



Accessing breast cancer care in a protracted conflict: Qualitative exploration of the perspectives of women with breast cancer in northwest Syria

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ABSTRACT

Background: Women with breast cancer in northwest Syria, an area of protracted armed conflict, face multiple intersecting challenges to accessing care which may relate to gender, social structures, and financial constraints. Our aim was to explore the perspectives of women with breast cancer in northwest Syria about the impact of their diagnosis and experiences of accessing care.

Methods: Women who accessed diagnosis or clinical care at the Syrian American Medical Society (SAMS) oncology centre in Idlib city during 2022 were identified from hospital records; they were invited to participate in semi-structured interviews conducted in Arabic by four local female-trained researchers. Participation was voluntary and informed consent was sought. Semi-structured interviews were conducted in August and September 2022 until thematic saturation was reached. Data were audio recorded and transcribed in Arabic before translation and thematic analysis using Nvivo to identify key emerging themes.

Results: 22 women with breast cancer were interviewed. Findings were categorised into three themes: 1. Challenges to accessing oncology care in northwest Syria 2. Interactions with healthcare workers 3. The role of community and society. All participants noted the financial strains which the breast cancer diagnosis placed on them and their families. Most also noted the additional strains of travelling long distances, either in northwest Syria or to Turkey, where referral would entail additional costs, bureaucracy or isolation from family or social support. Some participants described social impacts including the expectation that they would continue with household chores and childcare even while ill. Patients reported that strong faith, having children, compassion from healthcare staff and peer support as being important factors for coping with their diagnosis and treatment. **Conclusion:** Though there have been improvements to breast cancer care in northwest Syria, stock-outs and the lack of availability of radiotherapy may still force women to travel to Turkey for further investigations or treatment. Our findings suggest increased support for women with breast cancer as well as their families is required. This work is a starting point for future research on this topic both in northwest Syria and other areas in Syria.

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1. Introduction

Oncology care in Syria prior the March 2011 uprisings was heavily centralised and mostly provided in the two main cities of Damascus and Aleppo. Following the conflict and the fragmentation of Syria's health system, subnational health systems have emerged within each area of control; these are broadly areas under government control (including the south, central and coastal areas) northeast Syria under Autonomous Administration of North and East Syria (AANES) control, and the Northwest of Syria (NWS) under the control of the SIG (Syrian Interim Government) and the SSG (Syrian Salvation Government) (Abbara et al., 2021). The early withdrawal of the state and its services from areas outside of its control has left gaps in health and humanitarian care. These have partially been filled by humanitarian organisations (both local and international) as well as local health governance structures (including medical councils, health directorates) to fill the gap (Abbara et al., 2021). Despite some effective interventions and organisation, the range and number of active providers as well as external financial and political pressures have resulted in significant fragmentation within the health systems and at the national level (Abbara et al., 2021). This has resulted in inadequate healthcare provision, particularly for specialist services such as oncology care particularly in areas outside of government control.

The Syrian American Medical Society (SAMS) a US and Turkey registered humanitarian organisation has stepped in to provide some oncology services to northwest Syria utilising predominantly private donations. It has three diagnostic and treatment centres in northwest Syria in Idlib city, Jarablus city and al-Bab city; the latter is run in collaboration with the Turkish Ministry of Health (Syrian American Medical Society, 2023). These centres provide free services including diagnostics including mammography in Idlib centre and biopsy and histopathology services including basic immunohistochemistry in Al-Rai pathology laboratory. (Syrian American Medical Society, 2023). In addition, some NGOs like Relief international provide surgical treatment for breast cancer including mastectomies; these are available in Binnish, Harem, Darkoush, Ein El-Bayda, and Daret Azza. In 2022, a total of 11,461 oncology consultations were provided by SAMS in NWS, and 2827 doses of chemotherapeutic agents were administered free of charge.' (Syrian American Medical Society & Relief International, 2023). For treatment, chemotherapy and hormone therapy are provided however radiotherapy is not provided anywhere in northwest Syria. As such, patients must be referred to Turkey should they need this or more advanced treatments than are available; however, this was interrupted in the wake of the earthquakes in February 2023. (Sahloul et al., 2017; Atassi et al., 2022),

For women with cancer, including breast cancer, both treatment in the NWS and in Turkey present challenges relating to the security situation in northwest Syria, restrictive social or cultural norms, financial burden to them or their families and increasing limitations on travel. Of note, though cancer care in Turkey is provided for free, there are financial pressures associated with travel and accommodation. In addition, the bureaucratic process of requesting permissions for travel from both local and Turkish authorities resulted in delays in patients' treatment; this could be for up to 6 months which for many, meant their conditions worsened. (Syrian American Medical Society & Relief International, 2023).

