

Diagnosis Disclosure

Patient preferences and the role of the breast nurse navigator

Cynthia Cantril, RN, MPH, OCN®, CBCN®, Elizabeth Moore, BA, and Xiaowei Yan, PhD, MS



BACKGROUND: Receiving a breast cancer diagnosis can be traumatic and anxiety-producing. The way the diagnosis is disclosed to patients can affect their experience.

OBJECTIVES: The aim of this article is to determine patient preferences for being informed of a breast cancer diagnosis and the breast nurse navigator (BNN) role during the diagnostic experience.

METHODS: A survey was mailed to 517 patients with breast cancer. Summary statistics were performed on 199 completed surveys.

FINDINGS: Patients preferred to hear their diagnosis in person. BNNs were more likely to provide the right amount of support and resources compared to other providers. Patients described the following preferences: knowing results as soon as possible, having a personal touch/emotional support, receiving the information from an expert, and getting information about their disease and next steps.

KEYWORDS

patient experience; nurse navigation; diagnosis disclosure

DIGITAL OBJECT IDENTIFIER

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THE DIAGNOSTIC PHASE OF BREAST CANCER has been described as highly anxiety-producing (Harding & McCrone, 2013; Morse et al., 2014; Pineault, 2007). From the time patients hear the words “you have cancer” to the time they start treatment is described as one of the most stressful periods along the breast cancer trajectory (Lally, 2010). Therefore, it is imperative that patients receive the right kind of support during this time (Harding & McCrone, 2013) and that different communication techniques are considered for patients in different phases of the cancer continuum (Shim et al., 2016; Thorne et al., 2014). The trauma of a diagnosis may be compounded by the circumstances in which patients learn of their diagnosis. Examples reported by patients to the first author prior to starting this study include the following:

- A woman being called about her diagnosis when she was home alone breastfeeding 6-week-old twins and caring for her 3-year-old child
- A mother getting a call while on her son’s soccer field
- A real estate agent hearing her diagnosis via speakerphone while touring clients
- A vacationing woman who discovered her biopsy reports via her electronic health record portal

After learning their results in these ways, these patients were left to wait for additional information and support for days or weeks until they could see a provider. The patients reported that this experience of receiving their diagnosis greatly increased their anxiety and impaired their ability to cope, as supported by other research (Lebel et al., 2003; Pineault, 2007). Waiting to get information and experiencing the state of uncertainty amidst the breast cancer diagnosis process can be extremely disruptive (Lebel et al., 2003; Morse et al., 2014; Pineault, 2007). The experience can be profound and interfere with the ability to perform activities of daily living (Montgomery, 2010).

Overall, patients with cancer and their families face a plethora of communication challenges in seeking, receiving, and understanding information. Not getting information at the right time causes distress. Anxiety is reduced when informational needs are met (Harding & McCrone, 2013; Montgomery, 2010; Parker, Aaron, & Baile, 2008; Shim et al., 2016).

In the late 1980s, it was recognized that patients form opinions of their physicians based, in part, on how their diagnosis is told to them (Lind,