

Beyond Remission: An IN-Depth Exploration of Recovery Needs, Gaps, and Obstacles Faced by Working-Age Breast Cancer Survivors – A qualitative study.

Master thesis

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ONDERGETEKENDE

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Abstract

Background: Breast cancer (BC) is the most prevalent cancer in women worldwide, with approximately 1 in 7 women receiving a diagnosis during their lifetime. The survival rate of BC has increased from 47,600 to 75,000 in the Netherlands over the past two decades, due to advancements in treatment and early detection. As survivors navigate life with or beyond cancer, uncertainties and obstacles often arise, highlighting the importance of care for optimal recovery. Recovery care should ensure customisations to survivors' specific needs and obstacles. Unfortunately, many survivors experience gaps in current care, leading to a challenging transition from patient to living beyond cancer. Especially survivors of working age experience difficulties reintegrating into society after BC. To optimise recovery care, it is essential to properly identify the experienced recovery needs, gaps, and obstacles of working-age BC survivors.

Aim: This study focuses on exploring the needs, gaps, and obstacles during recovery, which working-age BC survivors in remission, in the Netherlands experience.

Methods: This study employed an exploratory qualitative design. Twelve female Dutch BC survivors participated in online semi-structured, in-depth interviews, which were recorded, transcribed verbatim, and thematically analysed.

Results: The analysis resulted in four themes of experienced needs, three themes of experienced gaps, and six themes of experienced obstacles. The needs are integrated care, psychological care, information provision, and coping guidance. The gaps are follow-up care, guidance during the transition period post-treatment, and obtaining information. The obstacles are long-term effects, coordination of healthcare, finances, participation in society, personal matters, and time factors.

Conclusions: The participants felt that the currently available recovery care in the Netherlands was insufficient. BC survivors expressed unmet needs and experience a sense of being lost in transition post-treatment. Encountered obstacles hinder their recovery and societal reintegration.

Recommendations: It is recommended that healthcare professionals should take a holistic approach, considering long-term effects and the work-home environments of survivors, to provide personalised care and information access. Future studies should focus on improving recovery care to address the experienced needs, gaps, and obstacles effectively.

Keywords: Breast cancer survivors; needs; unmet needs; obstacles; recovery care.

Samenvatting

Achtergrond: Wereldwijd is borstkanker (BC) de meest voorkomende kanker bij vrouwen, waarbij ongeveer 1 op de 7 vrouwen tijdens haar leven gediagnosticeerd wordt. Het aantal patiënten dat borstkanker overleeft (ex-borstkankerpatiënten) is dankzij ontwikkelingen in behandelingen en diagnostisering bijna verdubbeld in de afgelopen twee decennia, van 47.600 naar 75.000. Veel ex-borstkankerpatiënten ervaren onzekerheden en obstakels, wanneer de kankerbehandelingen stoppen. Dit benadrukt hoe belangrijk herstelondersteuning is om te kunnen herstellen. Helaas ervaren veel ex-borstkankerpatiënten dat de huidige zorg niet voldoet aan hun behoeften, waardoor ze tussen wal en schip raken tijdens hun transitie van patiënt naar gezonde burger. Vooral ex-borstkankerpatiënten die zich binnen de werkende leeftijd bevinden ervaren problemen bij re-integratie in de samenleving. Het is noodzakelijk om de behoeften, hiaten en obstructies met betrekking tot herstel van deze doelgroep te identificeren, zodat de herstelzorg geoptimaliseerd kan worden.

Doel: Het doel van dit onderzoek is om de behoeften, hiaten en obstructies te identificeren die zich voordoen tijdens het herstelproces van borstkankerpatiënten in remissie, die zich in de werkende leeftijd bevinden.

Methode: Het onderzoek had een exploratief kwalitatief studiedesign. Bij twaalf vrouwelijke ex-borstkankerpatiënten zijn online semigestructureerde interviews afgenomen. De interviews zijn opgenomen, letterlijk getranscribeerd en thematisch geanalyseerd.

Resultaten: De analyse resulteerde in vier thema's van ervaren behoeften, drie van ervaren hiaten en zes van ervaren obstakels. De behoeften zijn geïntegreerde zorg, mentale ondersteuning, informatieverstrekking en begeleiding gericht op omgaan met kanker. De hiaten zijn nazorg, informatieverkriging en de transitie periode wanneer de behandelingen zijn afgerond. De obstructies zijn langetermijneffecten, coördinatie van zorg, financiën, de maatschappij, persoonlijke omstandigheden en tijd.

Conclusie: Participanten vonden de beschikbare herstelondersteuning in Nederland ontoereikend. Ex-borstkankerpatiënten ervaren onvervulde behoeften en worstelen met de transitie periode na behandelingen. Obstructies belemmeren hun herstel en re-integratie in de samenleving.

Aanbevelingen: Zorgverleners moeten een holistische benadering hanteren, rekening houdend met langetermijneffecten, werk- en thuissituaties van ex-borstkankerpatiënten, om gepersonaliseerde zorg en toegang tot benodigde informatie te bieden. Toekomstige studies moeten gericht zijn op

het verbeteren van herstelzorg om de behoeften, hiaten en obstructies effectief aan te pakken.

Trefwoorden: Ex-borstkankerpatiënten; behoeften; hiaten; obstructies; herstelzorg.

Introduction

Breast cancer (BC) is the most prevalent cancer in women worldwide, with approximately 1 in 7 Dutch women being diagnosed during their lifetime, resulting in 18 000 diagnoses annually. However, BC rarely occurs in men (less than 1% of all cases)^{1–5}. Early detection and treatment advancements have led to a significant increase in Dutch BC survivors who are still alive 5 years after diagnosis, from 47 600 in 2000 to 75 000 in 2021^{6–9}.

The risk of cancer tends to increase with age. According to statistics, 65% of diagnoses are made before the age of 70, and 80% after the age of 50, indicating that BC is common in working-age women^{4,6,10}.

As survivors transition to living with or beyond cancer, they often experience uncertainties and obstacles^{11–16}. Many BC survivors face long-term effects, affecting their daily life. Different cancer treatments and types of tumours can cause different long-term effects. Common physical effects include fatigue, pain, lymphedema, neuropathy, and menopausal symptoms. Common psychosocial effects include anxiety, feelings of uselessness, loneliness, lack of social support, and decreased self-confidence. Cognitive difficulties mainly consist of problems with multitasking, thinking, remembering, and planning^{8,17–23}.