Data on cancer prevalence in Syria both pre and post the onset of the uprisings is unreliable. The Syrian National Cancer Registrar (SNCR) a hospital-based registry shows an increase in the total new cancer cases in females in the whole of Syria between 2009 (8386 cases) and 2020 (11,716) cases. This increase could be as a result of the WHO breast cancer screening program which began in 2019 though further evidence around this is needed (World Health Organization, 2020). Breast cancer continues to be the leading cancer diagnosis among Syrian women, accounting for 30% of cancer diagnoses among women, with 4388 (37.5%) of total registered cases (World Health Organization, 2018,

2021). However, this does not include data from areas outside of government control given the lack of access of the government to these areas, particularly in northwest Syria. A 2022 study by Atassi et al. described the findings of 1654 diagnostic pathology specimens obtained from Al-Rai Hospital laboratory; 20% of diagnoses were of breast cancer. (Atassi et al., 2022).

Cancer research in humanitarian crises and conflict or post-conflict settings remains under-explored with a continued misconception that infectious diseases are the priority in humanitarian response even during protracted crises. (Pramesh et al., 2022). However, particularly where conflicts or crises are protracted, there needs to be greater consideration of the broader needs of a health system which go beyond the immediately lifesaving as seen in Syria. Though there is increasing literature which explores cancer care in such settings, it remains under-studied with most research focused on settings unaffected by conflict. In protracted humanitarian settings, cancer care may be ignored both in response planning but also by funders given the comparatively insidious nature of cancer compared to traumatic injuries, the perceived (and perhaps actual) high costs of care compared to other interventions and the need for a stable for functioning health system to ensure patients receive the right management from diagnosis to treatment. However, further research which explores relevant questions on cancer in such settings both in Syria and other crises remains essential.

The aim of this study was to explore the perspectives of women who were diagnosed with breast cancer in northwest Syria about the impact of their diagnosis and experiences of accessing care.

2. Methods

This study was co-designed with local breast cancer specialists in northwest Syria and medical students who were working directly with the patients. We used a purposive then snowball sampling and inductive thematic analysis approach.

2.1. Inclusion and exclusion criteria for participants

Participants were eligible if they were adult, female patients of 18 years or older who were diagnosed with breast cancer and currently living in northwest Syria (including both host and internally displaced people). Patients who did not fit these criteria or who were unwilling or unable to participate were excluded.

2.2. Participant recruitment and selection

Patients were identified from a list of patients who had a diagnosis of breast cancer at SAMS Idlib oncology Centre. The first 90 patients from this list were screened; 40 were not approached as they did not have a working telephone number or Whatsapp. Another 25 did not enrol primarily because the patient list at the hospital has not been updated regularly, seven patients had already died, 13 were at a vulnerable late stage of breast cancer, while five patients declined because there was no incentive provided; 3 were not interviewed because a call could not be scheduled in the time period. Interviews were conducted with the remaining 22 women between August and September 2022.

The invitation to participate included information on the study purpose and process, including the right to withdraw at any time, all was in Arabic. In order to include participants who could not read or write, voice messages on Whatsapp were used to inform participants about the study, and interviewers read the information sheet word by word.

2.3. Data collection

MM, AS, BA, and MB conducted all in-depth interviews using WhatsApp calls as this is the main medium of communication that is used in the region in the absence of a telecommunication network. MM

is a Syrian researcher who has training and experience of conducting qualitative research in sensitive settings. She trained AS, BA and MB, all of whom were final year, female, medical students based in northwest Syria at the time of the study. MM conducted the first interviews with them and then conducted interviews independently when they were ready.

Each interview lasted between 30 and 60 min. We used a question guide developed for the purpose of the study, in consultation with all team members. Interviews were conducted in Arabic and where possible, it was in the local accent/dialect spoken by the patients, and with the presence of patients and interviewers only. The interviewing stopped after theoretical data saturation reached. Interviews were audio recorded, and transcribed in Arabic by MM, AS, BA, and MB prior to analysis.

2.4. Analysis

Data analysis was conducted in the spoken Arabic dialogue (colloquial Arabic) rather than formal Arabic to preserve as far as possible the details and expressions provided by patients, to enrich our findings. We analysed data using Braun & Clarke’s six-stage thematic analysis approach using NVivo 11 software. Firstly MM, AA, MH, AS, BA and MB familiarised themselves with the data. Secondly, MM independently developed draft coding frameworks to complement the deductive codes which were already defined with AA, MH, AS, BA, MB and the interview guide topics.

