10-30-2019

"Farewell" to Prognosis in Shared Decision-Making

Robert F. Johnson
Grand Valley State University, johnsor2@gvsu.edu

ScholarWorks Citation

Johnson, Robert F., ""Farewell" to Prognosis in Shared Decision-Making" (2019). *Peer Reviewed Articles*. 58.
https://scholarworks.gvsu.edu/kcon_articles/58

“Farewell” to Prognosis in Shared Decision-Making

“The absorbing fact about being mortally sick is that you spend a good deal of time preparing yourself to die…while being simultaneously and highly interested in the business of survival”
----Christopher Hitchens, in *Mortality*

The author and polemicist Christopher Hitchens describes an encompassing dilemma of life-limiting/terminal illness as a “double frame of mind.”[1] Planning and living day to day with the knowledge of an expected death is the challenge.[2] Many if not most people in a Western culture, the United States for example, desire to confront this dilemma while receiving prognostic information from their health care provider(s).[3,4,5] High levels of information need, including life expectancy, are often seen during all stages of a life-limiting illness, although it has been observed that family/caregivers tend to desire more prognostic information – and the person less – as a dying process evolves.[6]

In contrast, a communication preference based on a cultural imperative is living day to day without specific current knowledge of a life-limiting diagnosis and/or its prognosis. The person is not included in the discussion of this information. Lulu Wang, in her film “The Farewell” (2019) uses her own life experiences to dramatize such a situation.[7,8] A 31-year old Chinese-American woman, reflecting her life since age 6 in a Western ethos, struggles to accept the plan of her Chinese relatives to not inform the matriarch, her grandmother, of a diagnosis of advanced lung cancer. Her uncle explains that “It’s our duty to carry this emotional burden for her.”[9]

Acknowledging global migration patterns, this scenario is not unfamiliar to palliative care practitioners in the United States. Understanding and approaching this cultural consideration, among others, is an expected component of the palliative care curriculum.[10] For such practitioners the key principle is to respect a person’s autonomy, assuring that the person capable of decision-making endorses such a plan rather than relying entirely on separate discussions with family members. Most often one of these family members, preferably chosen by the capable person, serves as a proxy for receiving information and participating in shared decision-making.

This cultural perspective has a corollary in the practice of some healthcare professionals censoring information given to people in an attempt to avoid hurt, distress, or loss of hope. While well-intentioned this practice is most often misguided, resulting in more pronounced distress. A foundation for effective shared decision-making is not established.[11]

This choice to limit information about a terminal illness can also occur as a person's choice, separate from a setting of cultural influence.[12] Less well identified or discussed are these instances where an individual desires to limit the intake of information and participation in decision-making based on personal preference. This pattern has received attention recently in the work of Steve Scheier, an expert in organizational decision-making. Based on experiences during his wife's' eventual death from biliary cancer, he developed a Prognosis Declaration form designed for persons of any cultural background.[13] This form offers the following choices:

> "Tell me everything."
>
> "I've not decided what I want to know about my prognosis, so ask me over the course of my treatment."
>
> "I want to participate in my treatment, but I don't want to receive any information on my prognosis."
>
> "I don't wish to know any information about my prognosis but I authorize you to speak with [blank] about my case and to answer any questions that this person may have about my likely prognosis and treatment."

How do these Prognostic Declaration form choices interface with the process of shared decision-making, the currently recommended approach to communication regarding life-limiting illness and end-of-life issues?[14] Approaching this question leads to the discussion of certain points related to prognostic assessment, communication principles, and shared decision-making. Hopefully this exploration will lead to summary observations and points of practical advice for the palliative clinician regarding disclosure of prognostic information conforming to a person’s preference.

An experienced clinician recognizes any one of the Prognosis Declaration statements as inadequate on its own for developing a specific communication and management plan. However, these declarations, along with other available advance planning documentation and – most importantly – expressions of a decision-capable person during a significant end-of-life communication session - can be useful in coming to decisions and a plan for implementation aligning with the person’s values, preferences, and goals. Such communication would be conducted using the principles of shared decision-making.

Since its first mention in 1982, shared decision-making has come to be recognized as the preferred format for significant palliative care provider/person-family discussions.[14,15] This includes the disease categories most often seen in palliative care.[16,17,18,19,20,21,22] Shared decision-making in the setting of terminal illness and end-of-life care involves a process of integrating the expertise and communication skills of the health care professional with autonomous expressions of the decision-capable person as to their values, preferences, and goals in the context of the situation she is facing. The objective is to make informed, thoughtful, and collaborative decisions that will determine clinical management. This type of communication goes beyond the expectations of informed consent, being more comprehensive and attuned to the social and emotional needs of the person as well as the physical and technical aspects of a disease process. Accomplishing this level of effective communication in each of these disease categories ordinarily involves delivery of diagnostic and prognostic information to the decision-capable person, perhaps to varying levels of detail and expected involvement in decision-making but nonetheless significant.[23,24]

