RESEARCH COMMUNICATION

# Cultures, Subcultures and Late Presentation with Breast Cancer

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## Abstract

**Background: There has been an increased recognition of the importance of socio-cultural factors affecting late presentation in breast cancer. Socio-culturally mediated symbolic meanings, attached to "breasts" might importantly affect understandings of breast cancer in connection with late presentation. Objective: To explore symbolic meanings of "breasts" which might affect late presentation, as observed by the practitioners of complementary, alternative and religious (CAM) healing who worked with women with breast cancer in the Boston area, USA. Method: We conducted semi-structured interviews with 46 CAM practitioners who worked with approximately 70 CAM modalities. The interviews were entered into the database and analysed using thematic approach. Results: The CAM practitioners observed that late presentation is related to two symbolic meanings of "breasts". Firstly, "breasts" are a symbol of maternity and consequently some women delayed seeking medical help because such understanding affected their perceived capacity to take care of their families. Secondly, among White American women "breasts" are related to the culturally highly relevant concept of "beauty", but among African American women "beauty" is equated with "health". Such understandings lead to very different reasons for late presentation, different illness experiences and require different psycho-social intervention to support women. Discussion and conclusion: In planning and designing effective health promotion strategies and appropriate supportive care strategies for women coming from different cultural and sub-cultural backgrounds it is important to carefully examine concepts affecting late presentation in all their different social and (sub-)cultural settings**

**Keywords**: Breast cancer - symbolic meanings - USA - CAM practitioners - sub-cultures

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## Introduction

In recent years there has been an increased recognition of the importance of socio-cultural factors involved in late presentation of women with breast cancer (BC). The awareness of the significant role played by socio-cultural factors has become apparent especially in multi-cultural societies where different ethnic groups have very diverse survival outcomes despite living in a society with the same healthcare system. One of such countries is the USA where the majority of studies and reviews, presented in this article, originated.

Studies in US have repeatedly shown that BC mortality for African American women is much higher than that of White women despite their lower morbidity (Polacek et al., 2007; Gerend and Pai, 2008). The differences can be partly attributed to biological differences and a review has estimated that they account for up to two thirds of survival differences (Polite and Olopade, 2005) because African American women appear to have some unique genetic abnormalities requiring further investigations (Polite and Olopade, 2005), their tumours tend to be biologically more aggressive (Polite and Olopade, 2005; Gerend and Pai, 2008) and their treatments might get delayed because they suffer more often from "ethnic" neutropenia (Polite and Olopade, 2005).

All the reviews of the studies on socio-cultural factors affecting late presentation have also demonstrated that biological differences alone cannot explain the worse outcome for African American women. Many studies and their reviews have therefore explored how culturally related structural barriers impede access to early diagnosis and effective treatments. These studies demonstrated how different ethnic and socio-economic groups accessed cancer screening services, such as mammography with greater difficulties (Lannin, et al, 2002; Polacek et al., 2007) do not receive the most efficient therapies or combination of therapies (Polacek et al., 2007) and tend not to receive timely medical follow-up (Polite and Olopade, 2005; Gerend and Pai, 2008).

However, as mammography gap is closing (Gerend and Pai, 2008) the differences in survival outcomes between White and other disadvantaged groups still persist even when accounting for biological and socio-economic factors (Guidry et al., 2003; Polite and Olopade, 2005; Betancourt et al, 2010). Consequently, attention has been drawn to the beliefs that different disadvantaged ethnic groups hold about BC that may explain the gap in survival outcomes. Existing reviews have identified different contributing beliefs, such as hopelessness and pessimism (Guidry et

