

# Culture and breast cancer surgical decisions and experiences

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Breast cancer incidence is consistently lower in culturally and linguistically diverse (CALD) compared to Caucasian women.<sup>1</sup> Incidence of early (localized) breast cancer in CALD women, however, is rising due to lifestyle changes associated with migration and improved breast screening uptake.<sup>1</sup> For early breast cancer treatment, both breast conservation therapy (BCT), consisting of lumpectomy and adjuvant radiotherapy, and mastectomy offer similar overall survival rates.<sup>1</sup> Mastectomy uptake, however, has been increasing among BCT-eligible CALD women<sup>1</sup> irrespective of tumor pathology.<sup>2-4</sup> Patient culture and associated beliefs pertaining to breasts, femininity and health, have been suggested as contributing factors<sup>3,4</sup> though these remain under-explored. This is highly pertinent in westernized countries, like Australia; however, current research exploring these issues predominantly involves African-American and Hispanic women within America's privatized health system. This study therefore aimed to explore CALD women's perceptions of breast cancer surgery in Australia to better understand the extent of cultural influences upon their decision-making and post-treatment experiences.

This qualitative study used semi-structured interviews, conducted among participants recruited via social media campaigns, word-of-mouth and a local breast surgeon (AO). Eligibility criteria: CALD women aged  $\geq 18$  years, fluent in English, underwent mastectomy or BCT for breast cancer in NSW, Australia  $\leq 10$  years ago. Interviews explored factors affecting breast surgical decision-making and postsurgical experiences, with transcribed interviews thematically analyzed.<sup>5</sup>

Sixteen participants were recruited. Most participants were  $< 50$  years old at diagnosis ( $n = 9$ ). BCT was the commonest procedure ( $n = 11$ ); mastectomy ( $n = 7$ ) and two participants underwent both procedures for recurrent breast cancer. All participants had lived in Australia for  $\geq 10$  years, most were South-Asian migrants ( $n = 7$ ) and university educated ( $n = 15$ ).

Three themes emerged through thematic analysis: (a) Role of culture in surgical decision-making; (b) Postsurgical impacts; (c) Influence of health literacy on decision-making and impacts.

Culture did not directly influence participants' surgical decision-making, predominantly due to attitudes of "just more of being me, myself, not our culture," and perceived upbringing "in educated family, so I don't think it was cultural." Participants instead ascribed greater significance in decision-making to their surgeons' advice, given beliefs that "in this country, you don't have quacks. You have proper good doctors who will definitely lead you to right treatment...If you don't understand anything just follow the doctor." Some participants highlighted the cultural significance of doctors in decision-making—"doctor is god. If the doctor says do this thing, will do it"—though, all participants reiterated "it was shared decision" between doctors and themselves.

Our participants had minimal cultural concerns pertaining to breasts, which were considered important to their femininity, though more from "a general feeling about losing part of your body which people have identified with a really nice female body in any culture." Some participants chose mastectomy over BCT as "I was very scared it would come back," while others related breast surgical decision-making to age and childbearing as "I already had one child and we didn't want more children so what is the point? Maybe if they are younger, they might want [BCT]." Few participants extended this perception to post-mastectomy breast reconstruction (PMBR), deeming it "unnecessary. The doctors offered me breast reconstruction, but I already had a daughter."

Both mastectomy and BCT "affect[ed] everyday life like now wearing the bra and clothes," while mastectomy posed culture-specific challenges in "wearing a saree blouse because one side looks different." Participants' postsurgical impacts were amplified by mismatch between anticipated and experienced surgical outcomes resulting from use of "many big words that many people would not understand" and

minimization of statistical risk estimates—"I knew he said sometimes—most of the time when it says 'sometimes' we don't include ourselves in that. That's a big problem."

Cultural stigma about breast cancer contributed to psychosocial impacts since "when people come to know, people will have a different view about yourself, which you can see in their eyes," and some participants "avoid[ed] pooja functions [Hindu rituals] because they don't want someone who had this surgery and cancer." Further, several South-Asian participants expressed fear that their breast cancer diagnosis would compromise their daughters' marital prospects as "our culture they talk that mum has got the breast cancer now maybe the daughter will too," thus "prefer[ring] to keep quiet" about their diagnosis.

Additionally, decision-making and postsurgical experiences were influenced by participants' health literacy, as perceived higher educational background empowered participants—"I'm educated, so I understand...Otherwise, it's gonna be stressful"—and facilitated decision-making as "I could ask any question with my doctor." Less health literate participants felt "cancer is a death sentence" and experienced difficulties in decision-making as "I just accept whatever given to me...I don't even know what question to ask." Poor health literacy was attributed to lower prevalence of breast cancer within participants' cultural groups, beliefs that breast cancer "affected the more mature lady," and limited community discourse on breast cancer as "people if they hear the word 'cancer', they equate it to death...they don't even want to think about it."

Previous studies suggested a role of culture in surgical decision-making due to observed higher mastectomy rates in CALD vs Caucasian women after adjusting for various tumor factors.<sup>2-4</sup> Our CALD participants, an acculturated and educated group, however, denied overt cultural influences on their breast surgical decision-making. Instead, cultural influences appeared more implicit, reflected in their utmost trust in their surgeons' competency, and participants' correlations between breasts, and thus surgical decision, to childbearing. Other studies similarly report high reliance of CALD patients upon clinician recommendations<sup>6</sup>; however, this has not previously been explored among educated, acculturated CALD women like in our study. Our study therefore highlights the need for improving health literacy even among educated CALD women, given our participants' limited breast cancer awareness, subsequent fear-driven selection of mastectomy, and mistaken correlations of PMBR to childbearing status.

Breast cancer and surgery are associated with adverse psychosocial impacts in CALD women due to fear of community stigma.<sup>7</sup> Consistent with this, most of our participants (predominantly South-Asian) avoided disclosing their diagnosis within their cultural groups for fear of stigma, particularly toward other female family members. This, in turn, limited discussion of breast cancer and treatments among our participants' cultural groups,

potentially perpetuating lower health literacy and stigma. Other studies similarly reported that cultural stigma impedes breast cancer discussion and awareness in CALD women thereby affecting decision-making.<sup>8,9</sup>

Overall, our findings highlight the need for greater breast cancer awareness even among educated, acculturated CALD women to improve understanding and minimize culturally driven stigma, thereby improving decision-making and wellbeing. Approaches include clearer communication during consultations, including confirming patient understanding, and through breast cancer campaigns more targeted to CALD women.

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