
5-3-2021

“I Was Like an Autumn Leaf That Looks Pretty From the Outside, but Would Break Once You Touched It”: A Case Study of the Lived Experience of Breast Cancer Survival

Wafa Hamad ALmegewly

Community Health Nursing Department, College of Nursing, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia, whalmegewly@pnu.edu.sa

Dinah Gould

City London University, dinahgould@outlook.com

Sally Anstey

Cardiff University/ School of Healthcare Sciences, ansteys1@cardiff.ac.uk

Follow this and additional works at: <https://nsuworks.nova.edu/tqr>



Part of the [Nursing Commons](#)

Recommended APA Citation

ALmegewly, W. H., Gould, D., & Anstey, S. (2021). “I Was Like an Autumn Leaf That Looks Pretty From the Outside, but Would Break Once You Touched It”: A Case Study of the Lived Experience of Breast Cancer Survival. *The Qualitative Report*, 26(5), 1331-1344. <https://doi.org/10.46743/2160-3715/2021.4669>

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



Qualitative Research Graduate Certificate
Indulge in Culture
Exclusively Online • 18 Credits
LEARN MORE

NSU
NOVA SOUTHEASTERN
UNIVERSITY

NOVA SOUTHEASTERN

“I Was Like an Autumn Leaf That Looks Pretty From the Outside, but Would Break Once You Touched It”: A Case Study of the Lived Experience of Breast Cancer Survival

Abstract

In this hermeneutic phenomenological case study, we explored the lived experiences of one Saudi Arabian woman, Sahara, living with breast cancer and after, identifying her culture’s impact on the “meaning-making” process. We derived the data from a semi-structured interview and analyzed using interpretive phenomenological analysis (IPA). The themes were: (1) “discourse”: being a breast cancer patient; (2) “sociality”: the complex sense of living with visibility and invisibility; and (3) “selfhood”: regaining the sense of being normal. The study benefits healthcare providers, who need to understand women’s life-world, the impact of culture when designing a program of survival care, and the response to their needs.

Keywords

breast cancer, survivorship, case study, culture, lived experience, interpretative phenomenological analysis (IPA)

Creative Commons License



This work is licensed under a [Creative Commons Attribution-NonCommercial-Share Alike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Acknowledgements

This research was funded by the Deanship of Scientific Research at Princess Nourah bint Abdulrahman University through the Fast-track Research Funding Program

“I Was Like an Autumn Leaf That Looks Pretty From the Outside, but Would Break Once You Touched It”: A Case Study of the Lived Experience of Breast Cancer Survival

Wafa ALmegewly

Community Health Nursing Department, College of Nursing, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia

Dinah Gould

City London University, United Kingdom

Sally Anstey

Cardiff University, Wales

In this hermeneutic phenomenological case study, we explored the lived experiences of one Saudi Arabian woman, Sahara, living with breast cancer and after, identifying her culture’s impact on the “meaning-making” process. We derived the data from a semi-structured interview and analyzed using interpretive phenomenological analysis (IPA). The themes were: (1) “discourse”: being a breast cancer patient; (2) “sociality”: the complex sense of living with visibility and invisibility; and (3) “selfhood”: regaining the sense of being normal. The study benefits healthcare providers, who need to understand women’s life-world, the impact of culture when designing a program of survival care, and the response to their needs.

Keywords: breast cancer, survivorship, case study, culture, lived experience, interpretive phenomenological analysis (IPA)

Introduction

In Saudi Arabia, breast cancer is the most common female cancer, comprising about 30.1% of all cancers in women (Alrawaji et al., 2015), mostly affecting women aged 50 years and over. This number reflects the global incidence of breast cancer worldwide, where breast cancer is evidently the most frequent cancer among women (24.2% of all cancers), and the leading cause of death from cancer in women (15.0%; Globocan, 2018). Furthermore, breast cancer is common among premenopausal women, which may be contributed to factors such as early menarche, family history, and using oral contraceptives (Alsolami et al., 2019; Najjar & Easson, 2010). Therefore, it is recommended that an annual screening by mammogram starts at age 40 years old (The Saudi Center for Evidence Based Health Care, 2014), compared to age of 45 years in the US (Oeffinger et al., 2015). Also, in Saudi Arabia, breast cancer has a more aggressive nature in younger women as compared to younger western women, thus they could be at high risk for recurrence (Elkum et al., 2007). Al-Mutairi et al. (2016) found that the quality-of-life global¹ score on a scale of 100 for Saudi women with breast cancer is 31.15; this

¹ An Arabic version of the EORTC’s (European Organization for Research and Treatment of Cancer’s) Quality of Life C30 (Aaronson et al., 1993).

is the lowest mean score compared to 74.6, 72.5, 63.9, 63.7, and 45.3, for the United Arab Emirates, Tunisia, Bahrain, Jordan, and Kuwait, respectively (Rahou et al., 2016).