Thirdly, they developed a coding structure iteratively, collating codes related to study objectives and examining relationships between codes and research questions. A particularly important emerging theme for this paper, for example, came from data on gender inequality, as described in the findings section. AA reviewed initial themes, guided prioritisation, and resolved discrepancies. Fourth, they mapped themes. Fifth, all investigators refined and defined independent themes through discussion and further integration. Finally, all investigators reviewed and refined themes during reporting.

2.5. Ethics

This study was approved by the Human Investigations Committee at Yale University. Informed consent was obtained for all participants and

they could withdraw at any time until analysis was commenced. We had a named mental health professional who the participants could reach out to if they needed to. The interviewer would terminate the interview if any signs of distress were shown by the participants.

3. Results

Table 1 provides a summary of the characteristics of the 22 participants in this study; we have kept data minimal to avoid identification. The age distribution by age group is as follows: 2 were aged 21–30, 5 were aged 31–40, 9 were aged 41–50, 2 were aged 51–60 and 4 were aged 61–70. 13 of the 22 were IDPs. Of the fifteen where the stage of cancer was known, 8 were stage II, 6 were stage III and 1 was stage IV. Other details are in the table. No participants withdrew due to distress or other reasons.

Three main themes emerged with some sub-themes within these. The themes were 1. Challenges to accessing oncology care for patients living in northwest Syria 2. Interactions with healthcare workers 3. The role of community and society.

4. Challenges to accessing oncology care for patients living in northwest Syria

4.1. Quality of breast cancer care in northwest Syria

Most participants spoke well of the oncology services provided by healthcare staff in both northwest Syria and in Turkey. However, all reported a strong preference for access to oncology care in northwest Syria rather than Turkey and were pleased when services became available in Idlib in 2020. This reduced challenges which they faced including costs of transport and services in Turkey, being away from family or feeling isolated because of the linguistic barrier in Turkey, delays to permissions to cross the border and restrictions on companions. One participant noted that she had to stop her treatment in Turkey as she fainted during the trip and could no longer make the trip alone. However, even within northwest Syria, transportation was noted to be challenging. For example, patients in northern Aleppo noted the challenges of transport to the oncology centre in Idlib due to the costs and availability of private vehicles (few have a private care) costs of taxis (there is no public transport) check points, the long distances to travel,

Table 1
Characteristics of participants.

Participant	Age Range	Education Level	Employment	Family Status Single/Married/Divorced/Widowed	Displaced Yes/No	Cancer Stage (where known) ^a
Participant 1	31–40	University	Teacher	Married with children	No	–
Participant 2	41–50	Not educated	Housewife	Married with children	No	II
Participant 3	41–50	Preparatory	Housewife	Single	Yes	II
Participant 4	21–30	Secondary	Housewife	Divorced with children	No	IV
Participant 5	41–50	Not educated	Housewife	Married with children	Yes	–
Participant 6	51–60	University	Housewife	Married with children	No	III
Participant 7	41–50	Institute	Teacher	Married with children	No	–
Participant 8	31–40	Not educated	Housewife	Married with children	Yes	–
Participant 9	31–40	Preparatory	Housewife	Widowed with children	No	II
Participant 10	61–70	University	Retired Teacher	Widow without children	No	II
Participant 11	61–70	Primary	Housewife	Married with children	No	–
Participant 12	41–50	Secondary	Housewife	Married with children	Yes	III
Participant 13	41–50	Preparatory	Housewife	Married with children	Yes	II
Participant 14	31–40	Secondary	Housewife	Married with children	Yes	–
Participant 15	41–50	Primary	Housewife	Married with children	No	II
Participant 16	41–50	Secondary	Housewife	Married with children	No	II
Participant 17	41–50	Preparatory	Housewife	Married with children	No	–
Participant 18	21–30	Secondary	Housewife	Married with children	Yes	III
Participant 19	61–70	Preparatory	Housewife	Married with children	No	II
Participant 20	31–40	Preparatory	Housewife	Married with children	No	III
Participant 21	51–60	Primary	Housewife	Married with children	Yes	III
Participant 22	61–70	Not educated	Housewife	Married with children	Yes	III

^a Cancer state refers to the American Joint Committee on Cancer TNM system where I is for a tumour of 2 cm or less, II is where the tumour is more than 2 cm but less than 5 cm in diameter, III is where the tumour is more than 5 cm and IV is where the tumour is growing into the chest wall or skin.

ongoing insecurity and poor road infrastructure. Some spoke positively of Syrian organisations such as Mulham team who provided individualised patients support at home. Prior to the oncology centre opening in Idlib and the pathology Lab at Al-Rai hospital, certain services such as mammography or histopathology were unavailable or costly.

