domains for pediatric cancer and included an enabling environment, hospital-community integration, and communication. In our model, an enabling environment includes basic amenities, whereas hospital-community integration encompasses the provision of social needs. Respect and dignity include confidentiality and are separate from empowerment, which has replaced autonomy for the pediatric setting. Choice of provider is less relevant to global pediatric oncology, where the workforce is limited, and has been removed from the framework. Finally, emotional support and attention are contained within communication. Overall, our framework demonstrates multilevel factors in both the clinical and family environment that affect clinical interactions, and this model highlights communication as central to these interactions.

Corresponding Author: Dylan E. Graetz, MD, MPH, St. Jude Children's Research Hospital, 262 Danny Thomas Pl, Mailstop 721, Memphis, TN 38105-3678 (dylan.graetz@stjude.org).

[1]Department of Global Pediatric Medicine, St. Jude Children's Research Hospital, Memphis, Tennessee; [2]Solid Tumor Division, Department of Oncology, St. Jude Children's Research Hospital, Memphis, Tennessee; [3]Department of Psychology, Unidad Nacional Oncologia Pediatrica, Guatemala City, Guatemala; [4]Department of Medical Oncology, Cancer Institute (WIA), Chennai, India; [5]Department of Psychology, Fundacion Ayudame a Vivir, San Salvador, El Salvador; [6]Department of Oncology, Uganda Cancer Institute, Kampala, Uganda; [7]Division of Hematology and Oncology, Department of Pediatrics, Washington University, St. Louis, Missouri; [8]Bioethics Research Center, Department of Medicine, Washington University, St. Louis, Missouri

DOI: 10.1002/cncr.34160, **Received:** September 24, 2021; **Revised:** January 26, 2022; **Accepted:** January 31, 2022, **Published online** February 24, 2022 in Wiley Online Library (wileyonlinelibrary.com)