Due to obstacles related to diminished quality of life, limited social participation as well as the long-term effects of cancer and its treatment, recovery care is an important component of treatment for women with BC^{24,25}. Van der Stel has defined recovery as “Clinical, personal, social, and functional recovery (fulfilling roles in daily life)”²⁶. To achieve this, recovery care should incorporate a holistic perspective, ensuring customisation to concerns and needs of survivors^{27–31}.

BC survivors have various needs. A systematic review indicated that emotional/psychological, informational/health system, physical, and interpersonal/intimacy needs are frequently identified areas requiring support for BC survivors³². These needs persist due to factors such as untreated long-term effects and low satisfaction with currently available care, and can differ based on ethnicity, and age^{32–37}.

Despite multiple studies on survivorship, recovery care is often absent or not systematically provided for BC survivors³⁸. This is caused by several factors. For example, tools aimed at improving recovery have not been scientifically validated for their efficiency^{39–41}. Furthermore, the clinicians' role in cancer recovery care is often poorly defined, leading to a lack of awareness regarding the needs

of BC survivors, suboptimal communication between healthcare professionals and survivors, and an overall deficiency in quality care⁴². Additionally, the potential of peer support clinics to provide effective mental support remains underutilised, because of healthcare professionals' lack of awareness and failure to refer patients⁴³⁻⁴⁵. Lastly, traditional follow-up and surveillance care tends to overlook psychosocial concerns, risking the failure to meet key supportive needs of cancer survivors⁴⁶.

Insufficient recovery care leads to a gap between current care and survivors' needs, impacting clinical, personal, social, and functional recovery^{25,26,47-52}. This can lead to many survivors becoming lost in the transition from patient to living with or beyond cancer^{39,41,47,49,53}.

Especially, survivors of working age experience obstacles with reintegrating into society. Younger women reported age-specific issues related to fertility and early menopause, as well as increasing distress with their body image, relationships, sexual problems, childcare, and career management^{39,41,47,49,53-58}. These adverse effects negatively impact work capacity, productivity, finances, early retirement, and the reliance on assistance for domestic chores, causing significant personal, economic, and societal consequences. Improving recovery care, to promote the well-being and reintegration in society of this population, yields positive individual and societal outcomes⁵⁹⁻⁶¹.

Therefore, to improve recovery care in the Netherlands, it is essential to identify specific needs, gaps, and obstacles faced by working-age BC survivors in remission. Improving the quality of recovery care enhances the overall recovery for this population^{26,39,55,62-64}.

Aim

This study focuses on exploring the needs, gaps, and obstacles during recovery, which working-age BC survivors in remission, in the Netherlands experience.

Method

Study design

This study employed an exploratory qualitative design, using a thematic analysis⁶⁵. Data were collected through semi-structured, in-depth interviews^{66,67}. The consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for conducting qualitative research were followed (Appendix A)⁶⁸.

This study is preliminary to a large-scale qualitative cross-sectional Seed Money Project of the Hogeschool Utrecht (HU). This HU project aims to investigate needs, gaps, and obstacles experienced during recovery, and how recovery care supports participation in society after experiencing a medical episode. Explanations of the definitions 'needs', 'gaps', and 'obstacles' are provided in Table 1.

Table 1: Definitions

Needs	The required care or support of participants to achieve clinical (both physical and mental), social, and personal recovery ²⁶ .
Gaps	The differences between currently available care and needed care. This mainly revolves around additional components within the existing healthcare.
Obstacles	The barriers participants encounter whilst transitioning to the final stages of recovery, (living with the condition and living beyond the condition), according to Spaniol et al ⁶⁹ .

Population & domain

BC survivors were eligible for inclusion if they were adults of working age (≥ 18 and < 67 years old), living in the Netherlands, and currently in remission (no evidence of cancer)⁷⁰. Excluded were BC survivors who are presently diagnosed with cancer in other body parts, and BC survivors who are not able to speak Dutch, as there may be a language barrier. Concurrent chronic diseases with cancer were not excluded due to the complexity of attributing these diseases to either BC (treatment) or other factors⁷¹.

Consecutive sampling was used to recruit participants via social media and the researchers' network. The recruitment message was also sent to all Dutch peer support clinics, but less than 10% shared it. Associations related to BC expressed unwillingness to participate due to the high demand for research collaboration or the study's master thesis nature. Therefore, celebrities with BC were also requested to share the recruitment message via social media. Potential participants registered voluntarily via email, after which they received an information letter, following an appointment for the interview. The extent of non-response is unclear, due to the sampling method.

Literature suggests that data saturation mostly occurs after approximately twelve interviews, making it the minimum requirement of this study^{37,72,73}. Additional interviews were conducted if data saturation was not achieved. Eventually, a total of twelve BC survivors participated in the study. Four participants found the recruitment message through a peer support clinic, five through social media, and three through referrals of the researchers' network.

Data collection

Prior to the semi-structured interviews, an interview guide was created based on a topic list derived from a comprehensive literature scan incorporating theories and models corresponding to (BC) recovery^{25–31,39,43–45,47–52,55,62–64}. The topic list (Appendix B and Appendix C) encompassed three main themes: experiences regarding personal recovery, experiences regarding recovery care, and recovery (care) needs, gaps, and obstacles. To collect rich data, probing, prompting, and summarising techniques were employed^{67,74,75}. The interview guide (Appendix D) was assessed for feasibility using a pilot interview^{68,76}. All data were collected by the principal investigator (PI), who undertook courses related to qualitative research and performing interviews prior to conducting the interviews. Data collection was performed between March 28th and April 14th, 2023. Participants were interviewed and recorded online in Dutch using MS Teams by the PI. Microsoft Teams live transcription was used for verbatim transcribing^{77,78}. The duration of the interviews ranged from 38 to 107 minutes (median 44 minutes). No follow-up interviews were conducted. Prior to each interview, the PI explained the study's purpose and asked for permission to record the interview. Transcripts were checked for errors and were returned to the participants for comment and correction (member checking), before the data was analysed.

Data analysis

Data were thematically analysed in Atlas.ti (version 23.1.0)⁷⁹, using an inductive coding approach according to the 6 stages described by Braun and Clark (Appendix E)^{66,80}. Initial coding was performed by the PI, after which themes were generated. This process was refined through external discussions [WB]. Generated codes and themes were discussed with peers [GV,MR], and the supervisor [LH]. Interviews were conducted and analysed in an iterative process by the PI until data analysis showed the same themes, with no new findings, and data saturation was obtained. During data analyses, new codes were formulated and tested in subsequent interviews⁶⁶. Memos were written during data collection and analysis. Ultimately, the selected Dutch quotes were translated into English.

