

# When Do I Get My Brain Back?

## Breast Cancer Survivors' Experiences of Cognitive Problems

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**Background:** Many survivors report troubling cognitive problems that can persist long after active treatment and seriously affect their quality of life, particularly in terms of employment.

**Objectives:** The purpose of this study was to explore survivors' perceptions of their cognitive functioning.

**Methods:** Ten female breast cancer survivors receiving treatment in a community oncology setting participated in interviews or a focus group.

**Findings:** Six major themes were derived from the analysis: cognitive problems, effects on employment, emotional response, search for answers, coping mechanisms, and the providers' role. The breast cancer survivors reported psychological distress about perceived cognitive problems in concentration, memory, and other cognitive functions. They sought answers about the cause and were frustrated by a lack of information from providers. Although treatment strategies are limited, healthcare providers should validate patients' concerns by discussing possible cognitive limitations and should allow them to talk about the impact of cognitive problems on their lives.

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Cognitive problems have been reported in as many as 75% of cancer survivors (Jean-Pierre et al., 2012), and some breast cancer survivors report cognitive impairment as the most adverse side effect of treatment (Boykoff, Moieni, & Subramanian, 2009). Whether cognitive concerns reported after treatment are associated with the treatment itself, the underlying diagnosis, or prior undiagnosed deficits, is unclear (Asher, 2011). The co-occurrence of depression, fatigue, sleep disorders, hormonal imbalance, and aging also may affect survivors' cognitive impairment (Ahles, Root, & Ryan, 2012; Ancoli-Israel, 2012; Asher, 2011; Collins, Mackenzie, Stewart, Bielajew, & Verma, 2009). Although causes remain unclear, problems with memory, concentration, executive function, and learning may have particularly deleterious effects when survivors attempt to resume functional roles at home or in the workplace following active treatment and may persist long after that (Asher, 2011; Duijts et al., 2014; Hutchinson, Hosking, Kichenadasse, Mattiske, & Wilson, 2012; Nelson & Suls, 2013).

Although neuropsychological testing has been used to assess the degree of cognitive impairment in survivors, its impact has been explored less often from the survivors' perspective; however, Boykoff et al. (2009) concluded that survivors experience emotional distress about their cognitive problems despite attempting to compensate for them. Participants in the study by Boykoff et al. (2009) reported negative effects on their relationships with family and friends. Deleterious effects on their work led many to leave their jobs or find less demanding ones. In other qualitative studies conducted in the United States and abroad, survivors have reported that cognitive changes, particularly in memory and concentration, adversely affected their daily lives (Fitch, Armstrong, & Tsang, 2008; Mitchell & Turton, 2011; Myers, 2012; Player, Mackenzie, Willis, & Loh, 2014). Few women reported that their providers discussed potential cognitive problems with them, and they expressed frustration that providers did not validate their concerns or provide assistance (Mitchell & Turton, 2011; Munir et al., 2011).