



# Update on . . . Patient Education and Counseling

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*The focus of this column is to present topics of interest from a variety of journals to Oncology Nursing Forum readers. The topic of this issue is patient education and counseling.*



## Patient Preferences for Breaking Bad News

Breaking bad news in oncology care is an aspect of communication that warrants critical exploration. Clinicians who impart life-altering information need to feel empowered, and patients receiving the news should have the opportunity to request a preferred mode of delivery. Martins and Carvalho (2013) published a study that identified patient preferences as a guide for the way in which bad news should be received and how those preferences can reflect personality characteristics, including patients' health locus of control (HLC). HLC has been associated with health-related behaviors, particularly the patient's perceived control over his or her health as internal (i.e., determined by his or her own behavior), related to chance, or dependent on powerful others (PO). Levels of medical information needs tend to be lower in patients with higher scores on the chance dimension and on PO. The researchers hoped to use patient preference to identify specific ways in which bad news should be imparted.

Bad news is defined as any information that is likely to alter a patient's view of the future. Giving bad news has a profound impact on patients and clinicians, and clinicians who are inept in that mode of communication have been found to have higher distress levels. Researchers have documented enhanced patient satisfaction when delivery of bad news was done at an optimal level. Guidelines have been published to facilitate clinicians when disseminating bad news. However, when the guidelines were reviewed, only 56% of 245 relevant publications provided new data, and only 2% were intervention studies that addressed meaningful psychosocial patient outcomes.

Martins and Carvalho (2013) identified the need for consideration of patients' personality characteristics and how crucial they can be on health-seeking behaviors, illness, and medical interactions and outcomes. If physicians do not know patients well, breaking bad news is based on episodic, brief encounters that do not reflect the patients' preferred delivery method. Patients' preference have been identified and divided into content (clinician expertise), support (emotional comfort), and facilitation (setting).

Martins and Carvalho's (2013) study enrolled 72 patients with thyroid cancer in an ambulatory oncology clinic. Patients were asked to view a video that showed different approaches (i.e., empathetic professional, rough and ready expert, distanced expert, and emotionally burdened expert) for breaking bad news. Then, the patients were asked to choose the model they preferred. The use of a video was considered the most ethically sound choice because of the need to avoid interviewing patients following the actual receipt of bad news. The study included patients who had received a cancer diagnosis in the past, those who were informed of the possibility of a cancer diagnosis, and those who had been told of a negative biopsy. The researchers believed that the inclusion of patients with varied experiences allowed for the possibility to distinguish between patients with cancer and healthy participants. Data were analyzed using chi-square analysis, as well as Kruskal-Wallis and Mann-Whitney U tests. Interviews were content-analyzed.

Fifty-six (78%) participants preferred the empathetic professional model more than the other styles of delivering bad news. All 72 participants expressed a dislike for the rough and ready expert, nine (13%) preferred the distanced

expert, and seven (10%) preferred the emotionally burdened expert. Preferences varied significantly with HLC scores, presence of cancer, age, and education. Participants with higher internal locus of control and lower PO preferred the empathetic professional model. The article acknowledged the large body of research that has addressed typical ways of breaking bad news. However, the delivery model of choice for patients with cancer has yet to be determined. The consideration of personality characters as determined by the HLC may be pivotal for continuing the dialogue.

Martins, R.G., & Carvalho, I.P. (2013). Breaking bad news: Patients' preferences and health locus of control. *Patient Education and Counseling*, 92, 67–73. doi:10.1016./j.pec.2013.03.001

## Adolescent and Young Adult Supportive Care Needs

Adolescents and young adults (AYAs) with cancer often are the focus of medical research related to clinical management. Documentation of social information needs of the population aged 15–39 years has been limited (Kent et al., 2013). The Adolescent and Young Adult Health Outcomes and Patient Experiences (AYA HOPE) study is a population-based cohort study that examines psychosocial and physical functioning, medical care, and clinical trial involvement of AYAs. AYA HOPE surveyed 523 AYA patients 6–14 months following a cancer diagnosis. Participants reported on information needs for talking about the cancer experience with family and friends, as well as meeting peer survivors. Factors associated with each domain were examined using multiple logistic regressions.

Kent et al.'s (2013) article reported on the specific findings of AYA HOPE that were relevant to social information needs of AYA patients with cancer and survivors. Social support for those patients is critical because the need to establish new relationships is recognized as one of the most pivotal long-term challenges for AYA cancer survivors. Alleviation of social isolation for AYAs has the potential to enhance

overall well-being. AYA patients with cancer are at a greater risk for limited interaction with peers from the illness and associated treatment trajectory. Identification of the variance among AYA needs, as well as who is more likely to be in need of support, is a conduit for creating specific supportive care interventions.

The researchers provided a review of data related to talking about the cancer experience with family and friends and meeting peer survivors. About 25% reported needing to talk about the cancer experience with family and friends, and about 43% of participants reported wanting to meet peer survivors. Participants aged 20 years and older reported a greater need for meeting survivors, and Hispanic participants reported needing to talk about the cancer experience with

family and friends more frequently. Patients with symptom burden and patients who perceived receiving compromised quality of care reported a greater need for social support. Participants in the study came from a wide variety of cancer registries in the United States and included patients with uncommon cancers and diverse ethnicities.

Unaddressed social needs affect every developmental domain of patients with cancer. Focusing on social needs of AYA patients with cancer is vital to build awareness among the multidisciplinary healthcare team that renders care to those patients. The findings that illustrate compromised social needs among a variety of ethnicities, as well as patients who reported higher symptom burden, suboptimal clinical care, and insufficient support group availability, are building

blocks for the development of interventions, the creation of social support, and information dissemination.

Kent, E.E., Smith, A.W., Keegan, T.H., Lynch, C.F., Wu, X.C., Hamilton, A.S., . . . Harlan, L.C. (2013). Talking about cancer and meeting peer survivors: Social information needs of adolescents and young adults diagnosed with cancer. *Journal of Adolescent and Young Adult Oncology*, 2, 44–52. doi:10.1089/jayao.2012.0029

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Digital Object Identifier: 10.1188/14.ONF.103-104