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al., 2003), fatalism (Guidry et al., 2003; Betancourt et al, 2010) and decisive role of religion, spirituality and God in curing cancer (Polite and Olopade, 2005; Gerend and Pai, 2008). Women from disadvantaged communities also do not seek timely screening and medical attention because they might believe that BC is a disease of White women (Guidry et al., 2003) or that BC is a consequence of a physical trauma (Guidry et al., 2003). Women from ethnic minority backgrounds are also more distrustful of healthcare providers (Polite and Olopade, 2005; Polacek et al., 2007; Gerend and Pai, 2008; Betancourt et al, 2010) and are more likely to believe that medical interventions contribute to the spread of cancer (Polite and Olopade, 2005). Their strong kinship bonds and family obligations might also prevent them seeking timely help (Guidry et al., 2003; Polacek et al., 2007; Betancourt et al, 2010)

Despite recent interest in socio-cultural factors affecting understandings of BC and their relations to late presentation, many of the studies are quantitative explorations of selected beliefs which are frequently studied outside their social context. Such factors are also not studied in details but appeared as items on quantitative scales, devoid of meaning. In this paper I demonstrate why a quantitative approach might not be appropriate.

Firstly, I am going to discuss how practitioners of complementary and alternative medicine and religious healing (CAM) from Boston area in US who work with women with BC perceive symbolic meanings of "breast" which affect understandings of BC in their clients, and then I will continue to demonstrate how such understandings might affect late presentation. I will conclude by arguing that cultural factors must be studied in detail in all their subtle (sub-)cultural differences if they are to be a basis for culturally tailored, sensitive health promotion and intervention strategies.

## Materials and Methods

The data for this study comes by induction from a wider study 'The Many Meanings of Effectiveness, a Study of Healing Modalities Used by Women Treated for Breast Cancer' which was conducted in 2003 in the Boston area in USA by Centre for The Study of World Religions at Harvard University. The main aim of the study was to determine how CAM practitioners self-define and measure effectiveness of their therapies. This was deemed important because of the lack of this type of studies from the point of view of the practitioners themselves.

The research team identified CAM practitioners in various ways. Some of the practitioners were identified via pre-existing personal contacts. The team also placed an advert in a local BC advocacy group leaflet asking women with BC what types of complementary modalities or religious healing and which practitioners they had used. Some practitioners were identified through snow-balling – by asking practitioners who did or did not work with women with BC to recommend other practitioners who did.

A number of relevant hospital webpages was consulted (e.g. Beth Israel Hospital, Dana Farber Cancer Institute, Massachusetts General Hospital) which recommend, or organize access to, CAM modalities for cancer patients. The team also consulted a number of organizations (e.g. National Center for Complementary and Alternative Medicine, The Rosenthal Center for Complementary and Alternative Medicine) which give advice on which CAM modalities and practitioners might be most suitable for cancer patients.

Some practitioners were identified through the "Religion, Health and Healing Initiative" project which is being run at Harvard University's Center for the Study of World Religions. Such "toolbox" approach (in Sered & Agigian, 2008) enabled us to include a wide variety of practitioners, avoiding  in danger of capturing just one network or sub-set of practitioners. Further criteria for inclusion in this study were the practitioners self-identifying themselves as practicing non-biomedical modalities for, and working with women with BC. Their work had to be carried out in a "clinic" or an office. All of them also had to sign a written consent form and thus agreed to be interviewed at time and place, convenient to them.

*Interview procedures and analysis*

The semi-structured in-depth interviews lasted approximately from 60- 90 minutes. The participants were invited to discuss the modality or approaches that they used in their work, perceptions of their clients, their thinking of causes of BC, primary and secondary goals of their therapies and how they measured success of their approach. They were also invited to explain in what respects their work differed from conventional medicine and their referrals to other similar practitioners and biomedical healthcare providers. As spirituality and/or religion are an important aspect of most CAM modalities – at least from the point of view of the practitioners -  the participants were asked about the spiritual and/ or religious aspect of their healing.

The interviews were not tape-recorded for practical reasons but responses were documented by hand; all the written notes were entered into computerized database within the same day. Two researchers then coded independently for the codes and emerging themes, and later compared their findings for consistency of coding and to minimize any arbitrariness. Any potential differences in coding were resolved by agreement between the two coders. The thematic analytical approach was further refined by looking for negative cases, contrastive analysis and constant comparisons.