For those who needed to cross to Turkey for investigations or treatment, participants spoke highly of the care received however they described challenging bureaucratic procedures including for obtaining a cross-border permit authorisation. Others emphasised challenges related to transportation, the cost of treatment and living costs in Turkey as well as difficulties related to language and communication both en route and with healthcare staff in Turkey. Participant 18 reported that her experience of accessing care would improve if Turkish-Arabic translation was available more readily, saying:

“God help them, the hospital staff were very good and their attitude was good however it is a bit hard for us to understand what they say and we need a translator; I mean we need to push hard to find a translator.” (Participant 18)

Another echoed this saying:

“I don’t know the language [Turkish] and no one at the emergency department speaks Arabic, so I waited for 6 hours using body language until they understood what was hurting me. I was on chemotherapy and was alone no one was with me, which hurts me mentally, so the mental health of the patient is affected, especially that our disease [cancer] is not like any other simple disease” (Participant 1)

One participant reported that prior to the oncology centre in Idlib opening, she needed to consider being smuggled to Damascus (an area under government control) at a cost of around \$2000 per trip for a single dose of treatment. Another participant reported that she or her companions risked arrest by taking this route as she travelled from areas considered to be against the government. Now that services are provided in northwest Syria, she did consider this route with some participants reporting that the equipment in Idlib was newer than that available in Damascus. A participant notes:

“Initially, I started six chemotherapy sessions in Damascus but the travel there became difficult. However, I needed 30 radiotherapy sessions, something which is still not available in Idlib, so I had to go back to Damascus.” (Participant 7)

4.2. Financial strains and the travel costs for treatment

In SAMS oncology centres, care is provided without charge; however, for patients who travel to Turkey, though there are no charges for treatment, there are additional costs of travel and lodging which can accumulate. Out-of-pocket payments in a setting where around 90% of people live in poverty and unemployment is high can therefore be challenging. Most patients highlighted the effect of their financial situation and the cost of treatment on their well-being and their willingness to continue treatment. A participant said:

“I am suffering a lot and the financial situation is very bad; my husband doesn’t work and he is old. The cost of travel to Turkey for treatment is expensive.” (Participant 12)

Some households were forced to sell essential household items or work even while undergoing chemotherapy to afford the cost of treatment. For example, participant 8 mentioned that her husband had to sell their refrigerator among other things in order to continue her treatment.

“ We struggled a lot, because my husband doesn’t have a regular income. One day he works and another he doesn’t. We are staying in tents, and now because of the chemotherapy, I feel too hot in the tent, however I try not to complain. The living conditions are very

difficult. No one helps us with the cost of treatment. we had a freezer and refrigerator but we sold them so I can continue my treatment.” (Participant 8)

4.3. Challenges of accessing care in Turkey

Some patients chose to or are required to travel to Turkey for further treatment, particularly for radiotherapy which is unavailable in northwest Syria or if there has been a rupture in supplies of certain chemotherapy treatments. Permission, particularly for non-emergency cases, could be delayed, especially during the COVID-19 pandemic when borders were closed or more strictly controlled. One patient noted that she waited 6 months at the Turkish border until she was issued the “Health tourism ID card”, which provides authorization to enter Turkey for treatment. Participant 1 explained that by the time she had the required approvals to enter Turkey, cancer had spread into her bone marrow. She said:

“After COVID-19 they finally allowed for cold cases (other cases than ambulatory emergencies), which included us as cancer patients. By the time I reached Turkey, I was shocked to know that the cancer had spread into my bones, because of the delay in radiotherapy. It reached my chest bone. In Turkey the procedures are very boring and bureaucratic, I had to wait for 2 months in Turkey until I got a turn in radiotherapy.” (Participant 1)

“I was referred to Turkey in 2015 and I found it very difficult going back and forth. I suffered more from the travelling than my actual disease (cancer). In Turkey, they did the scan and monitored my situation and mentioned that I should be back after 3 months. However, it took a long time to get my authorization to enter Turkey again and by that time my cancer had spread to the other breast.” (Participant 7) 1.4. Feeling lonely and vulnerable: ‘alone without someone to accompany them’

The importance of care provided in SAMS’ facilities is further reinforced by most patients stating they preferred to have ongoing care in northwest Syria to be close to family members and children; this is particularly due to restrictions on accompanying family members after the start of the COVID-19 pandemic. This was particularly challenging for single mothers who were the sole carers and providers for their children. One noted:

“I have a small child, and no one helped me in taking care of her, so I couldn’t at that time travel to Turkey and leave her alone. However, the doctor referred me again to Turkey as the living expenses while getting the treatment here (in Turkey) was very expensive and I couldn’t afford it” (Participant 12)

“I don’t have extra money for the living cost there (Turkey); the doctor told me to choose either treatment in Turkey or here but I don’t have the courage to dare going to Turkey, as I don’t know anyone there and I don’t know how to write or to read.” (Participant 5)