Ethical considerations

This study adhered to the ethical principles for medical research involving human subjects described by the World Medical Association (WMA) Declaration of Helsinki (version 64th, October 2013)⁸¹, and followed the General Data Protection Regulation (EU GDPR)⁸². This study is approved by the research ethics committee (ECO) of the HU (reference number 239-001-2023)⁸³. Participants signed informed consent and were informed they could withdraw from the study at any time. No prior relationship existed between participants and the PI. Identifying information was removed from all data before analysis. The recorded interviews were discarded after finishing the study. The transcripts were dated, labelled, and stored confidentially and anonymously in Research Drive for 10 years, accessible only to involved HU project researchers.

Trustworthiness

The trustworthiness of this study was enhanced using several techniques^{84,85}. Member checking was employed for enhancing credibility, to ensure the accuracy of the transcripts and the alignment with participants perspectives. To ensure confirmability, an audit trail was created and stored in Research Drive, by documenting research decisions and processes. To ensure dependability, the analysis process and study findings were evaluated externally [WB], securing accurate interpretation of the data. The researcher enhanced transferability by providing thick descriptions of the participants and associated patterns, accompanied by quotes, to facilitate a comprehensive understanding of the connected context and to illustrate key findings. Peer debriefing was applied during data analysis to improve both credibility and confirmability, confirming truthful interpretation and minimise bias.

Results

Characteristics

Participant characteristics are presented in Table 2. All participants were women living in diverse regions of the Netherlands, with various types of BC and treatments. The mean age of the participants was 55 ± 5 years. The mean age at BC diagnosis was 44 ± 9 years.

Table 2: Demographic data of the participants

P	Gender	Age (years)	Age at diagnosis (years)	Type of breast cancer	Type of treatment	Region	Employment status
1	F	51	31	Hormone-sensitive, Unknown	Amputation, ALND, chemotherapy, radiation therapy, reconstruction, hormone therapy	Noord-Holland	Employed
2	F	60	51	Hormone-sensitive, DCIS	Amputation, ALND, reconstruction, hormone therapy	Zuid-Holland	Charity work
3	F	64	49	Unknown	Amputation, chemotherapy, reconstruction	Zeeland	Charity work
4	F	51	48	HER2-positive	Chemotherapy, lumpectomy ALND, radiation therapy, immunotherapy	Noord-Brabant	Unemployed
5	F	59	27 34 56	Unknown Recurrence HER2-positive	Lumpectomy, ALND, radiation therapy Surgery Surgery, ALND, chemotherapy, radiation therapy, immunotherapy	Noord-Holland	Unemployed (gradually resumption)
6	F	57	40	Hormone-sensitive, Unknown	Chemotherapy, Amputation ALND, reconstruction	Gelderland	Employed
7	F	50	43	Unknown	Amputation, chemotherapy, hormone therapy, reconstruction	Utrecht	Employed
8	F	59	52	Hormone-sensitive, Unknown	Lumpectomy, radiation therapy, chemotherapy, hormone therapy	Utrecht	Employed
9	F	43	37	Triple negative	Chemotherapy, surgery, radiation therapy	Noord-Brabant	Unemployed (rehabilitation program)
10	F	51	42	Triple negative	ALND, chemotherapy, lumpectomy, radiation therapy	Noord-Brabant	Employed
11	F	57	55	Unknown BRCA gene	Surgery, chemotherapy, radiation therapy	Gelderland	Employed
12 (pilot)	F	63	51	DCIS 1	Lumpectomy, amputation, reconstruction	Noord-Holland	Employed

ALND = Axillary Lymph Node Dissection; BRCA = BReast CAncer gene;
DCIS = Ductal Carcinoma In Situ; F = female;
HER = Human Epidermal growth factor Receptor; P = Participant.

Themes

The results are presented into the three main categories aligned with the research aim: Needs, Gaps, and Obstacles. Initial patterns emerged after coding four transcripts, and data saturation was achieved after analysing six transcripts. A total of twelve transcripts were analysed to confirm saturation. The themes are shown in Figure 1.