## Results

*Sample description*

Altogether we managed to interview 46 practitioners who together used in total over 70 modalities; participants usually worked with several rather than just one healing practice. Our sample included practitioners of religious healing, for example The Unitarian Universalist Church and the Temple Israel. Most of them were practitioners of complementary medicine (that is modalities which are different from, yet used in conjunction with official biomedicine). These modalities ranged from those

100.0
75.0
50.0
25.0
0
6.3
56.3
31.3
Newly diagnosed without treatment

officially recognized by the American National Institute of Health and have gained some biomedical evidence-base for their effectiveness, such as acupuncture (e.g. Korean, Japanese, Chinese) and various forms of bodywork (e.g. yoga, tai chi, shiatsu massage etc), to the modalities which drew on (multiple) traditional healing systems (for example, Hopi-Jewish-Buddhist-Hindu, Native American systems) and more marginal modalities whose evidence-base is yet to be established. The examples of the latter are "intuitive spatial design" (creating an optimal space for a dying BC patient) or "channeling" (communicating with the entities existing on planes of existence outside normal human perception).

A number of practitioners in this study were fully licensed and qualified psychotherapists of various orientations, who invited various complementary therapists to present their work to their clients with BC. Some practitioners were both religious experts and certified counselling psychologists. Interestingly, we also managed to include a practitioner who worked as an alternative healer meaning that a woman visiting this practitioner was not allowed to simultaneously undergo any medical therapies. It has to be noted that alternative practitioners in contemporary Western societies are very rare as they face legal prosecution if they advise a client not to pursue medical help.

These practitioners have had many interesting insights into the motivations and experiences of their clients suffering from BC. Some findings from this study have been reported elsewhere (Potrata, 2003; Sered and Agigian 2008). The practitioners pointed out the importance of symbolic meanings of "breasts", which in their opinion and observations affected how women experience BC, and which might be so central for women's self-identity that they might delay seeking timely help. Such symbolic meanings were the breast as symbol of nurturing, maternity and family, as an attribute of sexual attractiveness and a more general symbol of beauty.

*Breast as a symbol of nurturing and maternity*

The CAM practitioners had several interesting insights into how their clients experienced breasts as being associated with emotional and cultural meanings of nurturing, maternity and family. Certainly, there is an important practical aspect of cultural beliefs and practices that women are mainly responsible for childcare and for children's emotional and other well-being. One systematic review found that women might not pay attention to early symptoms or do not attend mammograms due to the lack of time because they have to take care of their families (Guidry et al., 2003; Polacek et al., 2007; Betancourt et al., 2010). Many women from ethnic minorities also hold an ideal of "sacrificing themselves" for their families (Ashing-Giwa et al., 2004) or putting their children first at the expense of themselves, hence regular health check-ups are not a high priority. A macrobiotic nutrition practitioner Michael in our study expressed the tendency of some women to over-nurture with over-indulging in food, especially sweets which in his opinion contributed importantly to BC on both symbolic and nutritional level.

Nevertheless, the practitioners in our study observed more than a practical concern over breastfeeding in their clients, the concerns which do not appear in otherwise exhaustive study on understandings of "breast" (Langellier and Sullivan, 1998). Rather than seeing the breast as having important function in breast-feeding, CAM practitioners pointed out the metaphorical and symbolic meaning - that women experienced distress because "breasts" are a symbol of maternity, caring and giving, and symbol of the capacity of the woman to take care of her children.

From this point of view, experiencing breast in connection with being able to care for the loved ones, especially children, breast were an important part of the self-perception of a woman and contributed to their distress. These practitioners, like psychotherapist Jennifer, who in her practice also invited CAM healers to her group meetings therefore often focused on the mother-children issues. Reflections on how to be a "good" mother despite not being able to "nurture" their children, or doing everything the women wanted for her children was an important part of her work. Furthermore, her sessions frequently involved not only a woman's children, but the whole families struggling to address the issues of a woman's illness, potential death and the influence of woman's disease on the family relationships. In these respects, the role of these practitioners was more than just working on how the issue of BC and how potential impending mortality might impact on other family members.