“I came to Turkey without a companion; even children who are over 8 years old need to come alone without someone to accompany them. This is a real problem for us.” (Participant 6)

Some patients noted that pathways in Turkey were not flexible enough for non-residents including those in northwest Syria. For example, appointments needed to be made in person resulting in delays. In addition, participants mentioned that there were capacity issues due to the increase in the number of referrals. This could mean that they needed to rent for long periods in Turkey if they were not accommodated in one of the limited free hosting centres. Patients spoke of the high pressures on oncology services for both Turkish citizens and Syrians:

“There is only one doctor to see almost 200 patients per day at the hospital that I was referred to. One time I stayed 2 months in Turkey

until my turn arrived; by that time the doctor said you will need another radiotherapy treatment.” (Participant 1)

5. Interactions with healthcare workers

For patients treated in northwest Syria and in Turkey, they spoke positively of how they were treated by staff, including of the importance of reassurance. Participant 6 noted that at the time of her mastectomy in Bab Al Hawa Hospital (a surgical referral hospital in northwest Syria) the doctor was reassuring both before and after the operation noting that, “*after I woke up from the operation, the doctor came and assured me that the operation went well and that the cancer was removed and he gave all types of reassuring words that made me feel good.*” (Participant 6)

Another participant noted:

“I would say there has been good care, especially in this kind of disease [breast cancer] because there are always question marks around what would happen with me. Thank God, they were very collaborative and there were some tips on what food to avoid during treatment. For example, the doctor at the hospital has many tips for each session.” (Participant 14)

Another participant noted that the way her doctor informed of the diagnosis helped her to cope. She said:

“*It didn’t affect me much, as the doctor paved the way and slowly informed me that it may be cancer; however, this is like another disease at the moment and there is no need to fear.*” (Participant 6)

However, some who were treated in Damascus noted that the information provided was limited, leaving them to find other sources of information or not know what to expect in terms of prognosis or treatment options. For some patients who were illiterate or had limited other sources of information available to them, this affected their understanding. Many investigations were provided to patients in English only and this also impacted on the ability of patients to understand their results and their implications unless they had someone who was able to help translate. Some participants noted the lack of information provided to them about the side effects of chemotherapy:

“It was difficult, as I was administered the chemotherapy and during the following 30 hours, vomiting and joint pain started; I lost my appetite and I was exhausted. Then after one week or 10 days, these side effects would go away, but I suffered from anaemia. There is not much instruction or information about the side effects or what I should eat; it is mainly about instructions to take the chemotherapy, appointments for X ray, and that is all.” (Participant 7)

“They didn’t provide me with any information about the side effect of treatment; they only said that I had to do 25 chemotherapy sessions, however, they stopped my treatment when I reached the 12th session without any explanation” (Participant 4)

Participants noted YouTube as the main source of information that patients sought out to obtain further information. For example, one patient sought information on YouTube for breast pain and discharge and noted that it could be cancer. The participant noted:

“I felt pain in my breast, under the breast, however, I got terrified because of the severe pain, and because the nipple was discharging yellow fluid. I was terrified, so I checked the symptoms on YouTube, and it confirmed my fear. So I decided to see a specialist gynaecologist, and when I saw her she asked for a mammography, she took the X-ray and asked for a biopsy; then she performed a small surgery and took a biopsy for me; after that, she said that I had cancer.” (Participant 8)

5.1. Gender-related challenges

The impact of gender and social norms was evident in how patients were told of their diagnosis and if they were informed directly. One participant reported that the doctor initially informed only her husband of the diagnosis:

“I asked my husband to come with me; he didn’t want to at the beginning, but I insisted and said I want to go and see the results myself Then we went to the hospital in Dana. The doctor took my husband aside and they talked privately. He told him that I had breast cancer and that I needed a mastectomy. I took the opportunity while I was changing the bandages to ask the doctor about my result. I told him even if it is breast cancer, I will thank God, as my husband doesn’t want me to know the result. I insisted on the doctor and begged him until I finally knew.” (Participant 8)

Another participant noted that the treatment plan for her disease was discussed with her male companion and never mentioned to them directly.

“*None of this information was told to me directly, they were only informing my brother directly.*” (Participant 9)

Another reported being kept in the dark about her diagnosis even while undergoing treatment.