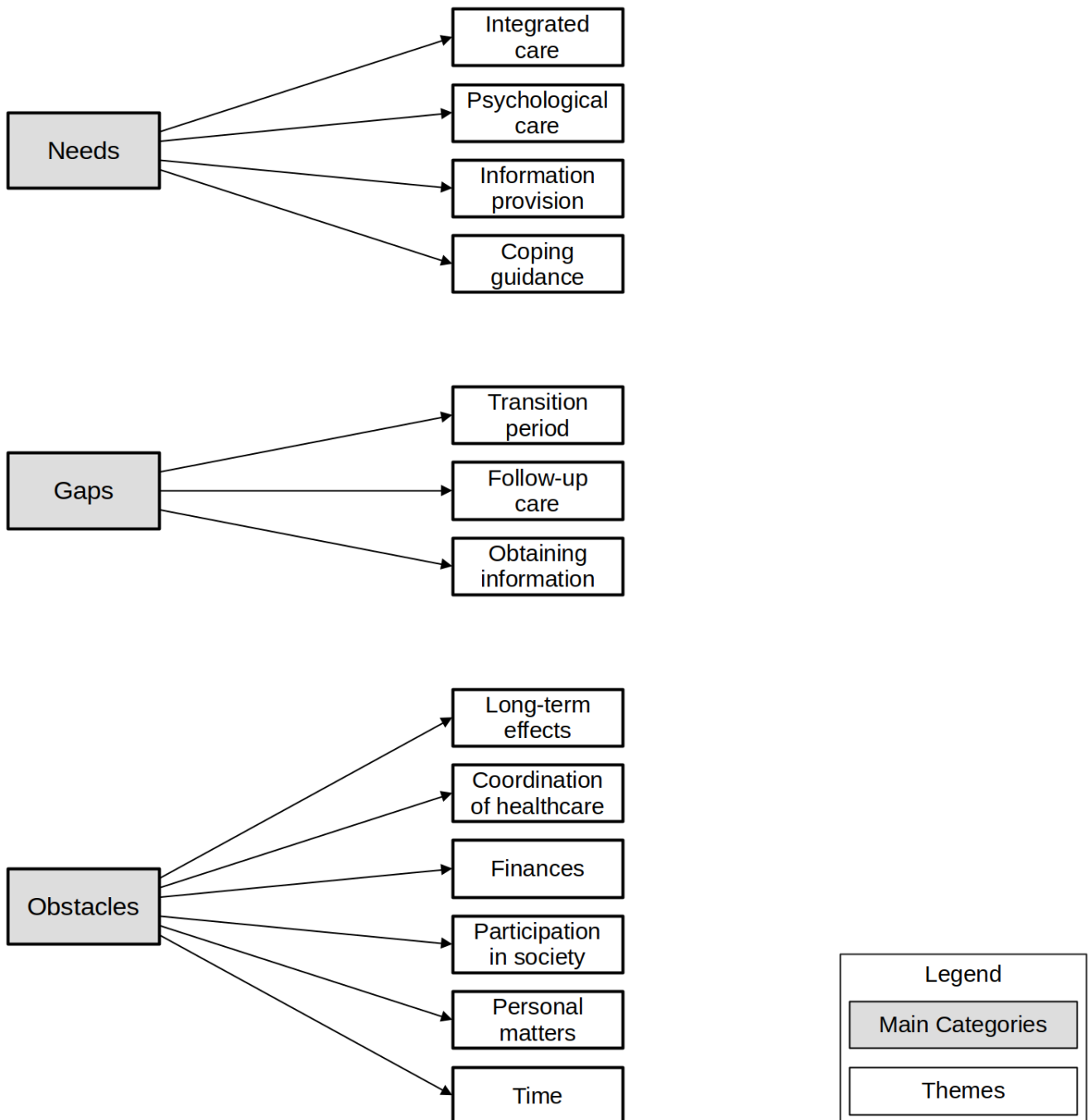


Figure 1: Thematic map

Needs

The themes and codes related to experienced needs are shown in Table 3.

Table 3: Themes and codes found for experienced needs

Themes	Codes
Integrated care	<ul style="list-style-type: none"> • Receiving a referral to a healthcare professional • Asking questions beyond one's own expertise • Customised therapy • Improved communication between professionals • Decision-making by breast cancer patients • More attention to the long-term effects • Follow-up appointments • Taking concerns seriously • Timely support
Psychological care	<ul style="list-style-type: none"> • Psychological support • Long-term goal • Talking about cancer • Social interaction with fellow cancer survivors • Increased need for attention • Requirement for affirmation
Information provision	<ul style="list-style-type: none"> • Recovery care • Long-term effects of cancer and its treatments • Financials
Coping guidance	<ul style="list-style-type: none"> • Tools/guidelines for coping and healing • Coaching or social work services • Guidance during reintegration

Integrated care

Almost all participants expressed needs regarding the provision of integrated (seamless, effective, and efficient) care. They emphasised the importance of receiving a referral to healthcare professionals or organisations (Q1). Additionally, several participants expressed the need for healthcare professionals to inquire about complaints outside their own expertise, a so-called holistic approach, so that customised therapy can be provided. They also emphasised the importance of improved communication and collaboration among healthcare professionals.

Furthermore, the importance of information on various treatment options and decision-making by BC patients was highlighted, as these treatment options can affect their future. Some participants recommended follow-up appointments so that professionals could ask them if there are ongoing issues, if they need additional care, and to schedule check-ups.

Multiple participants felt the need for more attention to long-term effects, since the knowledge and attention of healthcare professionals seemed insufficient. Many also expressed that healthcare professionals should take their concerns seriously (Q2) and provide timely support.

Textbox 1: Integrated care

- Q1: “But then it’s also good that they refer patients there, where patients can be helped. I found it myself by searching on Google, but it’s just nice if a healthcare professional also provides that information themselves, you know.” (P4)
- Q2: “So, they think something like, oh, it’s been on television again [. . .] And she says, people have all these questions again, and we notice that it gets busier. So, in that sense, it’s not taken seriously, which I find difficult.” (P2)

*“Q”: quotation, “P”: participant.

Psychological care

Many participants expressed needs related to psychological recovery care. Several of them reported a strong desire for psychological support (Q3), to achieve their long-term goals (Q4). Additionally, they felt the need to talk with others about their experiences and feelings, for example, through social interaction with fellow BC survivors. Participants also mentioned an increased need for attention from loved ones and healthcare professionals. Requirement for affirmation regarding unnecessary anxiety was also emphasised.

Textbox 2: Psychological care

- Q3: “They really need to dig into it, really dig into it. Into what it’s like after cancer, after such a serious disease, after all the treatments, after getting close to death. Because that’s what you do, even if you survive it. They really need to know how that affects someone [. . .] We also all know that it’s serious and that it’s horrible. But how to deal with it? How can you really process that real fear, that real trauma, how can you actually process that?” (P5)
- Q4: “I also need to make adjustments, because my recovery used to be about being less tired, no longer being sick, and becoming my old self again. But I believe that now, I’m slowly starting to make adjustments for myself. I also realise that the recovery process is different for everyone. If things go well, then everything is fine. However, if you have long-term issues that hinder your day-to-day life, it’s essential to learn how to deal with them and to accept things as they are, you see, and that you can adjust to your situation as it is.” (P9)

Information provision

Many participants expressed a need for information provision, particularly regarding the availability of recovery care (Q5). Participants also value information concerning long-term effects of cancer and its treatment. Lastly, it was mentioned that there is a need for information on finances such as sick leave, work, and (childcare) allowances.

Textbox 3: Information provision

- Q5: “If you’re hesitant to voice your concerns about issues, then I believe that there must be someone who provides access to such information. Without someone bringing it up, you may not be aware that the information is available, because, indeed, if no one tells you, you’ll never know. Having access to that information allows you to ask questions about it.”
(P1)

Coping guidance

Several participants expressed their need for tools/guidelines on how to cope and move forward post-treatment (Q6). Additionally, some participants mentioned that coaching or social work services can contribute to this. The need for additional guidance was specifically mentioned regarding the topic of reintegration (Q7).

Textbox 4: Coping guidance

- Q6: “But really, try to create something like a coherent structure of what can be done and what the possibilities are, as a form of care, a toolkit.” (P5)
- Q7: “A little more guidance, yes, from the moment you are finished with your treatment. I eventually had that later, because now they are still monitoring me, which is really nice. And it really makes a difference there. But I think that if you prioritise this aspect, starting from the treatments, and also pay more attention to people’s home situations, it would be helpful. Because some find it difficult to express everything, while others are more open.”
(P9)

Gaps

The themes and codes related to experienced gaps are shown in Table 4.