*Beauty and the breast*

Another theme related to the symbolic significance of the breasts, which has been raised by CAM practitioners was a negative effect that cancer and cancer treatments have on "beauty" of women, and how the fear of being no longer "beautiful" might prevent women from seeking timely help. The practitioners therefore partly ascribed late presentation to the fear of many women that they will no longer be "beautiful" which held a high cultural relevance to all their clients, whether they were of White, Latino or African-American ethnic background.

However, those practitioners who discussed relationship between symbolic importance of "beauty" and late presentation, pointed out very different understandings that various ethnic groups have with regards to what constitutes aesthetic ideal. For their White clients having beautiful breasts (preferably firm, big and perky) was an important attribute and symbol of sexuality, sexual attractiveness and "beauty" (see also Langellier & Sullivan, 1998). Some goals of the CAM modalities were therefore pragmatic, like addressing woman's physiological sexual changes. These issues are according to a recent study (Mercadante et al., 2010) largely ignored in clinical practice even though they have considerable negative impact on women. In contrast, the practitioners found addressing such issues an important part of their therapies. For example, Michael, a practitioner of Sufi and "karma therapy" (he removed dysfunctional archetypes, according to which people live, from their auras) believed that for a woman achieving satisfactory sexual life after the BC treatment and operation was an important goal of

his therapy.

The work of some CAM practitioners went beyond pragmatic goals of addressing physiological sexual problems. Such work might have included the issue of sexual attractiveness. For example, Joanna's group of women once discussed prosthetic breasts in relation to their aesthetic aspect – the issue of prostheses being another under-researched area where many misconceptions exist (Healey, 2003). A Qi Gong practitioner Joshua helped his BC clients to renegotiate and redefine their definitions of sexual attractiveness. He praised their beautiful postures, obtained by practicing QiGong, and encouraged them to see themselves as being sexually attractive according to different beauty standards, like "Latino" or "black", according to which "beautiful" means to have a big, firm and round bottom rather than big breasts.

Among White women, the sexual attractiveness was linked to having beautiful breasts. Some practitioners believed that White women delayed going to the doctor because they feared the loss of (a) breast(s) and consequently their sexual attractiveness and beauty. According to the participants in this study, the concept of "beauty" had a high relevance in Latino and African American subcultures as well. However, Joshua's strategy to help women with their lower self-esteem after radical interventions on the breasts indicates among Latino and African American women the breasts are a relatively unimportant attribute of sexual attractiveness and "beauty".

In these sub-cultures the main attribute of sexual attractiveness is having a firm and round bottom. Instead, in the Latino and African-American (sub)cultures, "beauty" is equated with "health". Whereas White women can be beautiful even though they are sick, or can successfully disguise their condition, sick Latino and African-American women are instantly not being "beautiful" when their BC diagnosis is confirmed. Consequently, a number of practitioners partly ascribed late presentation among the Latino- and African-American women to the high cultural relevance of "beauty" and its connection to "health".

## Discussion

Understanding (sub-)culturally mediated symbolic meanings attached to various body parts is important because they affect illness perceptions of the affected body part (in Lee et al., 2007) and according to Kleinman's Illness Narrative model (Kleinman, 1988) they affect health-seeking behaviours. The CAM practitioners had several novel insights about symbolic meanings of "breasts" and how these meanings affected not only when and how women sought timely medical help, but also their illness experiences and related supportive care.

The practitioners in the present study talked about "breasts" as a powerful symbol of maternity, nurturing and family. According to the practitioners the women might have delayed seeking help not only because of time and family obligations, but also because a potential diagnosis of BC would crucially affect symbolic value of maternity and caring. Interestingly, symbolic meaning of nurturing and maternity was anticipated by the feminist theorists who argued that the prevalent focus on the breasts as symbol of sexual attractiveness is due to sexists and sexual Western stereotypes, endorsed by men and male healthcare practitioners (Langellier and Sullivan, 1998).