The existing literature of breast cancer survivorship has shown women surviving breast cancer have experienced long-term consequences from the different types of cancer treatment, and these consequences include alterations in mental health, physical abilities, social life, and relationships (Banning et al., 2009; Hall et al., 2014; Levkovich et al., 2017). Younger women with breast cancer have been more susceptible to psychological and physical side-effects when compared with older women (Bantema-Joppe et al., 2015; Champion et al., 2014). Lally and Underhill (2012) described breast cancer as a transitional process; in this process, the woman in a state of well-being becomes a person with breast cancer. Once diagnosed, she receives treatment in phases. After the cancer has been treated, the woman “re-enters” her life. For breast cancer survivors, this final phase of transitional survival or “re-entry” could be challenging because they no longer need treatment, but at the same time, they miss the need for extra care (Allen et al., 2009; Powers et al., 2014). This description of a cancer survival experience could result from a complex interaction of the self, the body, and society (Astrow, 2012). McCann, Illingworth, Wengström, Hubbard, and Kearney (2010) claimed that the completion of the curative treatment does not mean the end of suffering; rather, it signifies another challenge, especially when it comes to making sense of the lived experience within a culture’s influence.

There is a considerable body of literature on breast cancer experience (Davis et al., 2014; Smith et al., 2015; Tompkins et al., 2016). The Saudi healthcare literature is full of studies looking at the attitude, knowledge, protective measurements related to screening, and breast self-examination among Saudi women (Al-Amoudi & Abduljabbar, 2012; Alsaif, 2004; Amin et al., 2009; Sait et al., 2010). A few studies in both western and Saudi literature have explored the lived experience of cancer survival, specifically within the context of breast cancer, survivor’s identity, and role of culture in shaping the women’s experiences either positively or negatively (da Costa Vargens & Berterö, 2007; Kaiser, 2008; Sabo & Thibeault, 2012; Williams & Jeanetta, 2016). According to Kaiser (2008), it is assumed women are crafting their own linguistic and conceptual interpretations that reflect their breast cancer experience. Knowledge of the culture’s impact on the perception of cancer survival is missing but should be considered a vital component of the subjective experience of illness through the description of people’s way of life (Kagawa-Singer & Blackhall, 2001). The phenomenological literature on breast cancer has often described the creation of individual and life events with no reference to the influence of culture and how women could understand their lived experience. In terms of the methodological use, most of the studies were phenomenological and the data was interpreted thematically with no further in-depth analysis or referencing to the culture, social interaction, and how women interpreted their life-worlds.

The present study was important because most of the existing studies which related to survival from breast cancer have been undertaken in western countries who often embrace the survivorship experience reflecting the cancer advocacy organizations’ perspectives, which may not resonate with what is happening in Saudi Arabia. Also, this study might be the starting point for developing cultural competency, psych-sociological assessment, and better supportive services for women with breast cancer.

Study Aim and Methodology

This hermeneutic phenomenological case study explores, in-depth, the experience of being a breast cancer survivor for a Saudi woman named Sahara (pseudonym) and seeks to explore how cultural discourses and beliefs support her understanding of breast cancer. Heidegger founded interpretative phenomenology, claiming that human experiences are

informed by social, cultural, and political contexts (Heidegger, 1996). The participants were involved in co-creating an interpretation and reconstruction of the meanings of their interactions through different lenses of gender, culture, ethnicity, religion, relationships, and language (Van Manen, 2016). Heidegger (1996) was drawn in exploring the individual sense of existence in the world they experienced as “being-in-the-world.” The Heideggerian phenomenology, has informed developing interpretive phenomenological analysis (IPA) by Smith et al. (2009) which emphasize on high level of sense making by moving from describing the data to critical, linguistic, and conceptual analysis.

From a theoretical perspective, the use of life-world philosophical framework has informed the analysis process in mapping the results to achieve an understanding of the lived experience of breast cancer from discourse, social, and selfhood perspectives. The life-world can be described as the meaningful world that is lived and experienced and where people encounter their sense of self, embodiment, relations with others, spatiality, temporality, projects, discourse, and mood (Ashworth, 2003). The life-world includes various fractions that enable producing phenomenological descriptions through structural analysis. These are discourse (describes the used language, educational, ethical, cultural forms, and discourses that illustrate the situation), sociality (relates to how one’s condition affects relationships with others), and selfhood (indicates the sense of agency, feeling, and social identity; Ashworth, 2003).

Sahara’s case study was taken from a larger interpretive phenomenological study of 18 Saudi women’s experiences and perceptions of breast cancer survival. Her case was selected for presentation because of its full description of the lived experience and the challenges associated with living with and after breast cancer. The uniqueness of Sahara’s story and her decision to uncover hidden life events, beliefs, and values all afforded an opportunity to revisit her lived experience of breast cancer and for her voice to be heard. Although IPA researchers tended to use small sample ranged between 6 and 10 participants (Smith et al., 2009), the application of using a hermeneutic phenomenological case study has been very successful in many studies concerning anger, Parkinson, and HIV (Eatough & Shaw, 2017; Eatough & Smith, 2006; Vella, 2016). The ideographic approach in IPA emphasizes the importance of understanding of particular experience by a particular person, at a particular time (Smith et al., 200).

This study is part of Ph.D. project done by the first author about the lived experience of breast cancer survivorship among Saudi Arabian women. Both second and third authors were academic supervisors for the first author.

Methods

Ethical Considerations

Ethical approval was gained from both the university and the specialist hospital in Saudi Arabia where Sahara was treated. Formal voluntary consent was granted by Sahara as part of the Ph.D. project before her interview, explaining she can withdraw at any time during the study. Her name and other identifying information were changed for confidentiality purposes.