“They told me that I have a virus in the blood, even when I was receiving chemotherapy. They told me it was a strong medication to kill the virus and they didn’t mention at all that it is cancer” (Participant 17)

Some noted that little consideration or opportunity were given to discussion around the impact of mastectomies on their self-perception and gender. One example is around opportunities for breast implants after surgery. A participant noted:

“I don’t know how much [breast implants] cost. I am planning to ask the doctor about this, because this is the most important thing. It improves women’s mental health after the mastectomy, because otherwise women feel something missing of their femininity” (Participant 18)

Some women had challenges undergoing an abortion so that they could continue chemotherapy; under Syrian law, it is prohibited and in Turkey it was challenging for patients to access it. One participant said:

“It seems that I was pregnant, which I didn’t know, and they said they cannot do abortion for me. They suggested that I should do the abortion by myself, so they said, ‘You go, you do the abortion and then come back for treatment.’” (Participant 8)

6. The role of community and society

Community and society had both positive and negative impacts on patients during their treatment and recovery. A prominent view was that the community expected women to be responsible for childcare and household chores even if they were unwell. Some spoke of help from other women after they received their diagnosis. She stated:

“My neighbours and sister-in-law helped [with childcare and chores]. I had a good neighbour and my mother-in-law has been helping me up till now, thank God. I also counted on help from my children and taught them how to do house chores to help.” (Participant 9)

The diagnosis had an impact on the participants’ relationships with their husbands with some noting a great deal of support while others were deserted. Participants noted:

“My husband did the impossible and left the family and went with me to Turkey; he never left me alone. The amount of support I got from him made me feel that there is someone who really believes I can recover and survive. This had an important role.” (Participant 13)

“My parents-in-law supported me, and my husband, in particular, helped me in Turkey as my parents are not around. He was the first one to support me, thank God. The emotional and psychological part of this disease is important. As long as you have someone next to you supporting you, you will forget about the disease and he was there next to me all the time” (Participant 17)

The role of society could also be important here with some participants noting that due to the negative societal view of female cancer patients, there was an encouragement of men to remarry if the patient could no longer do the household chores or childcare. Participants noted:

“My parents and sisters live far away. The comments from the community were that ‘she has cancer and soon her husband will marry again as if she is dead.’ But I have a strong faith in God, and hopefully he [my husband] will not let me down” (Participant 12)

“For example, I know many cases where, as soon as they [women with cancer] started the treatment, their husbands married other women which affected them and their well-being. Thank God, my husband remained with me and didn’t marry another woman.” (Participant 7)

Three women reported this had happened to them during treatment as they could not bear children or continue with their household chores. One participant reported this caused her more hurt than the treatment for her breast cancer.

“Cancer wasn’t as shocking for me as when my husband left me You feel you are not useful for anything anymore; this is harder than the disease [cancer] itself.” (Participant 18)

“He [my husband] wanted kids and said how long will you keep me with a son; we only have one daughter so he got engaged, and I said I don’t have a problem” (Participant 8)

Some participants described their children being taken away from them while they were undergoing treatment with men having rights of the children over the mother should they separate. One participant said:

“I have three children. In the beginning, my sister took care of my son who was 7 months old and the other children were taken care of by my parents. Then the community started saying my husband needs to marry again and have another wife to take care of the children. He did this and took the children, so they are far away from me now.” (Participant 4)

6.1. Religion and family as a source of comfort

Participants described their faith in God and their children as sources of comfort and to support coping. This kept them going through treatment and after the diagnosis. A participant noted:

“Thank God, I am accepting God’s decision. At the beginning I was devastated and afraid for my children, then I told myself I am one of many other patients.” (Participant 5)

“Of course, my husband and my children all supported me and lifted my moral spirit. I told them I count on God’s will and I will accept anything God’s plan decides for me. So I was always in positive attitude till now thank God.” (Participant 11)

“My daughter insisted that I travel for my treatment and she said she will be fine. The doctor told me that it would be better to miss my

daughter for a year than to lose her forever. My husband also encouraged me to continue my treatment.” (Participant 12)

A participant also highlighted the importance of patient-to-patient peer support and described that a small group of female breast cancer patients was established informally when she was in Turkey. They supported each other when they were alone and attended chemotherapy sessions together. She noted:

“In Turkey, I was living with other patients at the same guesthouse with other patients with breast cancer. We lived together and continued in the same place altogether for over a year. We became sisters. We ... shared our experiences which helped me a lot.” (Participant 15)

7. Discussion

Exploring the perspectives of women with breast cancer in northwest Syria about their experiences of accessing care is essential to understanding the challenges which they face. This is important as their voices are often missing from health services planning which directly affect them. From their words, we note several challenges which include the availability of diagnostics and management for breast cancer in northern Syria, logistic and bureaucratic challenges as well as societal challenges which women, diagnosed with breast cancer face. The participants highlighted different factors which were sources of support to them during this time; such factors or initiatives are essential to capitalise on whether organically e.g. support groups with other women with breast cancer or more formally through provisions from civil society organisations. These sources of support can be capitalised on, whether formally through healthcare providers or organisations or informally through providing spaces where they can come together to discuss and share their experiences.

