Concealing Breast Cancer Status: A Qualitative Study in India

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Abstract : Background: Concealing of cancer-related information is seen in many low-and-middle-income countries and may be associated with multiple factors. Comparatively, there is lack of information about, how breast cancers diagnosed women disclose cancer-related information to their social contacts and vice versa. To get more insights on the participant's experience, opinions, expectations, and attitudes, a qualitative study is a suitable approach. Therefore, this study involving in-depth interviews was planned to lessen this gap. Methods: Interviews were conducted separately among breast cancer patients and their caregivers with semi-structured qualitative interview guide. Purposive and convenient sampling was being used to recruit patients and caregivers, respectively. Ethical clearance and permission from the tertiary hospital were obtained and participants were selected from the Udupi district, Karnataka, India. After obtaining a list of breast cancer diagnosed cases, participants were contacted in person and their willingness to take part in the study was taken. About 39 caregivers and 35 patients belonging to different breast cancer stages were recruited. Interviews were recorded with prior permission. Data was managed by Atlas.ti 8 software. The recordings were transcribed, translated and coded in two cycles. Most of the patients belonged to stage II and III cancer. Codes were grouped together into to whom breast cancer status was concealed to and underneath reason for the same. Main findings: followings are the codes and code families which emerged from the data. 1) Concealing the breast cancer status from social contacts other than close family members (such as extended family, neighbor and friends). Participants perceived the reasons as, a) to avoid questions which people probe (which doesn't have answers), b) to avoid people paying courtesy visit (to inquire about the health as it is Indian culture to visit the sick person) making it inconvenient for patient and caregivers have to offer something and talk to them, c) to avoid people getting shocked (react as if cancer is different from other diseases) or getting emotional/sad, or getting fear of death d) to avoid getting negative suggestion or talking anything in front of patient as it may affect patient negatively, e) to avoid getting stigmatized, f) to avoid getting obstacle in child's marriage. 2) Participant concealed the breast cancer status of young children as they perceived that it may a) affect studies, b) affect emotionally, c) children may get scared. 3) Concealing the breast cancer status from patients as the caregivers perceived that they have fear of a) worsening patient's health, b) patient getting tensed, c) patient getting shocked, and d) patient getting scared. However, some participants stressed important in disclosing the cancer status to social contact/patient to make the people aware of the disease. Conclusion: The news of breast cancer spreads like electricity in the wire, therefore, patient or family avoid it for many reasons. Although, globally, due to physicians' ethical obligations, there is an inclination towards more disclosure of cancer diagnosis and status of prognosis to the patient. However, it is an ongoing argument whether patient/social contacts should know the status especially in a country like India. **Keywords :** breast cancer, concealing cancer status, India, qualitative study

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