In terms of the researcher and participant relationship, the first author had an insider and outsider role through the data collection and its analysis. As an insider, being a Saudi woman sharing similar cultural beliefs with Sahara, helped in building a trustful relationship and increasing the level of disclosure of some private personal issues. Also, through interaction, such feelings like sense of healing, learning, and self-awareness were commented by Sahara when the recorded interview was stopped. As an outsider, to promote transparency, reflective

diaries were used to document all the events related to data collection, translation, and data interpretations.

Participant

The participant is referred to as Sahara. She is a Saudi and at the time of the interview, she is 34, the youngest in her family, a college graduate, and twice divorced. Her three sons live with her first husband (their father). She works as a pharmacist and is financially stable. In 2013, she was diagnosed with stage II breast cancer; she underwent a lumpectomy and was treated with chemotherapy and radiotherapy. She had a positive prognosis, had a reconstructive surgery, and completed her treatment a year before her interview. She married a second time after her treatment, and she was the second wife, but the relationship broke down. Seeking marriage is typical for a Saudi young woman like Sahara, as she was looking to be loved and feel secure, and especially after her father's new marriage seemed to hold up the family structure after her mother's death.

Data Collection

Sahara responded to the face-to-face recruitment process of the doctoral project at a specialist cancer hospital in Saudi Arabia. After the initial contact with Sahara, the first author gave her an information sheet; this sheet explained the purpose of the study, set out her rights, introduced the interview approach, and explained the consent procedure. Following information giving and consent, the first author conducted a semi-structured interview in Arabic and tape-recorded with permission. Then, the data was transcribed and translated into English.

The interview was designed chronologically, starting with the breast cancer diagnosis, treatment, and beyond, as illustrated in Table 1. The interview began with general questions and moving to more critical questions (Kvale & Brinkmann, 2009). The interview questions were created from the literature to tackle the gaps and inspired by work done by (Kaiser, 2008) who highlight the cultural influence on women's lived experiences. Also, they were reviewed by experts in the field to ensure they were culturally appropriate.

Table 1

Example of Interview Questions

| Categories | Example |
|---|---|
| Part 1: opening question Breast cancer diagnosis and experiences during cancer treatment | To start off, please tell me about your experience with breast cancer, how you came to be diagnosed with cancer. |
| Part 2: transition questions Life after treatment | Would you please tell me in more detail about your life after treatment? How was it for you when your treatment ended? In what ways are you different now from before the diagnosis? Are there any ways in which you have not changed? |
| End question | In what ways do you think healthcare providers could help you cope with your experience of surviving breast cancer? |

The interview guide was divided into two parts. The first covers some of Sahara's history with breast cancer diagnosis and treatment. The open question helps to prepare and encourage her leading up to the topic. The second part includes questions about life after completion of treatment and the challenges she may encounter.

Data Analysis

The data was analyzed using interpretive phenomenological analysis (IPA; Smith et al., 2009). IPA aims to understand the world of the participant with a description that focuses on life events, experience, relationships, culture, and language. Also, Sahara's individual sense of being was labelled and described through the "life-world context." Rooted in phenomenology, this constitutes the meaningful world in which people live and experience their sense of self, body, relationships, time, language, and activity (Ashworth, 2003).

In the process of taking the first step in the data analysis, the first author immersed herself in Sahara's story by reading and rereading the transcripts and listening to the audio recordings at least once to enable the researcher to zone in on the data and be familiar with the text. During this process, detailed descriptive, conceptual, and linguistic notes were created that reflect the essence of Sahara's life-world. For example, under the linguistic notes, metaphors like, "I was like an autumn leaf that looks pretty from the outside, but would break once you touched it," and their possible meanings were illustrated. The codes from the annotated transcript were created; then, the analysis was shifted from dealing with transcript to creating list of themes which were connected and clustered to detect patterns. Lastly, a master table of the subordinate and superordinate themes created. Themes were located according to life-world fractions as follows: discourse (describes the used language, educational, ethical, cultural forms, and discourses that illustrate the situation), sociality (relates to how one's condition affects relationships with others) and selfhood (indicates the sense of agency, feeling, and social identity; Ashworth, 2003).

Results

The following table represents themes of Sahara's life world that reflect her lived personal experience of breast cancer and beyond.

Table 2

Themes of Sahara's Life-World

| Themes | Subthemes |
|-----------|--|
| Discourse | Being a breast cancer patient |
| Sociality | Living the visibility and invisibility |
| Selfhood | Being normal |

Discourse

Being a Breast Cancer Patient

Sahara's story of breast cancer started when she felt a lump in the lower part of her breast. At that time, she was 34 years old, so she never thought the lump could be breast cancer, which is commonly linked to old age. She claimed she would never forget the day she was diagnosed. The possibility of having breast cancer left Sahara anxious, and she could barely sleep at night up until the date the results were due:

He [the doctor] looked at me with a sorrow in his eyes. ... I said to him, "I have breast cancer?" He said, "Yes, I am sorry." My eyes were filled with tears, and I said, "I can't tell my parents about that ... how can I go on vacation with them tomorrow to Turkey? How can I tell them?"

The first thought that came into her mind when she received the news was her parents, not her children, not her friends, and not even her health condition. She went on vacation with her family with this heavy secret and hid her disease away from her family, despite living in the same house. She did not want to upset her parents, especially her sick mother who was diagnosed with liver failure: "I wasn't as afraid of losing my health as I was afraid of losing my parents or making them sad."