Table 4: Themes and codes found for experienced gaps

Themes	Codes
Transition period	<ul style="list-style-type: none"> • Falling into a 'black hole' • Mental processing begins after completion of treatments • Little understanding from society • Life continues • People assume that you are cured/healthy again • Difficulty with moving on from cancer • Reinventing the wheel • Discontinuation of care
Follow-up care	<ul style="list-style-type: none"> • Insufficient guidance/support • Limited recovery care in hospitals • Initiating recovery care • Limited recovery care in hospitals • Healthcare professionals have limited understanding of breast cancer survivors • No information provided regarding the necessity of check-ups
Obtaining information	<ul style="list-style-type: none"> • Self-research is required • Inadequacy in information provision regarding treatment consequences/long-term effects • Having unanswered questions

Transition period

Most participants in this study described experiencing a profound void or falling into 'black hole' post-treatment (Q8). Mental processing begins at this phase. The lack of understanding, support, and guidance from society could make it even more challenging for them (Q9). Life continued, and others assumed that the BC survivors were cured/healthy again. Many participants found it difficult to move forward after BC. They described this period as having to reinvent the wheel (Q10), a process they must undertake independently, without continuation of care.

Textbox 5: Transition period

- Q8: “Yes, actually, when I had the last chemotherapy, I found it a bit scary. I almost thought: ‘Oh, I’ll just do another cycle because as long as I have chemotherapy [. . .] nothing will happen anyway.’ It was kind of like, how my husband described it, he said: ‘It’s like you’ve always had floaties, and now you have to swim without them.’ So it kind of felt that way.” (P7)
- Q9: “I think that highlights the black hole the most. It may sound selfish, but you actually need a little extra attention [. . .] You notice that everyone else is busy, and their lives move forward, but yours isn’t for a while. And then you could really use a little extra support, that would make such a big difference if some people in your social circle would take notice.” (P4)
- Q10: “After that, it feels like you’re facing a lot of challenges, and you can easily fall into a black hole. You have to rediscover yourself, not just your identity, but also how you fit into your work, social environment, everything.” (P9)

Follow-up care

Several participants highlighted gaps in their follow-up care, reporting insufficient guidance/support and limited availability of recovery resources from the hospital (Q11). Consequently, they attempted to initiate recovery care themselves (Q12). It was mentioned that healthcare professionals have limited knowledge of BC survivors. It was also reported that no information was provided regarding the necessity of check-ups, resulting in falling off the healthcare professionals’ radar.

Textbox 6: Follow-up care

- Q11: “People experience a gap where something essential is missing. There is missing something, some recovery care, I strongly believe that.” (P2)
- Q12: “And then I thought, well actually, there where I experienced a gap between treatments and the mental aspect myself, I realised that I could potentially fill that gap. That’s why I decided to enrol on a coaching skills course.” (P10)

Obtaining information

Many participants reported that receiving recovery care required them to proactively self-search for available resources to access care (Q13-14). Accessing or acquiring adequate information regarding treatment consequences is difficult, causing participants to remain with unanswered questions. If

they had been aware of potential consequences earlier, they could have conducted a more targeted search for solutions or reconsidered certain therapies.

Textbox 7: Obtaining information

- Q13: “Is there a platform for recovery care where you can go to, because I haven’t found one yet”. (P5)
- Q14: “Luckily, I discovered the OncoReflex treatment on my own, even though my oncologist was not aware of the existence of OncoReflex as a treatment option for people experiencing neuropathy after chemotherapy.” (P11)

Obstacles

The themes and codes related to experienced obstacles are shown in Table 5.

Table 5: Themes and codes found for experienced obstacles

Themes	Codes
Long-term effects	<ul style="list-style-type: none"> • Physical effects • Cognitive effects • Psychosocial effects
Coordination of healthcare	<ul style="list-style-type: none"> • Healthcare professionals limit focus to own expertise • Failure to listen or refer to patient needs • Incomprehension of treatment decisions • Discharge from hospital • Recovery care reliant on region or hospital • Receiving psychological support too early in the recovery process • Premature information provision • Information overload
Finances	<ul style="list-style-type: none"> • Limited financial resources for healthcare • Limited availability of treatments • Financial stress • Ineligibility for subsidies and benefits
Participation in society	<ul style="list-style-type: none"> • Lack of support from social agencies • Being forced to resume life quickly • Difficulty with reintegration • Misunderstanding from work/employers
Personal matters	<ul style="list-style-type: none"> • Emotional/Anger towards healthcare providers • Busy family life • Limited social network • Lack of support from others • Difficulty connecting with fellow cancer survivors • Feeling burdened by healthcare needs • Difficulty articulating past issues
Time	<ul style="list-style-type: none"> • Recovery requires time • Limited time available in healthcare • Waiting for recovery care

Long-term effects

All BC survivors experience long-term health effects, which impact their daily life and hinders their recovery. They mentioned physical effects that hinder daily activities, such as work, domestic tasks, and hobbies, as well as cognitive effects, like chemo brain (reduced concentration, memory, and energy) also affecting their daily functioning. Additionally, participants mentioned psychosocial effects,

including anxiety and decreased body confidence, which made living beyond cancer difficult (Q15-16). Many participants find it necessary to adapt to their long-term effects and lived experiences before achieving full recovery (Q17).

Textbox 8: Long-term effects

- Q15: “What if they would get it because of me, and their children would get it. That process continues, and that has such a bad influence on you. I’m not afraid of my own recurrence, that’s just life, but I’m scared for my children.” (P11)
- Q16: “Look, I’m in a relationship. But, I have to tell you honestly, he went through the whole process with me, and he accepts me the way I am. But it could be a reason for me not to start a relationship with someone new, because it doesn’t look good. It’s really horrible, and it’s very different to strip naked and see such an unappetising physique if your partner has been involved in the process.” (P8)
- Q17: “And at one point we concluded, we have a scar on our soul and sometimes that scar starts to pull. And even though it hurts elsewhere, the emotions are stirred up there, where that scar on your soul is.” (P1)

Coordination of healthcare

Healthcare professionals limit their focus very specifically to their own expertise, leaving participants unsure about where to turn to with their questions (Q18). Failure to listen to participants’ needs was also reported, with some participants feeling that their complaints were downplayed (Q19). Participants also mentioned that they found it difficult that treatment choices were not understood or blocked by healthcare professionals.

Several participants struggled with being discharged from the hospital due to its limited capacity. They subsequently had to receive follow-up care from their general practitioner or through population screening. Additionally, several participants found it challenging that the healthcare provision depended on the region in which they lived.

Participants also experienced obstacles in receiving recovery care and information too early. An overload of information, which results in not knowing how to cope with it, was also a mentioned obstacle (Q20).