90% of the population across Syria live in poverty and with inadequate shelter, leaving very little for out of pocket expenditures on health (OCHA, 2022). All participants highlighted that the costs associated with additional investigations, transportation or travel whether within northwest Syria (for example from parts of northern Aleppo governorate) to the centre in Idlib city or to Turkey were high and this placed additional strains on them and their families. This is seen in other contexts where the economic burden of cancer can result in increased out of pocket expenditure (for both medical and non-medical needs), loss of income and lost productivity (Alzehr et al., 2022; Wilkes et al., 1994).

Though some participants commented about support which some civil society organisations provided with transport, most women volunteered that the impact of their diagnosis would have been lessened if oncology centres and treatments (especially radiotherapy which is unavailable in northwest Syria) could be provided locally. This would remove the need to travel to Turkey (Sahloul et al., 2017). The latter is more pertinent in the wake of the earthquakes, given the impact on south eastern Turkey, no patients from northwest Syria could enter even for oncology care (Aljazeera, 2023). Beyond this, stock-outs of chemotherapy medications were often reported, something which could relate to the almost sole reliance on cross-border aid through one border crossing from Turkey to Syria and lengthy supply chain processes. (ARAB NEWS, 2023)

As in other settings, women stressed the importance of family and community support as vital towards their wellbeing while undertaking treatment. In some instances, family members or the wider community supported costs for transport and living costs in Turkey while patients undertook treatment. A United States based qualitative study with survivors of breast cancer also found that that emotional and social support provided for these women from their families, health providers and spiritual leaders plays an important role in their continuation of treatment (Toledo et al., 2020). However, the financial costs of supporting the treatment for one family member could jeopardise the survival of

others by draining their resources. In our study one participant mentioned her family needed to sell equipment essential for everyday life and appropriate nutrition for her children so she can pay for her travel to Turkey. This is similar to the case of many low-resource settings where family is the only insurance or welfare available. A Pakistan based study found that health expenditures are borne by the family which can be an essential factor in decision making; they note that the concept of the financial survival of the family is a harsh reality (Aslam et al., 2005). Having children was noted as something which gave participants a determination to continue treatment despite hardships. This has also been described in a European setting where breast cancer patients with dependent children described how the need to support their children in everyday life became very important for them during the treatment and gave them a positive perspective and attitude towards ongoing treatments (Billhult and Segesten, 2003).

Important factors were noted around interactions with healthcare staff, how news about the diagnosis was broached and how explanations were given. Traditionally, Syrian medical culture is paternalistic with healthcare providers avoiding telling patients a serious diagnosis as a means of protecting them; as such, they may tell family members first. This was challenged by some of the participants in the study who wanted to know the outcomes of tests and to have them described in ways they could understand. Despite the strength shown by many of the participants who were interviewed, attitudes from family members and healthcare workers emphasised their fragility rather than their strengths. Disclosures around breast cancer show cultural differences with western medical practice favouring full disclosure to the patient while Korean, Japanese, and Native American cultures may find that revealing the full diagnosis to patients directly is inappropriate and it is not practised (Mitchell, 1998). The way information is communicated is key with a systematic review by Van der Valken et al. noting that communicating positively and collaboratively improved feelings of hope and trust in recovery among patients and enhanced their understanding (van der Valken et al., 2020).

Some women faced significant social and protection challenges in relation to their diagnosis including abandonment or the removal of their children, causing further distress. Even if her husband did not favour this, societal pressures often forced this issue, especially against women of reproductive age. A systematic review by McCutchan's et al. found that cancer is perceived as a source of shame and stigma in many Asian and African countries and that the fear of social rejection could negatively affect the health-seeking behaviour among patients (McCutchan et al., 2021). Abandonment after a breast cancer diagnosis has also been described in Kenya where women faced stigma from the community and from relatives (Sherman and Okungu, 2018). There are also community assumptions that women may not be able to fulfil their reproductive or marital roles, pushing the community or close family to push the husband towards divorce or to marry another woman. Though chemotherapy may have a negative effect on fertility, pregnancy may not be detrimental after successful treatment of breast cancer (Meirow and Nugent, 2001). As such, staff must prioritise fertility discussions with both the patient and her husband soon after diagnosis and before chemotherapy (McCray et al., 2016).