Sahara struggled with the new situation and the sudden change in her life for which she was not ready. On reflection, Sahara weighed up the benefits and risks of either revealing the news to her parents or hiding it, but, in the end, she wanted to avoid upsetting her mother, who was seriously ill. Therefore, she assumed the negative impact of breast cancer which culturally linked with death, might be more challenging for her mother if she found out, more challenging than for herself.

During breast cancer treatment, Sahara hid the side effects of treatment from her mother using various techniques, such as cutting her hair, wearing a wig, wearing make-up, and giving excuses such as catching a virus if she looked tired. Sahara described how her mother was upset after seeing her daughter with short hair because she used to have long pretty hair: "I told her [mother] that my hair became weak, and I would like to follow the trend as some of my friends have short hair."

Sahara continued her obligation as a daughter towards her family by taking care after her parents and maintaining family's dynamic; she did not present a sick role to them. She described wanting to retain the image of being the strongest one on whom people can depend, the normal one who people want to see. Despite her tiredness from the last cycle of chemotherapy, she stayed with her hospitalized mother. She prayed to God to give her strength and never break down, especially when she knew her mother was dying.

Sahara suffered in silence, wore the mask of normality in front of her family, so no one could witness her pain:

I used to lock myself in my room to be alone to express my feelings ... I screamed, cried so no one can hear my pain or see my weakness. After that, I went out of my room like nothing happened, acting as a normal person in front of my family.

Despite Sahara's attempts to balance her physical and emotional distress and family demands, her hidden life meant she lost some of the assistance that comes with a breast cancer

diagnosis, for example, receiving social and psychological support from people who were close to her, like her mother:

It's hard when you need the most supportive person such as your mother to be beside you, but you just couldn't tell her your need ... you needed her to pray for you, but you could not ask her [cries].

Sociality

Living the Visibility and Invisibility

Sahara described her struggle living with the visibility and invisibility of breast cancer at the personal and social levels. She became selective in whether to be open or secretive about her condition when deciding to attending social occasions. She explained she acted according to her audience's perception of breast cancer and their awareness of her condition. For example, she explained her attempts to look modest in front of people who knew her and might have believed breast cancer was a deadly disease: "When I go to places where people know the nature of my disease, I make sure to have a simple look with no make-up."

Different scenarios ran in Sahara's head. If she went to social events where people did not know her history of breast cancer, she would try to act normally:

If I went to place/parties where people there didn't know about my disease, I'm acting normally ... being myself, hmm, the one before cancer who loves dancing and trying new things. Because I can't see the sympathetic look or get a wrong judgement.

For Sahara, keeping her disease hidden enabled her to protect herself and others, take account of others' expectations and the social norms of those who might perceive her as near death, and avoid feelings of pity and discomfort. She struggled with the conflict of living between the beautiful appearance that she wanted people to see and her feeling of being normal again and the hidden inner self that showed her weakness and her fear of people's judgements. This struggle was noted when she used the metaphor of an "autumn leaf"; other opposite qualities were identified, such as strength and weakness, fake and reality, and beauty and ugliness: "I was like an autumn leaf that looks pretty from the outside but would break once you touched it."

Selfhood

Being Normal

After the breast cancer treatment finished, restoration of the sense of normality in Sahara's world took on many perspectives, such as getting married, resuming her daily life, and having breast reconstruction to regain the sense of being a normal female. She justified her choice of getting married after treatment completion by stating she felt lonely and was looking to be loved, especially after her mother's death and her father's new marriage, which presented a sense of security to her: "I got married to a man who already knew about my case. ... I was doing my duties as a wife normally and that made me feel that I'm really a normal person."

Sahara described how she became "obsessed" [her word] with trying beauty products related to making the breast shape feel more feminine and showing her husband she is still normal and attractive even after the lumpectomy:

I used to exaggerate everything in my relationship with him like putting on heavy make-up and wearing beautiful expensive clothes just to show him [husband] how pretty I am and to cover my poor body image. I didn't like him either touching my breast or seeing it.

However, her marriage, which she described as a "positive escape," did not last long. She spoke about how unhelpful her husband was, reminding her of her disease and weakness:

I was still going to the hospital appointment alone; he needed me only to fulfil his sexual needs. He didn't understand that all I needed at that time was to have a person who took care of me and showed me love rather than being the one who should give it.

Another form of seeking normality was to go back to work after an absence for more than 8 months of treatment. At work, she felt compassion and sorrow in both men and women's eyes. She explained she tried to be the same person they knew before the disease: the "pharmacy's butterfly" [her words]. Her work colleagues used to call her this name because of her positive energy. She explained the decision to go back to work was to prove to herself that she could still work and achieve at the same level as before cancer. However, she described going back to work was not as easy as expected because of the development of some cognitive issues resulting from breast cancer treatment: "Sometimes, I couldn't remember the name/dose or what this medication is for. I have a fear of making mistakes while calculating a patient's dose ... I prefer to have someone check the work after me ..."

Also, she explained how her work colleagues' sympathetic views caused a problem and jealousy between other employees who thought she was getting special treatment or privileges because of her disease:

I'm often telling them that my health condition is a red line, and they shouldn't cross it ... if they want to speak with me about work that will be fine, but anything except that the answer will be "No." They are gazing at my body to know whether I had a mastectomy or not.