Textbox 9: Coordination of healthcare

- Q18: “I have also talked about it with my general practitioner. He told me that it was actually the hospital’s responsibility. So they’re just pointing fingers at each other, which shows that there are some serious problems with the way healthcare is being provided.” (P12)
- Q19: “I have talked to a nurse about the lasting impacts [. . .] She told me: ‘Oh, you know, that will all be gone eventually. You’ll be back to your old self again in a year.’” (P9)
- Q20: “I was given a bunch of leaflets that made me think: ‘I don’t want anything to do with this whole cancer situation’. I still needed those treatments, so those brochures, I had no interest in reading them. So yeah, they’re still tucked away in a cupboard somewhere.” (P7)

Finances

Participants reported obstacles in paying for the perceived recovery care themselves, as the financial compensation for this type of healthcare is very limited. Consequently, there is often a restricted number of treatments available, leading to the treatment process ending before treatment goals were achieved. Participants also experienced financial stress related to reintegration and the termination of benefits (Q21).

Textbox 10: Finances

- Q21: “In fact, I was told to do it, and if I didn’t comply with their instructions, then they said they would take action and that meant they would quit all the payments. And yes, we couldn’t afford that. We couldn’t manage if I really had no income at all.” (P9)

Participation in society

Several participants emphasised that they struggle with participating in society post-treatment. They reported receiving little support, or resistance, from social agencies (Q22). Participants even mentioned being forced to return to work while they were not yet ready, which hindered their reintegration (Q23). Additionally, misunderstanding from employers was identified as an obstacle.

Textbox 11: Participation in society

- Q22: “So the Unemployment Benefit said: ‘If you’re going to reintegrate, and you don’t get paid for it, that’s your own problem. But you keep jobs away from the labour market, so you don’t receive any benefit.’ And the Disability Insurance Act said: ‘Huh? If you start working, you won’t be getting paid any more.’ So I had to go back to work and I wouldn’t get a dime.” (P1)

- Q23: “My doctor also advised me that I should take it easy [...] but no one listened, and furthermore, whatever I tried, I wanted to talk to the insurance doctor and explain my situation, but that was also not accepted [...] And that employment expert kept saying, yes, you have to get back to work.” (P9)

Personal matters

The obstacles related to recovery care and reintegration evoke various emotions in participants, such as anger, sadness, and helplessness. Additionally, participants encountered personal obstacles, such as a busy family life, a small social network, little involvement from others, or difficulty connecting with fellow cancer survivors. Feeling burdened by the care request, which prevented the participants from expressing their complaints, was also a common obstacle to obtaining the necessary recovery care.

Time

Several participants mentioned that they find recovery support services time-consuming and struggle to manage them alongside other appointments and fatigue. Participants cited limited availability of time during check-ups with oncologists and other healthcare professionals as an obstacle. Delays in receiving recovery care were also mentioned as an obstacle, potentially worsening participants' symptoms (Q24).

Textbox 12: Time

Q24: “It’s only just beginning, now, after all these years. I can finally find out what I can do and what’s still possible, instead of simply continue doing everything, and experiencing that a lot of things are no longer possible.” (P9)

Discussion

This study explored the needs, gaps, and obstacles faced by working-age BC survivors in remission during recovery. Participants emphasised the need for integrated and psychological care, information provision, and coping guidance. They highlighted a gap in guidance during the transition period, follow-up care, and obtaining information. Furthermore, they mentioned long-term effects, coordination of healthcare, finances, participation in society, personal matters, and time as obstructions.

Our study's findings align with previous literature on BC survivors' needs, mainly related to information provision, psychological care accessibility, and continuation of care^{32–36}. Prior research concerning cancer in general indicated that survivors face limitations in physical, emotional, and practical aspects post-treatment. They are not receiving appropriate guidance and information provision, and concerns are often neglected during traditional follow-up appointments^{36,46,47,86}. As mentioned in our study, this is attributed to limitations in healthcare providers' knowledge and inadequate communication between healthcare providers and patients^{87–89}. Like our study's participants, survivors do not receive timely recovery care^{36,46,47,86}. Several studies indicated that many healthcare professionals also encounter these obstacles. They often feel poorly equipped due to the lack of time and knowledge. They require treatment guidelines and information regarding long-term effects and resource allocation^{87,90–92}.

Our participants experienced gaps regarding guidance, follow-up care, and obtaining information, regardless of the time since diagnosis and treatment. This corresponds to literature emphasising the need for continuous healthcare throughout the BC journey^{33,37}. Multiple participants of our study attempted to fill the gap in healthcare provision themselves, by offering guidance to others. Unmet needs cause survivors to experience feelings of loneliness, helplessness, and societal misconceptions⁹³. This experience aligns with the feeling of being lost in a 'black hole' and lacking support and guidance, as found in our study.

Financial and societal obstacles such as treatment costs, reduced income, insufficient support during reintegration, and inability to work, as mentioned in our study, are confirmed by previous literature⁹⁴; multiple studies reported reduced work engagement. BC survivors experience obstacles whilst re-integrating, including unhealthy work environments, inflexible schedules, and lack of support from employers and colleagues⁹⁵. This is in accordance with a study that indicated that only 32% of Dutch cancer survivors discuss work-related issues with their healthcare professionals, and that work-related psychosocial care is not yet systematically provided⁴⁷.

Strengths and limitations

The qualitative design of this study provided a more detailed exploration of experiences and perspectives faced by BC survivors, than prior quantitative research regarding (unmet) needs and experiences during recovery, which is important to tailor recovery care to survivors' unique situations⁹⁶. Since obstacles during recovery were also discussed, a more comprehensive understanding of challenges, like healthcare coordination and societal participation after BC was achieved. Our study's attention to detail strengthens the ability to compare across various medical conditions within the extensive HU Project. Another strength is the maximum variation of the range of treatments that participants have received, leading to diverse obstacles and needs in their recovery. Moreover, this study is strengthened by conducting a pilot interview, and the number of interviews. The use of the checklist of Braun & Clark and the COREQ checklist strengthened the transparency of this study^{68,80}. Methodological choices such as recording, member checking, peer debriefing, and memo writing strengthened the study⁸⁴.

A limitation of the study is that initial coding, defining, and naming themes were performed by one researcher. However, peer debriefing and external evaluation improved the trustworthiness of the analysis. Another limitation is the sampling method, which introduces constraints of transferability⁹⁷. Coincidentally, only women above the age of 42 participated in this study. Furthermore, as mentioned by the study participants, various factors such as long-term effects, the ability to articulate unmet recovery needs, time since diagnosis, the treating hospital, region of residence, and social network involvement may influence variability in experienced needs, gaps, and obstacles⁴¹. Therefore, the data is not transferable to all women, and men with BC. Nevertheless, maximum variation is anticipated across the different phases of recovery identified by Spaniol et al. based on the time since diagnosis and responses to the interview questions⁶⁹. Despite the well-known fact that survivors have trouble reintegrating into society, it was notable that only a few organisations cooperated in sharing the recruitment message for our study. This made it challenging to reach the required population. Furthermore, conducting online interviews can be viewed as a limitation. However, interviewing online provides a secure environment for both the researcher and participant, and enhances the availability to discuss sensitive issues⁹⁸. This was substantiated by the participants' extensive amount of information shared during the interviews.