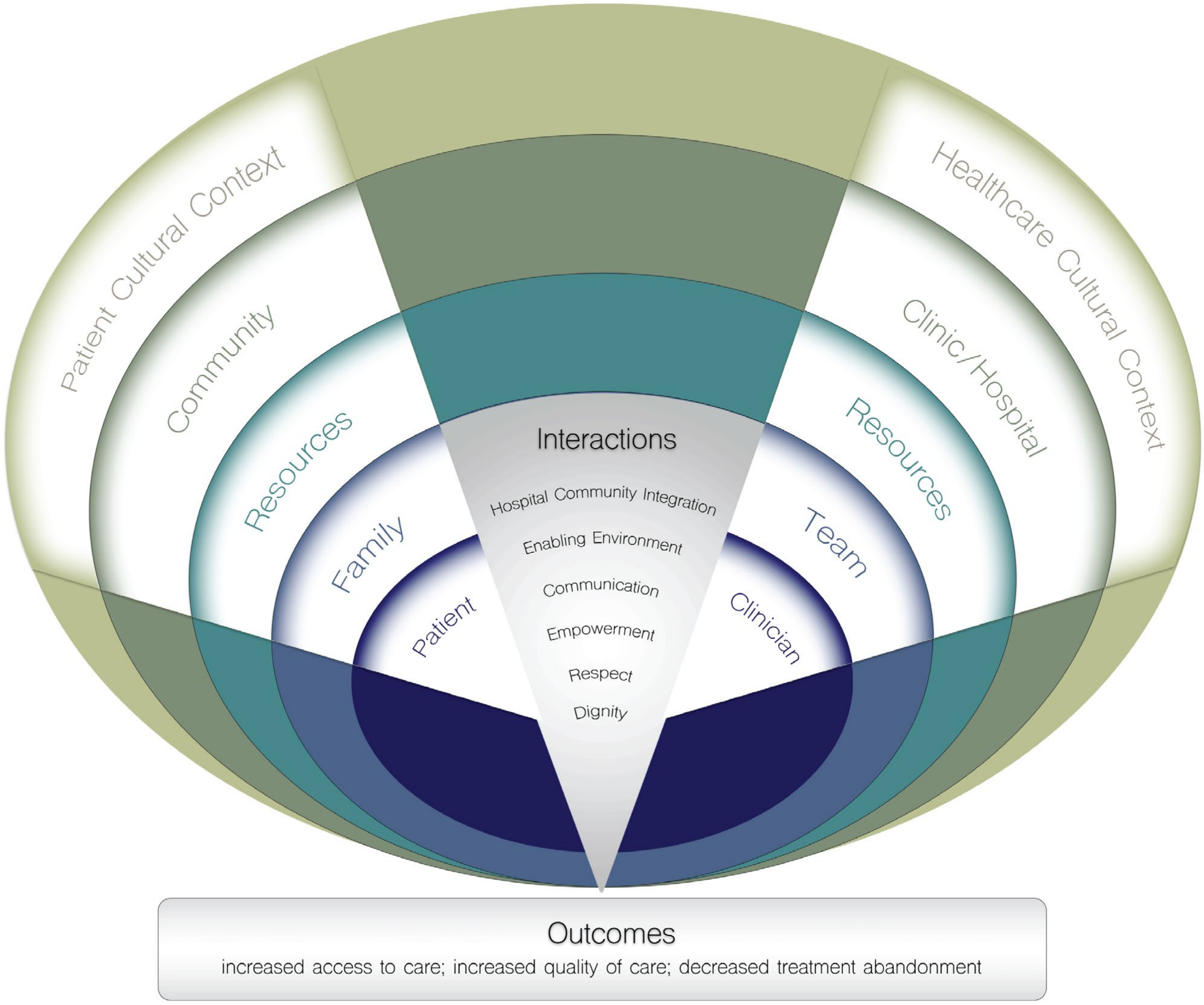

Figure 1. Model for culturally adaptive patient-centered care.

Although communication is fundamental to this framework, *communication* can itself be interpreted in many ways. Models of communication predominantly take 2 forms: process models and functional models. Process models focus on specific clinician behaviors that should be emulated to fulfill communication goals. An example of a process model for communication is the SPIKES protocol for delivering bad news.[20] This protocol includes 6 concrete steps: 1) setting up the interview, 2) assessing the patient's perception, 3) obtaining the patient's invitation, 4) giving knowledge and information to the patient, 5) addressing the patient's emotions with empathic responses, and 6) strategy and summary. These steps are designed to be straightforward and easy to follow and have been demonstrated to be useful and effective in high-resource settings. However, they may not be globally applicable without adaptation. For example, some families might feel supported by having their emotions directly addressed,[21] whereas other families might prefer clinicians to focus on instrumental care for the child and find solace in the perceived competence of the medical team.[22] Functional models, conversely, maintain the "equifinality" of communication; this means that multiple unique communication interactions can lead to the same functional outcome or goal.[16] In functional models, the goal is to interact with the patient in a way that meets the patient's unique communication needs. The focus of a functional model is on the outcomes of communication interactions rather than the specific processes that one must follow.

We argue that a functional model is more appropriate for adaptation to different cultural settings in global health. Equifinality is important within high-income countries, such as the United States, to ensure that approaches to communication are adapted to each patient and family and for each particular situation. This adaptability is even more important when a model for communication is being applied in LMICs. Thus, nested within our framework for culturally adaptive patient-centered care is a functional communication model that our group previously developed for pediatric oncology (Fig. 2).[22-24] This model was adapted from adult oncology,[25] and we have demonstrated its potential applicability in LMICs.[17,26,27]

Our functional communication model contains 8 core functions of pediatric cancer communication: building relationships, exchanging information, enabling family self-management, providing validation, managing uncertainty, responding to emotions, supporting hope, and making decisions. Six of these functions (building relationships, exchanging information, enabling family self-management, managing uncertainty, responding to emotions, and making decisions) have been linked to cancer outcomes in the United States,[16] a country with a diverse population including multiple cultures and languages. These same functions have been highlighted to varying degrees in communication literature from LMICs.[17] The 2 novel functions in pediatric oncology, supporting hope and providing validation, were identified as themes in recent communication research from Guatemala, a middle-income country.[26,27] Given these early data, we believe that this model can be applied to global pediatric communication research.

APPLYING A FUNCTIONAL COMMUNICATION MODEL IN LMICs

To explore the applicability of this functional communication model in LMICs, we describe examples of how it can be adapted to the unique cultural aspects of communication in 4 LMICs: India (V.R.), Guatemala (A.C.-S.), El Salvador (C.E.S.), and Uganda (J.B.K.).