The metaphor "red line" indicated a strong warning to others to stop thinking about her disease experience because it would be considered a very sensitive topic that she did not want to share it with public, especially at work.

Discussion

The following discussion provides an in-depth interpretation of Sahara's lived experience through breast cancer diagnosis, treatment, and beyond. It enables more insight into Sahara's life-world and how her culture influences the process of meaning-making. The dimensions of the life-world and existing literature are used in this section to articulate Sahara's lived experiences.

Discourse

When Sahara found out about her diagnosis, her initial thought was mostly related to her family, especially her sick mother, which suggested her mother was her priority. The belief of "family comes first" is rooted in Saudi culture, and Sahara's first thought of family matches the Saudi public's expectation of what a daughter must do, because the concept of caring is

central to the Islamic religion (Halligan, 2006). Women try to protect their family and show their loyalty because they are seen as the “pillar” of the family in their culture. (Goldblatt et al., 2013). Arab women tend to protect their family and hide any stressful issues that might disturb the wellbeing of the family, especially children (Fearon et al., 2019).

Despite Sahara’s professional medical background and her knowledge of breast cancer survival, which she could have used to break the news to her family, she chose to keep it hidden. Hiding the disease suggested her awareness of the public stigma linked to breast cancer, which is commonly reported in many eastern studies as the “bad one” (Banning et al., 2010; Hammoudeh et al., 2017; Jassim & Whitford, 2014). Many Arabian studies report the public perception of breast cancer is linked to death, and its possibility of being an infectious disease (Al-Azri et al., 2014; Doumit et al., 2010). Based on the latter perceptions, Sahara expected the negative impact on her mother if she found out, given that the people in Saudi Arabia had a low level of awareness of breast cancer (Abdallah et al., 2015).

Sociality

For Sahara, keeping her emotions and stress under control in front of her family and friends was very important. Despite her attempts to protect her family and self from feelings of pity, she often felt alone, which has been described as a threat that could hinder cancer patients’ attempts to adjust to living with cancer (Benoot et al., 2014). Furthermore, Sahara’s decision to keep her cancer hidden left her with no chance of getting support from family and friends, which has proved to be very important in helping breast cancer patients cope well (Cappiello et al., 2007; Cimprich et al., 2005). Living between visibility and invisibility contributed to a struggle in changing roles; she felt the need to take over the mothering role by hiding her illness and protecting her mother from pain, so the mother/daughter dynamics were altered. She also continued in her role as a caregiver to her mother rather than a care receiver.

According to cultural terms, such as protecting the family, having to deal with people’s curiosity, and dealing with a view of breast cancer that is often stigmatized, eventually led to Sahara being sheltered from any reminders of disease and death and focusing on a world in which she could just be normal. This lack of disclosure of illness was like that of those Saudi people living with HIV: they hide their HIV and select to whom they disclose the condition (Omer et al., 2014). This conflicts with the current western survival concept, which calls for an embracing of the breast cancer experience (Allen et al., 2009; Davis et al., 2014; Documet et al., 2012), seeking help from friends and family, and focusing on positive behaviour (Escalera et al., 2019; Mishel et al., 2005).

Selfhood

When Sahara completed breast cancer treatment, she engaged in a normalizing process just to regain a sense of who she was before the breast cancer experience. Normality is related to the ability to accept a chronic condition and cope with it (Charmaz, 1995). The importance of feeling normal leads many cancer survivors to accommodate the feeling of loss by maintaining a normal appearance in front of others, especially on social occasions (Henshall et al., 2017). In Sahara’s case, she got married and concealed her feelings. So she could feel connected to her husband, she suffered inwardly and tried to do things to compensate for her low body image. Fear of change in a sexual relationship with partners and getting divorced were reported in previous studies in Lebanon and Pakistan (Banning et al., 2009; Doumit et al., 2010).

After Sahara’s divorce and her father’s marriage, future concerns related to being lonely and finding love and support emerged. This fear is related to the cultural position of Saudi

women who need male support and guardianship (Hamdan, 2005). In Syria, women reported their concerns about reduced chances of getting married because of breast cancer (Nizamli et al., 2011). Although a male-dominant culture is often linked to Islam, the difference between cultural factors and Islamic rules and regulations is significant (Al-Amoudi & Abduljabbar, 2012). Some religious scholars used to silence many Saudi women's voices in the name of Islam. Also, they tried to apply a constant pressure on women in order to maintain the Saudi traditions and values (Pharaon, 2004). On the other hand, Saudi Arabia has undergone many changes when it comes to the Saudi women's status in social, political, and economic issues to achieve the country vision 2030. These developments involved enabling Saudi women to practice their rights such as, traveling abroad, working, and driving a car without any gradian's male approval.

This hermeneutic phenomenological case study is one of the first attempts to understand the experience of living beyond a breast cancer diagnosis from a premenopausal Saudi woman's perspective. Sahara's breast cancer story now has a place in her culture; the meaning-making is derived through cultural, social, and historical perspectives. Sahara's story and other women who participated in Ph.D. project have contributed to knowledge about the experience of breast cancer in Saudi Arabia in the light of its culture specifically in relation to the woman's role in society and the impact of religious beliefs. It presented a deep analysis of different forms of being and the life-world from the unique perspective of a young Saudi female breast cancer survivor. The IPA approach helped in articulating and understanding Sahara's lived experience and the sense of being by giving her a voice and enabling the hidden feelings to be released.