Implications

This study highlighted a deficiency in the coordination and continuation of healthcare during recovery after BC, and it displays a need for information on available recovery care sources. Therefore, it is recommended to enhance the provision of information regarding available facilities such as cancer

support centres, specific therapies, and rehabilitation programs. This study also identified challenges beyond healthcare. Hence, it is recommended that healthcare professionals should take a holistic approach and ask questions considering obstacles such as long-term effects and survivors' work and home environments, to provide personalised recovery care throughout the entire BC journey.

The interviews were utilised for exploratory purposes; however, the richness of the data offers the potential to enable further studies regarding the experienced consequences of BC, the currently available recovery care, and the development of a grounded theory to explain survivors' experienced difficulty in participating in society after BC. Future research should focus on adolescents and young adults due to the absence of participants below 42 in our study. Furthermore, future research should focus on improving recovery care for all phases of recovery (by addressing integrated care, taking concerns seriously, providing guidance and offering information regarding rehabilitation programs and long-term effects) to effectively address the explored needs, gaps, and obstacles⁶⁹. However, it is recommended to gather insights from healthcare professionals and social agencies regarding this topic, before integrated recovery care can be optimised.

Conclusion

This study identified the needs, gaps, and obstacles working-age BC survivors in remission experienced during their recovery. BC survivors have many needs, regarding integrated care, psychological care, information provision, and coping guidance. They encounter gaps in follow-up care, obtaining information and the transition period when treatments are finished. They also experience many obstacles concerning long-term effects, coordination of healthcare, finances, difficulties to participate in society, personal matters, and time factors which make it difficult to recover and reintegrate when treatments are finished. These findings provide valuable insights into recovery experiences of BC survivors and highlight areas that can be improved in recovery care.

References

1. World Cancer Research Fund International. Worldwide cancer data [Internet]. Available from: <https://www.wcrf.org/cancer-trends/worldwide-cancer-data/> [Accessed on: 2023 Mar 3]
2. Integraal kankercentrum Nederland. Incidentie borstkanker [Internet]. Available from: <https://iknl.nl/kankersoorten/borstkanker/registratie/incidentie> [Accessed on: 2023 Feb 3]
3. Nederlandse Kankerregistratie. Incidentie per jaar, aantal. Borstkanker [Internet]. Available from: <https://nkr-cijfers.iknl.nl/#/viewer/15985c52-dac0-483b-bebd-eb513710fc57> [Accessed on: 2023 Feb 3]
4. Rijksinstituut voor volksgezondheid en milieu. Kans op borstkanker. [Internet]. Available from: <https://www.rivm.nl/bevolkingsonderzoek-borstkanker/over-borstkanker/kans-op-borstkanker> [Accessed on: 2023 Feb 3]
5. Volksgezondheidszorg.info. Borstkanker: Leeftijd en geslacht [Internet]. Available from: <https://www.vzinfo.nl/borstkanker/leeftijd-en-geslacht> [Accessed on: 2023 Feb 9]
6. Integraal kankercentrum Nederland. Prevalentie borstkanker [Internet]. Available from: <https://iknl.nl/kankersoorten/borstkanker/registratie/prevalentie> [Accessed on: 2023 Feb 3]
7. Gast KC, Allen SV, Ruddy KJ and Haddad TC. Novel approaches to support breast cancer survivorship care models. *The Breast* 2017 Dec; 36:1–13. DOI: 10.1016/j.breast.2017.08.004. Available from: <https://doi.org/10.1016/j.breast.2017.08.004>
8. Kanker.nl. Cijfers over kanker [Internet]. Available from: <https://www.kanker.nl/algemene-onderwerpen/cijfers-over-kanker/uitleg-cijfers-over-kanker/overleving-van-kanker> [Accessed on: 2022 Oct 15]
9. Our World in Data. Cancer death rates are falling; five-year survival rates are rising [Internet]. Available from: <https://ourworldindata.org/cancer-death-rates-are-falling-five-year-survival-rates-are-rising> [Accessed on: 2022 Oct 27]
10. Pink ribbon. Borstkanker: Cijfers en feiten [Internet]. Available from: <https://www.pinkribbon.nl/over-borstkanker/cijfers-en-feiten.html> [Accessed on: 2023 Feb 3]
11. Denlinger CS, Ligibel JA, Are M, Baker KS, Broderick G, Demark-Wahnefried W et al. NCCN Guidelines Insights: Survivorship, Version 1.2016. *Journal of the National Comprehensive Cancer Network* 2016 Jun; 14:715–24. DOI: 10.6004/jnccn.2016.0073. Available from: <https://doi.org/10.6004/jnccn.2016.0073>

12. Mullen E and Mistry H. Managing Cancer Survivorship Issues. *The Journal for Nurse Practitioners* 2018 Apr; 14:337–43. DOI: 10.1016/j.nurpra.2017.12.022. Available from: <https://doi.org/10.1016/j.nurpra.2017.12.022>
13. Aaronson NK, Mattioli V, Minton O, Weis J, Johansen C, Dalton SO et al. Beyond treatment – Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer Supplements* 2014 Jun; 12:54–64. DOI: 10.1016/j.ejcsup.2014.03.005. Available from: <https://doi.org/10.1016/j.ejcsup.2014.03.005>
14. Nederlandse Federatie van Kankerpatiënten organisaties. Sociale steun, begrip en nazorg bij kanker: wat is jouw ervaring? Rapportage Finale Versie 25 Oktober 2021 [Internet]. Available from: <https://nfk.nl/onderzoeken/sociale-steun-begrip-en-nazorg-bij-kanker-wat-is-jouw-ervaring> [Accessed on: 2022 Nov 23]
15. Nederlandse Federatie van Kankerpatiënten organisaties. Zorgen of angst bij kanker: wat is jouw ervaring? Rapportage Februari 2022 [Internet]. Available from: <https://nfk.nl/onderzoeken/zorgen-of-angst-bij-kanker-wat-is-jouw-ervaring> [Accessed on: 2022 Nov 23]
16. Cancer.Net. What is cancer survivorship [Internet]. Available from: <https://www.cancer.net/survivorship/what-cancer-survivorship> [Accessed on: 2022 Oct 28]
17. Weber D and O'Brien K. Cancer and Cancer-Related Fatigue and the Interrelationships With Depression, Stress, and Inflammation. *Journal of Evidence-Based Complementary: Alternative Medicine* 2016 Nov; 22:502–12. DOI: 10.1177/2156587216676122. Available from: <https://doi.org/10.1177/2156587216676122>
18. From Cancer Patient to Cancer Survivor. National Academies Press, 2005 Oct :68–71. DOI: 10.17226/11468. Available from: <https://doi.org/10.17226/11468>
19. Stanton AL, Rowland JH and Ganz PA. Life after diagnosis and treatment of cancer in adulthood: Contributions from psychosocial oncology research. *American Psychologist* 2015 Feb; 70:159–74. DOI: 10.1037/a0037875. Available from: <https://doi.org/10.1037/a0037875>
20. Duijts SFA, Egmond MP van, Spelten E, Muijen P van, Anema JR and Beek AJ van der. Physical and psychosocial problems in cancer survivors beyond return to work: a systematic review. *Psycho-Oncology* 2013 Dec; 23:481–92. DOI: 10.1002/pon.3467. Available from: <https://doi.org/10.1002/pon.3467>
21. American Cancer Society. Long-term Side Effects of Cancer [Internet]. Available from: <https://www.cancer.org/treatment/survivorship-during-and-after-treatment/long-term-health-concerns/long-term-side-effects-of-cancer.html> [Accessed on: 2022 Oct 27]