In India, decision-making is affected by a patient and family's ability to make informed, voluntary choices about the patient's health care, which varies according to the clinical and cultural context. An important part of autonomy is being able to decide when to defer decisional authority to others.[28] At a nongovernmental hospital in Chennai, a common plea from caregivers is, "You are the doctor; you know what is best for my child, so you decide and treat." Many parents are poor, are overwhelmed by their child's illness, and have no prior understanding of cancer. They entrust

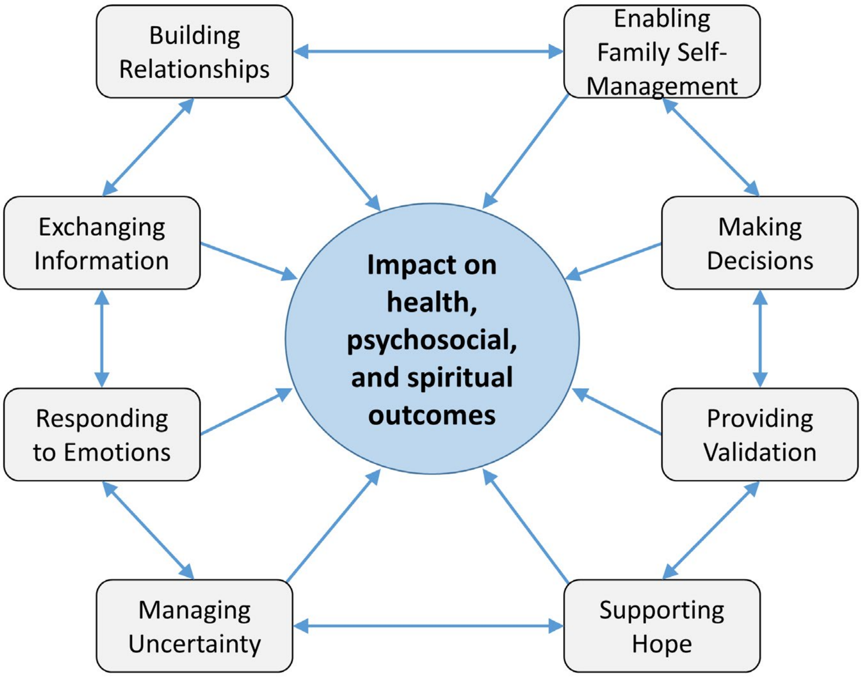

Figure 2. Functional model for pediatric cancer communication.

all decision-making regarding their child's treatment to the medical staff because they believe that they do not have the knowledge or capacity to make decisions. Additionally, the involvement of pediatric patients in decision-making is highly variable around the world. Many parents in LMICs, including India, do not want their children to be told about their cancer diagnosis.

At the pediatric cancer center in Guatemala City, decision-making is similarly clinician-driven. Rather than prioritizing autonomy and parental authority by outlining the risks and benefits of various choices, interdisciplinary clinicians encourage families to participate in recommended therapy by promoting honesty during diagnostic communication, and they often involve extended family members to engender trust. Although children and adolescents in Guatemala are not directly involved in decision-making, they are informed about their disease and have a separate space for education and diagnostic communication, with child life specialists providing this support.

Pediatric cancer communication in El Salvador, like that in Guatemala, is conducted by an interdisciplinary team consisting of a physician, a psychologist, a social worker, and sometimes a nurse educator. The psychosocial team in El Salvador takes on the role of a patient navigator and meets with the families to check for understanding, answer questions, and address doubts. This relieves some of the burden from busy physicians and gives parents, who may not be able to access or approach their physician, a safe space to express their concerns. In El Salvador, as in India and Guatemala, physicians represent knowledge and authority. Many of the patients are poor and uneducated. Clinical teams thus focus on communicating that the child is sick and needs lifesaving treatment. Children in El Salvador are usually informed about their care; however, there are times—particularly near the end of life—when a family prefers to withhold information from the child, and the clinical team respects this decision.

In Uganda, most families similarly defer to the clinician and specifically the physician to make the best decision for their child. Clinicians are careful about the amount of information that they provide upfront because they are concerned about scaring parents and abandonment rates are high. As in many other LMICs, communication in Uganda is often provided by an interdisciplinary team. Nurses, rather than psychosocial providers, provide most of the counseling and are available to clarify information discussed by the physician. Children in Uganda are almost never involved in communication; however, extended family members, particularly on the paternal side, may be included.