This story suggests that, similar to Sahara, many Saudi women who are breast cancer survivors may struggle to understand their lived experiences and struggle to resume their activities of daily living. Looking at the experience of living with breast cancer and beyond, through Sahara's eyes, provides the opportunity for healthcare providers to understand what women go through and helps to show there are invisible and real problems. Raising awareness of the concept of "living with cancer and beyond" and how women might map their future in terms of self- management and not suffering alone are important. This study might help health professions in providing culturally competent breast cancer care, knowing the dynamic of cultural interaction between patient and surroundings, meeting psycho- sociological needs, and providing better supportive services.

References

- Aaronson, N., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N., Filiberti, A., Flechtner, H., Fleishman, S. B., de Haes, J. C. J. M., Kaasa, S., Klee, M., Osoba, D., Razvi, D., Rofe, P. B., Schraub, S., Sneeuw, K., Sullivan, M., & Takeda, F. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute*, 85(5), 365-376.
- Abdallah, A., El-Gharabawy, R., & AL-Suhaibany, H. (2015). Knowledge, attitude and practice about breast cancer among women in Saudi Arabia. *International Archives of Medicine*, 8(248), 1755-1847.
- Al-Amoudi, S., & Abduljabbar, H. (2012). Men's knowledge and attitude towards breast cancer in Saudi Arabia. *Saudi Medical Journal*, 33(5), 547-550.
- Al-Azri, M. H., Al-Awisi, H., Al-Rasbi, S., & Al-Moundhri, M. (2014). Coping with a diagnosis of breast cancer among Omani women. *Journal of Health Psychology*, 19(7), 836-846.
- Al-Mutairi, K., Al-Helih, E., Al-Ajlan, A., & Vinluan, J. (2016). A cross-sectional assessment of quality of life of colorectal cancer patients in Saudi Arabia. *Clinical and*

- Translational Oncology*, 18(2), 144-152.
- Allen, J., Savadatti, S., & Levy, G. (2009). The transition from breast cancer 'patient' to 'survivor'. *Psycho-Oncology Journal*, 18(1), 71-78.
- Alrawaji, A., Alzahrani, W., Alshahrani, Z., & Alomran, F. (2015). *The Saudi health council national health information center Saudi cancer registry: Cancer incidence report Saudi Arabia 2015*. Ministry of Health. <https://nhic.gov.sa/eServices/Documents/E%20SCR%20final%206%20NOV.pdf>
- Alsaif, A. (2004). Breast self-examination among Saudi female nursing students in Saudi Arabia. *Saudi Medical Journal*, 25(11), 1574-1578.
- Alsolami, F., Azzeh, F. S., Ghafouri, K., Ghaith, M., Almaimani, R., Almasmoum, H., Abdulal, R. H., Abdulaal, W. H., Jazar, A. S., & Tashtoush, S. H. (2019). Determinants of breast cancer in Saudi women from Makkah region: A case-control study (breast cancer risk factors among Saudi women). *BMC Public Health*, 19(1), 1-8.
- Amin, T., Al Mulhim, A., & Al Meqihwi, A. (2009). Breast cancer knowledge, risk factors and screening among adult Saudi women in a primary health care setting. *Asian Pacific Journal of Cancer Prevention*, 10(1), 133-138.
- Ashworth, P. (2003). An approach to phenomenological psychology: The contingencies of the lifeworld. *Journal of Phenomenological Psychology*, 34(2), 145-156.
- Astrow, A. (2012). Cancer survivorship and beyond. *Journal of the American Medical Association*, 308(16), 1639-1640.
- Banning, M., Hafeez, H., Faisal, S., Hassan, M., & Zafar, A. (2009). The impact of culture and sociological and psychological issues on Muslim patients with breast cancer in Pakistan. *Cancer Nursing Journal*, 32(4), 317-324.
- Banning, M., Hassan, M., Faisal, S., & Hafeez, H. (2010). Cultural interrelationships and the lived experience of Pakistani breast cancer patients. *European Journal of Oncology Nursing*, 14(4), 304-309.
- Bantema-Joppe, de Bock, G., Woltman-van Iersel, M., Busz, D., Ranchor, A., Langendijk, J., Maduro, J. H., & van den Heuvel, E. (2015). The impact of age on changes in quality of life among breast cancer survivors treated with breast-conserving surgery and radiotherapy. *British Journal of Cancer*, 112(4), 636-634.
- Benoot, C., Bilsen, J., Grypdonck, M., & Deschepper, R. (2014). Living alone during cancer treatment: An exploration of patients' experiences. *Qualitative Health Research*, 24(8), 1057-1067.
- Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast cancer survivors: Information and support after treatment. *Clinical Nursing Research*, 16(4), 278-293.
- Champion, V., Wagner, L., Monahan, P., Daggy, J., Smith, L., Cohee, A., Ziner, K. W., Haase, J. E., Miller, K. D., Pradhan, K., Unverzagt, F. W., Cella, D., Ansari, B., & Sledge, G. W., Jr. (2014). Comparison of younger and older breast cancer survivors and age-matched controls on specific and overall quality of life domains. *Cancer Journal*, 120(15), 2237-2246.
- Charmaz, K. (1995). The body, identity, and self. *The Sociological Quarterly*, 36(4), 657-680.
- Cimprich, B., Janz, N., Northouse, L., Wren, P., Given, B., & Given, C. (2005). Taking charge: A self-management program for women following breast cancer treatment. *Psycho-Oncology Journal*, 14(9), 704-717.
- da Costa Vargens, O., & Berterö, C. (2007). Living with breast cancer: Its effect on the life situation and the close relationship of women in Brazil. *Cancer Nursing Journal*, 30(6), 471-478.
- Davis, C., Myers, H., Nyamathi, A., Lewis, M., & Brecht, M.-L. (2014). The meaning of survivorship as defined by African American breast cancer survivors. *Journal of Transcultural Nursing*, 27(3), 277-285.