7.1. Future considerations

Based on the participants' perspectives and the challenges they report, there remains an urgent need for dedicated funding for patients with breast cancer. We propose the main ways in which women with breast cancer can be supported in NWS. This includes localisation of cancer services across NWS in locations which are equitable and accessible to the population. This would improve the prognosis by cutting on delays in treatment, improved community support, and at the same time would reduce the cost currently paid to other health system in the neighboring countries. Though there are currently oncology services in NWS, they are insufficient to meet the needs of the whole population,

certain chemotherapeutics are not consistently available and radiotherapy facilities are not available in the area. Given the high-cost nature of these services compared to both the other needs in the area and compared to other lifesaving services, it has been challenging for local humanitarian organisations to channel funds for such services. However, SAMS and other organisations are using private funds to strengthen services in the area; however, this may present ethical tensions should funding cease as noted by Marzouk et al. in her study of cancer care among refugees in Jordan (Marzouk et al., 2019).

The other main way in which our research can support improved practice involves low cost or no-cost interventions. These relate to communication by healthcare providers, the provision of easy to understand information in different formats e.g. Arabic language leaflets or videos and the provision of opportunities to ask questions with answers appropriate to the level of enquiry and understanding of the participants. Many women reported that they obtained information from other women with breast cancer or from social media - as such, medical organisations should aim to make such information available in different formats appropriate to the setting, including for women who cannot read (Atassi et al., 2022). The holistic needs of patients must also be considered; this includes needs around transport or accommodation (Sahloul et al., 2017).

From this research, the need to strengthen formal or informal social support systems (something which has been fragmented by the conflict (Koç and Saraç, 2020)) as participants found this to be a source of strength. This may be something which local organisations can do through the provision of space whether in person or virtual (the latter for whom who are able to) to share their feelings and experiences. This is something which is provided in other countries by dedicated breast cancer charities.

7.2. Strengths and limitations

To our knowledge, this is the first qualitative study exploring this topic conducted in Syria and provides valuable insights as to the health and non-health related experiences of women with breast cancer in an area of active conflict. The interviews were conducted by female interviewers, three of whom lived in the local areas in local dialects of Arabic, allowing for better rapport with the participants and strengthened the ability of this research to capture locally relevant social and cultural factors which may not otherwise have been elucidated. Despite strengths, there are limitations. First, there may be a potential sampling bias as we could not reach breast cancer patients who did not have a registered phone number or WhatsApp, who may be more vulnerable and have less access to services than those with mobile phones. Second, interviews were conducted remotely to avoid the interviewers travelling to mitigate associated risks in an area of active conflict. Though this improved access, it limited the observation and multi-faceted and nuanced understanding of the interviewees' words. However, the three main interviewers were female, from the local area and were immersed in the setting; this supported cultural understanding and building trust with the patients as they could relate and understand their background. The context in north west Syria is unique in some aspects even when compared to other parts of Syria; for example, it has been among the most affected areas by the ongoing conflict with limited travel possible both within and outside of the area. This can make some themes around access to care hard to extrapolate to other parts of Syria. However, for the themes which focus on interactions with healthcare workers and the role of community and society, there are aspects which are relevant to other parts of Syria. Finally, although we did not include direct questions in the interviews about COVID-19 and its effect on patients' access to oncology services, women reported some challenges in use and access during the pandemic.

8. Conclusions

This research suggests that current access to services for women with breast cancer in northwest Syria do not meet their needs and this is likely to have worsened since the February 2023 earthquakes.

We note that despite the many challenges which the women faced, there were factors which could provide comfort or support and these could be enhanced to better support them through their treatment journey. Funding for cancer care in conflict remains challenging as it is comparatively high cost compared to other interventions in humanitarian settings. However, particularly in protracted crises, there needs to be appropriate programming and access to services; these may include screening to support early diagnosis and treatment and to minimise costs of delayed diagnoses. Overall, localisation of cancer services in northwest Syria could ameliorate some of the challenges which women with breast cancer face; this requires dedicated funding streams and prioritisation.

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Ethical approvals

Ethics: This study was approved by the Human Investigations Committee at Yale University. Informed consent was obtained for all participants and they could withdraw at any time until analysis was commenced. We had a named mental health professional who the participants could reach out to if they needed to. The interviewer would terminate the interview if any signs of distress were shown by the participants.

CRedit authorship contribution statement

Manar Marzouk: Conceptualization, Formal analysis, Investigation, Methodology, Supervision, Writing – original draft, Writing – review & editing. **Mohamed Hamze:** Data curation, Supervision, Writing – review & editing. **Jamil Debel:** Supervision. **Alaa Alshemali:** Data curation, Writing – review & editing. **Boushra Alhussein Alameen:** Data curation, Writing – review & editing. **Mariam Bakkour:** Data curation, Writing – review & editing. **Bayan Galal:** Data curation. **Anees B. Chagpar:** Supervision. **Bassel Atassi:** Supervision. **Kaveh Khoshnood:** Supervision. **Aula Abbara:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Visualization, Writing – review & editing.

Declaration of competing interest

The authors have declared that no competing interests exist.

Data availability

The data that has been used is confidential.

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