The discussion of shared decision-making in relation to our current topic, autonomous choices to decline prognostic information and limit involvement in decision-making, should mention described limitations of this practice. These include the challenge for health care professionals to formulate an accurate prognostic assessment,[25,26,27,28] uncertainty as to the optimal communication strategies for expressing the prognostic assessment,[29,30] inability of a person receiving a prognostic assessment to then formulate realistic expectations,[31,32] and various forms of cognitive bias.[33] There is currently a lack of evidence that shared decision-making results in better outcomes compared to other forms of decision-making.[34]

While shared decision-making has weaknesses, it can be supported as the best currently available approach for aligning patient values, preferences, and choices with actual management.[14] The following are offered as considerations, sometimes recommendations, for maintaining the spirit of shared decision-making even when a person declines or limits participation.

Autonomy. While shared decision-making should be considered the default position for entering into end-of-life discussions, the ethical principle of autonomy includes the capable choice of opting out of all or part of the shared decision-making process. The principle is respected because of the intent and effort of the shared decision-making participants, acknowledging the complexities and shortcomings involved in achieving an outcome consistent with the ethical goals.

"I" is for Invitation. Recall that the original description of the SPIKES mnemonic, a useful guideline for remembering the important features of a significant person/family discussion, includes the idea of inviting ("I") the person to express the desired extent of information delivery and type of decision-making process.[35] Most familiar to United States practitioners is a capable person requesting full information disclosure and participation in shared decision-making. With or without a Prognosis Declaration, including this key component of a communication interaction will elicit or include values and preferences with regards to prognosis awareness and extent of participation in decision-making.

Sliding Scale. Persons requesting a limitation on disclosure of prognostic information can have their involvement in decision-making tailored to the level of information available. A person may request a general statement of prognosis ("this situation is terminal") while not receiving more specific attempts at estimating duration or trajectory. Significant involvement in decision-making could still take place with or without the involvement of a representative who received more detailed information not disclosed to the person. Decision-making could be retained by the person with the decisions influenced, or not, by the representative(s).

Aprognosia. A situation presented by BJ Miller and Shoshana Berger depicts a person declining prognostic information.[13] While not intuitive to many, this can be the preferred stance to optimize the "double frame of mind" for some. This can be respected with diligent attention by all involved to information content and the agreed upon decision-making strategy. In this situation it would be significantly preferable to have a designated representative with whom a proxy shared decision-making process could take place.

What, not Why. Persons by choice lacking full information disclosure may well still go on to participate in the logistics and physical realities of different interventions. These patients should receive detailed information about these issues. In effect, the explanations would describe fully what is being done rather than why.

A Process, not an Event. The Prognosis Declaration choices appropriately include a provision for a change in preference, in either direction, as the person's life evolves. This points out the importance of appropriate interval reassessments of information needs and decision-making preferences.

No News is Good news. A situation of concern is the person declining prognosis information but at the same time requesting comprehensive but likely unhelpful interventions. Doubt, denial, distrust, or other influences can result in the same circumstance for a person receiving full prognostic information. Patience, compassion, and ongoing communication are required from the palliative clinician in either case.

A fixed belief that shared decision-making cannot occur without significant disclosure of prognostic information leading to reflexive negative or dismissive responses to a person's request for limiting prognostic information related to a life-limiting/terminal illness should be avoided by palliative care clinicians. This is true whether the request is culturally-based or due to personal preference. Respecting the request is consistent with the principle of autonomy. Inviting and then individualizing a person's information and decision-making preferences is always a part of shared decision-making. While more challenging, the desirable outcomes of effective shared decision-making can still be achieved when a person requests limited or no prognostic information.

References:

1. Hitchens C. *Mortality*. New York: Twelve; 2012.
2. Gubar S. Living intimately with thoughts of death. New York Times. July 25, 2019.
3. Hagerty RG, Butow PN, Ellis PA, Dimitry S, Tattersall HN. Communicating prognosis in cancer care: a systematic review of the literature. Ann Oncol 2005;16:1005-1053.
4. Innes S, Payne S. Advanced cancer patients' prognostic information preferences: a review. Palliat Med 2009;23:29-39.
5. Hagerty RG, Butow PN, Ellis PA, Lobb EA, Pendlebury S, Leighl N, Goldstein D, Lo SK, Tattersall HN. Cancer patient preferences for communication of prognosis in the metastatic setting. J Clin Oncol 2004;22:1721-1730.
6. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MHN. A systematic review of prognostic/end-of-life communication in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. J Pain Symptom Manage 2007;34:81-93.
7. Chen BX. The cultural truth at the heart of the lies in "The Farewell." New York Times. July 24, 2019.
8. Ito R. A family's real-life lie and the movie that complicated it. New York Times. July 5, 2019.
9. Lane A. Join in. The New Yorker. July 22, 2019.
10. Guadalupe GR. Cultural considerations in palliative care and serious illness. In: Wittenberg E, Ferrell BR, Goldsmith J, Smith T, Glajchen M, Handzo GF, eds. Textbook of Palliative Care Communication. Oxford University Press; 2015: Chapter 19.
11. Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. Palliative Medicine 2002;16:297-303.
12. Barnato AE. Challenges in understanding and respecting patients' preferences. Health Affairs 2017;36:1252-1257.
13. Miller BJ, Berger S. Don't tell me when I'm going to die. New York Times. June 22, 2019.
14. Institute of Medicine. Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, DC: National Academies Press; 2015.
15. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship. Washington, DC: US Government Printing Office; 1982.
16. Wiener RS. Can shared decision-making of physicians and patients improve outcomes in lung cancer screening? Yes. Chest 2019;156:12-14.
17. George NR, Kryworuchko J, Hunold KM, Ouchi K, Berman A, Wright R, Grudzen CR, Kovalerchik O, LeFebvre EM, Lindor RA, Quest TE, Schmidt TA, Sussman T, Vandenbroucke A, Volandes AE, Platts-Mills TF. Shared decision making to support the provision of palliative and end-of-life care in the emergency department: a consensus statement and research agenda. Academic Emergency Medicine 2016;23:1394-1402.

18. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared decision making in ICUs: an American College of Critical Care Medicine and American Thoracic Society policy statement. Crit Care Med 2016;44:188-201.
19. Moss AH. Revised dialysis clinical practice guideline promotes more informed decision-making. Clin J Am Soc Nephrol 2010;5:2380-2383.
20. Ferrell BR, Temel JS, Temin S, Smith TJ. Integration of palliative care into standard oncology care: ASCO clinical practice guideline update summary. J Oncol Pract;13:119-121.
21. Allen LA, Stevenson LW, Grady KL, Goldstein NE, Matlock DD, Arnold RM, Cook NR, Felker GM, Francis GS, Hauptman PJ, Havranek EP, Krumholz HM, Mancini P, Riegel B, Spertus JA. Decision making in advanced heart failure: a scientific statement from the American Heart Association. Circulation 2012;125:1928-1952.
22. Curtis JR. Palliative and end-of-life care for patients with severe COPD. Eur Respir J 2008;32:796-803.
23. Brom L, Pasman HRW, Widdershoven GAM, van der Vorst MJDL, Reijneveld JC, Postma TJ, Bregje D. Patient's preferences for participation in treatment decision-making at the end of life: qualitative interviews with advanced cancer patients. PLos ONE 2014;9:e100435.
24. Bomba P. Supporting the patient voice: building the foundation of shared decision-making. Generations 2107;41:21-30.
25. Kalanithi P. How long have I got left? New York Times. January 24, 2014.
26. Fisher M, Saxon R. Uncertainty in end-of-life care and shared decision making. Critical Care and Resuscitation 2012;14:81-87.
27. Christakis NA, Lamont EB. Extent and determinants of error in physicians' prognoses in terminally ill patients: prospective cohort study. BMJ 2000;320:469-473.
28. Fine PG. Hospice underutilization in the U.S.: the misalignment of regulation policy and clinical reality. J Pain Symptom Manage 2018;56:808-815.
29. Krawczyk M, Gallagher R. Communicating prognostic uncertainty in potential end-of-life contexts: experiences of family members. BMC Palliative Care 2016;15:59.
30. Masterson MP, Applebaum AJ, Buda K, Reisch S, Rosenfeld B. Don't shoot the messenger: experiences of delivering prognostic information in the context of advanced cancer. Am J Hosp Palliat Med 2018;35:1526-1531.
31. Feemster LC, Curtis JR. "We understand the prognosis but we live with our heads in the clouds": Understanding patient and family outcome expectations and their influence on shared decision making. Am J Respir Crit Care Med 2016;193:239-241.
32. Laferton JAC, Kube T, Salzmann S, Auer CJ, Shedden-Mora MC. Patients' expectations regarding medical treatment: a critical review of concepts and their assessment. Front Psychol 2017;8:233.
33. Ozdemir S, Finkelstein EA. Cognitive bias: The downside of shared decision making. JCO Clin Cancer Inform 2018;2:1-10.
34. Hajizadeh N, Uhler L, Herman SW, Lester J. Is shared decision making for end-of-life decisions associated with better outcomes as compared to other forms of decision making? A systematic literature review. MDM Policy and Practice 2016;1:1-12.
35. Baile WF, Buckman R, Lenz R, Glober G, Beale EA, Kudelka A. SPIKES - a six step protocol for delivering bad news: application to the patient with cancer. The Oncologist 2000;5:302-311.

Published as:

Johnson RF. Farewell to Prognosis in Shared Decision-Making? American Journal of Hospice and Palliative Medicine. 2020;37(6):409-412. https://dx.doi.org/10.1177/1049909119885323