- Documet, P., Trauth, J., Key, M., Flatt, J., & Jernigan, J. (2012). Breast cancer survivors' perception of survivorship. *Oncology Nursing Forum Journal*, 39(3), 309-315.
- Doumit, M., El Saghir, N., Abu-Saad Huijer, H., Kelley, J., & Nassar, N. (2010). Living with breast cancer, a Lebanese experience. *European Journal of Oncology Nursing*, 14(1), 42-48.
- Eatough, V., & Shaw, K. (2017). 'I'm worried about getting water in the holes in my head': A phenomenological psychology case study of the experience of undergoing deep brain stimulation surgery for Parkinson's disease. *British Journal of Health Psychology*, 22(1), 94-109.
- Eatough, V., & Smith, J. (2006). I was like a wild wild person: Understanding feelings of anger using interpretative phenomenological analysis. *British Journal of Psychology*, 97(4), 483-498.
- Elkum, N., Dermime, S., Ajarim, D., Al-Zahrani, A., Alsayed, A., Tulbah, A., Malik, O. A., Alshabanah, M., Ezzat, A., & Al-Tweigeri, T. (2007). Being 40 or younger is an independent risk factor for relapse in operable breast cancer patients: The Saudi Arabia experience. *BioMed Central Journal*, 7(1), 222.
- Escalera, C., Santoyo-Olsson, J., Stewart, A. L., Ortiz, C., & Nápoles, A. M. (2019). Social support as a moderator in the relationship between intrusive thoughts and anxiety among Spanish-speaking Latinas with breast cancer. *Psycho-Oncology Journal*, 28(9), 1819-1828.
- Fearon, D., Hughes, S., & Brearley, S. (2019). Experiences of breast cancer in Arab countries. A thematic synthesis. *Quality of Life Research*, 29(2), 1-12.
- Globocan. (2020). *Breast*. The Global Cancer Observatory. <https://gco.iarc.fr/today/data/factsheets/cancers/20-Breast-fact-sheet.pdf>
- Goldblatt, H., Cohen, M., Azaiza, F., & Manassa, R. (2013). Being within or being between? The cultural context of Arab women's experience of coping with breast cancer in Israel. *Psycho-Oncology Journal*, 22(4), 869-875.
- Hall, D., Mishel, M., & Germino, B. (2014). Living with cancer-related uncertainty: Associations with fatigue, insomnia, and affect in younger breast cancer survivors. *Supportive Care in Cancer Journal*, 22(9), 1-7.
- Halligan, P. (2006). Caring for patients of Islamic denomination: Critical care nurses' experiences in Saudi Arabia. *Journal of Clinical Nursing*, 15(12), 1565-1573.
- Hamdan, A. (2005). Women and education in Saudi Arabia: Challenges and achievements. *International Education Journal*, 6(1), 42-64.
- Hammoudeh, W., Hogan, D., & Giacaman, R. (2017). From a death sentence to a disrupted life: Palestinian women's experiences and coping with breast cancer. *Qualitative Health Research*, 27(4), 487-496.
- Heidegger, M. (1996). *Being and time: A translation of Sein und Zeit*. SUNY Press.
- Henshall, C., Greenfield, S., & Gale, N. (2017). The role of self-management practices as mechanisms for re-establishing normality in cancer survivors. *Qualitative Health Research*, 27(4), 520-533.
- Jassim, G., & Whitford, D. (2014). Understanding the experiences and quality of life issues of Bahraini women with breast cancer. *Social Science & Medicine Journal*, 107(10), 189-195. doi:10.1016/j.socscimed.2014.01.031
- Kagawa-Singer, M., & Blackhall, L. (2001). Negotiating cross-cultural issues at the end of life. *Journal of the American Medical Association*, 286(23), 2993-3001.
- Kaiser, K. (2008). The meaning of the survivor identity for women with breast cancer. *Social Science & Medicine Journal*, 67(1), 79-87.
- Kvale, S., & Brinkmann, S. (2009). *Interview: Learning the craft of qualitative research interviewing* (2nd ed.). Sage