Specific traditional beliefs can also affect decision-making and preferences for information exchange. Parents in limited-resource settings, including India, Guatemala, El Salvador, and Uganda, rely on relatives, friends, and social media for information and may be tempted by magical cures offered by alternative providers. In Uganda specifically, the church plays a major role, with many families opting for prayers over chemotherapy and hoping for a miracle. Many families in LMICs not only believe in alternative therapies but are overwhelmed by financial constraints imposed by treatments, job loss, and family separations. The interaction of these factors, rooted in their beliefs, makes it more attractive for families to turn toward resources in their local community, which often include alternative providers or religion. Tackling misinformation and belief in alternative medicine requires engagement with caregivers' friends, relatives, and community. In Guatemala, oncologists partner with psychologists, who take a biopsychosocial-spiritual approach in which they spend time learning about a family's cultural and socioeconomic context, including traditional beliefs. Although some pieces of information exchange may be most important for families with low health literacy, it is our experience that other aspects of communication, such as belief in alternative medicine and the impact of community, relatives, and social media, transcend social and economic barriers.

LOOKING FORWARD

These insights are important as we consider how our functional communication model might be adapted and applied globally and why process models developed in high-income countries might be insufficient. For example, Western models of autonomy and shared decision-making are unlikely to apply to cultures that prioritize relational autonomy[29] and family-centric decision-making. Involving children during upfront cancer communication contrary to their family's wishes could contribute to mistrust. Other communication process priorities established in high-resource settings, such as protecting time and space for important conversations, might be unrealistic and thus unhelpful for clinicians in LMIC settings.

Supporting communication around the world requires a communication framework that is highly adaptable to local circumstances and cultures. We propose that a functional model of communication is best suited for this adaptation. It is essential that future research seeks to further understand how this functional communication model manifests in different cultural contexts. Otherwise, incorrect assumptions may lead to culturally insensitive care and interventions that are at best ineffective and at worst may harm the clinical relationship and worsen childhood cancer outcomes. Future work should focus on establishing and validating this functional model for pediatric cancer communication in LMICs. This research may involve testing the model in various settings by adapting quantitative tools previously used to establish and validate the model in high-income countries. Additionally, qualitative interviews with clinicians, families, and patients can explore how communication functions manifest in different cultural settings and which, if any, domains are missing. This approach would allow global communication researchers to compare findings, share discoveries, and build on a common conceptual framework.

Once established, each function can be paired with specific process models developed to guide clinicians as they meet the needs of families at an individual, institutional, or regional level. Process models will allow clinicians to operationalize each broad communication domain and translate the functional model into specific actions used to deliver high-quality communication. Process models must be tailored to the culture in which the care is being delivered, and thus they are best developed by researchers and clinicians within the country where they will be used. Our functional framework can be used to guide future research focused on creating and validating such process models. The broad application of an adaptable functional framework, paired with the development of process models for each community or country, will expedite communication research and implementation of interventions and allow us to move more quickly from theory to practical improvements in pediatric cancer care for children everywhere.

FUNDING SUPPORT

This work was funded by the American Lebanese Syrian Associated Charities of St. Jude Children's Research Hospital.

CONFLICT OF INTEREST DISCLOSURES

Dylan E. Graetz reports a 2020 Conquer Cancer Young Investigator Award from the American Society of Clinical Oncology. The other authors made no disclosures.