This theoretical argument was partly empirically supported by the study on symbolic meanings of breasts among American Koreans (Lee et al., 2007). This study reported that for the American Koreans, the breasts are associated with maternity and many believed that breast-feeding is an important prevention against BC. However, the study did not find a direct connection between symbolic meanings of maternity, family and nurturing and late presentation. On the contrary, the association has been made by several practitioners in the present study, who pointed out that women might delay seeking help because potential diagnosis would affect capacity to take care of one's family on both pragmatic and symbolic level. Moreover, the symbolism also affected illness experiences since the practitioners frequently had to address distress caused by mother-children issues, prompted by cancer diagnosis.

The practitioners in this study also pointed out strong cultural and symbolic relevance of the "breasts" as important attributes of sexual attractiveness and "beauty". This study is in line with many others which explored the psychosocial impact of BC on "body image" and sexuality, especially in relation to cancer therapies (Kornblith et al., 2003; Helms et al., 2008; Emilee et al., 2010) arguing to what degree and in what circumstances BC (therapies) affect body image and sexuality of the affected women. Importantly however, in our study the preoccupation and connection of "breasts", "sexual attractiveness" and "beauty" was observed by the practitioners mostly for White women. They contended that White women might have delayed seeking timely help because of fear of being "mutilated" by BC therapies (and other related changes, like losing hair) and especially interventions on the breasts importantly influence symbolic understandings of "beauty".

Yet the practitioners emphasised that "breasts" are an important symbolic attribute of beauty only among White women. This observation on considering sexual attractiveness related to beautiful breasts as being culturally dependant is corroborated by the study among Korean Americans which found out that especially older American Korean women experienced breasts, particularly big, as shameful and several participants wore tight clothes to flatten them (Lee et al., 2007). In our research it has been pointed out that even though "beauty" is culturally highly relevant in White, Latino and African American sub-cultures, in Latino and African American sub-cultures "beauty" is synonymous with "health". In these cases women delayed seeking timely medical attention because admitting they were sick would immediately have rendered them not "beautiful".

Symbolic representations of why a woman is beautiful according to the CAM practitioners differs importantly in White, Latino and African American sub-cultures even though "beauty" has a high cultural relevance among the women in all three groups. Diverse ways of understanding "beauty" affected divergently late presentation and

why the women might seek medical help too late. The practitioners also implied that different understandings of "beauty" required sub-culturally sensitive, tailored approaches of how to best support these women and their families. For example, whereas helping affected White women to redefine their sexual attractiveness to different beauty standards, is irrelevant to Latino and African American women since the "breasts" are not a symbol of sexual attractiveness, Latino and African American women require intervention on how to be "beautiful" even though they are no longer healthy. The findings from the present study therefore pointed out that it is important to study not only socio-cultural factors affecting late presentation, but careful examination of concepts in different social settings is important to plan and articulate effective health promotion strategies, awareness campaigns and appropriate supportive care strategies for women coming from different cultural and sub-cultural backgrounds.

This study has several important limitations which need to be recognised to appropriately interpret the results. It has been conducted among CAM practitioners who only mediated the experiences of their clients diagnosed with BC. Nevertheless, even though women's experiences are reported only indirectly, most of the practitioners had worked with a substantial number of women from this patient population and could perceive certain characteristics and trends, and claim a good overview of the issues that the women faced. When discussing the patient population that they worked with it is further important to stress that the practitioners in this study only worked with a particular subset of this patient population – with women who were open enough to try any or several of such therapies. As the significant predictors for the use of such therapies are higher education (Ashikaga et al., 2002; Astin et al., 2006) and having private insurance (Henderson and Donatelle, 2004) it is therefore the White women who are much more likely to use CAM modalities, and the therapists themselves commented that they mostly worked with White women. The practitioners also did not report on Asian Americans, probably because these patients visit traditional, rather than CAM practitioners.

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