- Lally, R., & Underhill, M. (2012). Transition to breast cancer survivorship: A longitudinal qualitative follow-up study of two-year survivors. *Journal of Psychosocial Oncology*, 30(1), 97-127.
- Levkovich, I., Cohen, M., & Karkabi, K. (2017). The experience of fatigue in breast cancer patients 1–12 month post-chemotherapy: A qualitative study. *Behavioral Medicine*, 45(1), 7-18.
- McCann, L., Illingworth, N., Wengström, Y., Hubbard, G., & Kearney, N. (2010). Transitional experiences of women with breast cancer within the first year following diagnosis. *Journal of Clinical Nursing*, 19(13-14), 1969-1976.
- Mishel, M., Germino, B., Gil, K., Belyea, M., LaNey, I., Stewart, J., Porter, L., & Clayton, M. (2005). Benefits from an uncertainty management intervention for African–American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 14(11), 962-978.
- Najjar, H., & Easson, A. (2010). Age at diagnosis of breast cancer in Arab nations. *International Journal of Surgery*, 8(6), 448-452.
- Nizamli, F., Anoosheh, M., & Mohammadi, E. (2011). Experiences of Syrian women with breast cancer regarding chemotherapy: A qualitative study. *Nursing & Health Sciences*, 13(4), 481-487.
- Oeffinger, K., Fontham, E., Etzioni, R., Herzig, A., Michaelson, J. S., Shih, Y., Walter, L. C., Church, T. R., Flowers, C. R., LaMonte, S. J., Wolf, A. M. D., DeSantis, C., Lortet-Tieulent, J., Andrews, K., Manassaram-Baptiste, D., Saslow, D., Smith, R. A., Brawley, O. W., Wender, R., & American Cancer Society. (2015). Breast cancer screening for women at average risk: 2015 guideline update from the American Cancer Society. *JAMA*, 314(15), 1599-1614.
- Omer, T., Lovering, S., & Al Shomrani, M. (2014). The lived experience of living with HIV/AIDS in the western region of Saudi Arabia. *Diversity & Equality in Health and Care*, 11, 215-223.
- Pharaon, N. (2004). Saudi women and the Muslim state in the twenty-first century. *Sex Roles*, 51(5), 349-366.
- Powers, N., Gullifer, J., & Shaw, R. (2014). When the treatment stops: A qualitative study of life post breast cancer treatment. *Journal of Health Psychology*, 21(7), 1371-1382.
- Rahou, B., El Rhazi, K., Ouasmani, F., Nejjari, C., Bekkali, R., Montazeri, A., & Mesfioui, A. (2016). Quality of life in Arab women with breast cancer: A review of the literature. *Health and Quality of Life Outcomes*, 14(46), 1477-7525.
- Sabo, B., & Thibeault, C. (2012). “I’m still who I was” creating meaning through engagement in art: The experiences of two breast cancer survivors. *European Journal of Oncology Nursing*, 16(3), 203-211.
- Sait, W., Al-Amoudi, S., Tawtai, D., & Abduljabbar, H. (2010). The knowledge of breast cancer among young Saudi females. *Saudi Medical Journal*, 31(11), 1242-1244.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis theory, method and research*. Sage.
- Smith, K., Klassen, A., Coa, K., & Hannum, S. (2015). The salience of cancer and the “survivor” identity for people who have completed acute cancer treatment: A qualitative study. *Journal of Cancer Survivorship*, 10(3), 457-466.
- The Saudi Center for Evidence Based Health Care. (2014) *Clinical practice guideline on the use of screening strategies for the detection of breast cancer*. Saudi Arabia: Ministry of Health.
- Tompkins, C., Scanlon, K., Scott, E., Ream, E., Harding, S., & Armes, J. (2016). Survivorship care and support following treatment for breast cancer: A multi-ethnic comparative qualitative study of women’s experiences. *BioMed Central Health Services Research*,

16(1), 401.

Vella, M. (2016). The unknown/the unanticipated: A surgical journey of correcting HIV related abdominal lipodystrophy. *Qualitative Health Research*, 26(4), 518-531.

Van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy*. Routledge.

Williams, F., & Jeanetta, S. (2016). Lived experiences of breast cancer survivors after diagnosis, treatment and beyond: Qualitative study. *Health Expectations Journal*, 19(3), 631-642.

Author Note

Wafa ALmegewly is an assistant professor in Community Health Nursing Department in the College of Nursing, Princess Nourah bint Abdulrahman University. The focus of much of her research to date has been on quality of life in patients with cancer, culture, and patients' experience. Please direct correspondence to whalmegewly@pnu.edu.sa.

Dinah Gould is an honorary visiting professor City London University. She undertakes research to explore health need and innovations in health care using observational and intervention methodologies. Please direct correspondence to anstey1@cardiff.ac.uk.

Sally Anstey is a senior lecturer of Adult Nursing in Cardiff University, School of Healthcare Sciences. Her research activities include cancer, end-of-life care, mental health, and patient voices in education. Please direct correspondence to dinahgould@outlook.com.

Acknowledgements: This research was funded by the Deanship of Scientific Research at Princess Nourah bint Abdulrahman University through the Fast-track Research Funding Program

Declaration of Conflicting Interests: The author(s) declare(s) that there is no conflict of interest.

Copyright 2021: Wafa ALmegewly, Dinah Gould, Sally Anstey, and Nova Southeastern University.

Article Citation

ALmegewly, W., Gould, D., & Anstey, S. (2021). "I was like an autumn leaf that looks pretty from the outside, but would break once you touched it": A case study of the lived experience of breast cancer survival. *The Qualitative Report*, 26(5), 1331-1344. <https://doi.org/10.46743/2160-3715/2021.4669>