REFERENCES

1. Atun R, Bhakta N, Denburg A, et al. Sustainable care for children with cancer: a Lancet Oncology Commission. *Lancet Oncol*. 2020;21:e185-e224. doi:10.1016/s1470-2045(20)30022-x
2. Sisk BA, Mack JW, Ashworth R, DuBois J. Communication in pediatric oncology: state of the field and research agenda. *Pediatr Blood Cancer*. 2018;65:e26727. doi:10.1002/pbc.26727
3. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Arch Pediatr Adolesc Med*. 2009;163:519-524. doi:10.1001/archpediatrics.2009.57
4. Greenzang KA, Cronin AM, Kang TI, Mack JW. Parental distress and desire for information regarding long-term implications of pediatric cancer treatment. *Cancer*. 2018;124:4529-4537. doi:10.1002/cncr.31772
5. Mack JW, Fasciano KM, Block SD. Communication about prognosis with adolescent and young adult patients with cancer: information needs, prognostic awareness, and outcomes of disclosure. *J Clin Oncol*. 2018;36:1861-1867. doi:10.1200/jco.2018.78.2128
6. Kamihara J, Nyborn JA, Olcese ME, Nickerson T, Mack JW. Parental hope for children with advanced cancer. *Pediatrics*. 2015;135:868-874. doi:10.1542/peds.2014-2855
7. Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol*. 2007;25:5636-5642. doi:10.1200/jco.2007.12.6110
8. Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Atun R. Estimating the total incidence of global childhood cancer: a simulation-based analysis. *Lancet Oncol*. 2019;20:483-493. doi:10.1016/s1470-2045(18)30909-4
9. Brown O, ten Ham-Baloyi W, van Rooyen DR, Aldous C, Marais LC. Culturally competent patient-provider communication in the management of cancer: AN integrative literature review. *Glob Health Action*. 2016;9:33208. doi:10.3402/gha.v9.33208
10. Surbone A. Cultural aspects of communication in cancer care. *Support Care Cancer*. 2008;16:235-240. doi:10.1007/s00520-007-0366-0
11. Schouten BC, Meeuwesen L. Cultural differences in medical communication: a review of the literature. *Patient Educ Couns*. 2006;64:21-34. doi:10.1016/j.pec.2005.11.014
12. Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Girardi F, Atun R. Global childhood cancer survival estimates and priority-setting: a simulation-based analysis. *Lancet Oncol*. 2019;20:972-983. doi:10.1016/s1470-2045(19)30273-6
13. Friedrich P, Lam CG, Itriago E, et al. Magnitude of treatment abandonment in childhood cancer. *PLoS One*. 2015;10:e0135230. doi:10.1371/journal.pone.0135230
14. Arora RS, Eden T, Pizer B. The problem of treatment abandonment in children from developing countries with cancer. *Pediatr Blood Cancer*. 2007;49:941-946. doi:10.1002/pbc.21127
15. Arora RS, Pizer B, Eden T. Understanding refusal and abandonment in the treatment of childhood cancer. *Indian Pediatr*. 2010;47:1005-1010.
16. Street RL, Mazor KM, Arora NK. Assessing patient-centered communication in cancer care: measures for surveillance of communication outcomes. *J Oncol Pract*. 2016;12:1198-1202. doi:10.1200/jop.2016.013334
17. Graetz DE, Garza M, Rodriguez-Galindo C, Mack JW. Pediatric cancer communication in low- and middle-income countries: a scoping review. *Cancer*. 2020;126:5030-5039. doi:10.1002/cncr.33222
18. World Health Organization. People-Centred Health Care: A Policy Framework. World Health Organization; 2007.
19. Darby C, Valentine N, Murray CJL, de Silva A. World Health Organization (WHO): Strategy on Measuring Responsiveness. World Health Organization; 2003. GPE Discussion Paper Series 23.
20. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5:302-311.
21. Young B, Hill J, Gravenhorst K, Ward J, Eden T, Salmon P. Is communication guidance mistaken? Qualitative study of parent-oncologist communication in childhood cancer. *Br J Cancer*. 2013;109:836. doi:10.1038/bjc.2013.413
22. Sisk BA, Friedrich A, Blazin LJ, Baker JN, Mack JW, DuBois J. Communication in pediatric oncology: a qualitative study. *Pediatrics*. 2020;146:e20201193. doi:10.1542/peds.2020-1193
23. Sisk BA, Schulz GL, Blazin LJ, Baker JN, Mack JW, DuBois J. Parental views on communication between children and clinicians in pediatric oncology: a qualitative study. *Support Care Cancer*. 2021;29:4957-4968. doi:10.1007/s00520-021-06047-6

24. Sisk BA, Schulz GL, Kaye EC, Baker JN, Mack JW, DuBois J. Clinicians' perspectives on the functions of communication in pediatric oncology. *J Palliat Med*. 2021;24:1545-1549. doi:10.1089/jpm.2021.0090
25. Epstein RM, Street RL Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Institutes of Health; 2007. NIH Publication 07-6225.
26. Graetz D, Rivas S, Fuentes L, et al. The evolution of parents' beliefs about childhood cancer during diagnostic communication: a qualitative study in Guatemala. *BMJ Glob Health*. 2021;6:e004653. doi:10.1136/bmjgh-2020-004653
27. Graetz DE, Rivas SE, Wang H, et al. Communication priorities and experiences of caregivers of children with cancer in Guatemala. *JCO Glob Oncol*. 2021;7:1529-1536. doi:10.1200/go.21.00232
28. Schneider CE. The Practice of Autonomy: Patients, Doctors, and Medical Decisions. Oxford University Press; 1998.
29. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Med Ethics*. 2019;26:76. doi:10.1186/s12910-019-0417-3