22. Lovelace DL, McDaniel LR and Golden D. Long-Term Effects of Breast Cancer Surgery, Treatment, and Survivor Care. *Journal of Midwifery and Women's Health* 2019 Jul; 64:713–24. DOI: 10.1111/jmwh.13012. Available from: <https://doi.org/10.1111/jmwh.13012>
23. Tommasi C, Balsano R, Corianò M, Pellegrino B, Saba G, Bardanzellu F et al. Long-Term Effects of Breast Cancer Therapy and Care: Calm after the Storm? *Journal of Clinical Medicine* 2022 Dec; 11:7239. DOI: 10.3390/jcm11237239. Available from: <https://doi.org/10.3390/jcm11237239>
24. Obembe AO and Eng JJ. Rehabilitation Interventions for Improving Social Participation After Stroke. *Neurorehabilitation and Neural Repair* 2015 Jul; 30:384–92. DOI: 10.1177/1545968315597072. Available from: <https://doi.org/10.1177/1545968315597072>
25. Loibl S and Lederer B. The Importance of Supportive Care in Breast Cancer Patients. *Breast Care* 2014; 9:230–1. DOI: 10.1159/000366526. Available from: <https://doi.org/10.1159/000366526>
26. Stel J van der. Inleiding in de psychische gezondheidszorg. Boom, 2017 :127–59
27. Vardy JL, Chan RJ, Koczwara B, Lisy K, Cohn RJ, Joske D et al. Clinical Oncology Society of Australia position statement on cancer survivorship care. *Australian Journal of General Practice* 2019 Dec; 48:833–6. DOI: 10.31128/ajgp-07-19-4999. Available from: <https://doi.org/10.31128/ajgp-07-19-4999>
28. National Cancer Institute. Supportive care [Internet]. Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/supportive-care?redirect=true> [Accessed on: 2022 Mar 2]
29. Institute for Positive Health. Positieve gezondheid, wat is het [Internet]. Available from: <https://www.iph.nl/positieve-gezondheid/wat-is-het/> [Accessed on: 2022 Nov 2]
30. Huber M, Vliet M van and Boer I. Heroverweeg uw opvatting van het begrip 'gezondheid'. *Ned. Tijdschr. Geneeskd.* 2016 Feb; 160:A7720
31. Nekhlyudov L, Mollica MA, Jacobsen PB, Mayer DK, Shulman LN and Geiger AM. Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research, and Policy. *JNCI: Journal of the National Cancer Institute* 2019 May; 111:1120–30. DOI: 10.1093/jnci/djz089. Available from: <https://doi.org/10.1093/jnci/djz089>
32. Khajoei R, Ilkhani M, Azadeh P, Anboohi SZ and Nabavi FH. Breast cancer survivors-supportive care needs: systematic review. *BMJ Supportive & Palliative Care* 2023 Mar :spcare-2022-003931. DOI: 10.1136/spcare-2022-003931. Available from: <https://doi.org/10.1136/spcare-2022-003931>

33. Vivar CG and McQueen A. Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing* 2005 Sep; 51:520–8. DOI: 10.1111/j.1365-2648.2005.03524.x. Available from: <https://doi.org/10.1111/j.1365-2648.2005.03524.x>
34. Au A, Lam W, Tsang J, Yau Tk, Soong I, Yeo W et al. Supportive care needs in Hong Kong Chinese women confronting advanced breast cancer. *Psycho-Oncology* 2012 Jun; 22:1144–51. DOI: 10.1002/pon.3119. Available from: <https://doi.org/10.1002/pon.3119>
35. So WK, Chow KM, Chan HY, Choi KC, Wan RW, Mak SS et al. Quality of life and most prevalent unmet needs of Chinese breast cancer survivors at one year after cancer treatment. *European Journal of Oncology Nursing* 2014 Jun; 18:323–8. DOI: 10.1016/j.ejon.2014.03.002. Available from: <https://doi.org/10.1016/j.ejon.2014.03.002>
36. Tompkins C, Scanlon K, Scott E, Ream E, Harding S and Armes J. Survivorship care and support following treatment for breast cancer: a multi-ethnic comparative qualitative study of women's experiences. *BMC Health Services Research* 2016 Aug; 16. DOI: 10.1186/s12913-016-1625-x. Available from: <https://doi.org/10.1186/s12913-016-1625-x>
37. Aamir M, Ameri MA, Ganesan S, Alharmoudi F, Alshehhi A, Alhashmi F et al. Understanding the psychosocial needs of breast cancer survivors in the United Arab Emirates: a qualitative study. *Discover Psychology* 2022 Nov; 2. DOI: 10.1007/s44202-022-00056-0. Available from: <https://doi.org/10.1007/s44202-022-00056-0>
38. Moller UO, Beck I, Ryden L and Malmstrom M. A comprehensive approach to rehabilitation interventions following breast cancer treatment - a systematic review of systematic reviews. *BMC Cancer* 2019 May; 19. DOI: 10.1186/s12885-019-5648-7. Available from: <https://doi.org/10.1186/s12885-019-5648-7>
39. Shapiro CL. Cancer Survivorship. *New England Journal of Medicine* 2018 Dec; 379. Ed. by Longo DL:2438–50. DOI: 10.1056/nejmra1712502. Available from: <https://doi.org/10.1056/nejmra1712502>
40. Jacobsen PB, DeRosa AP, Henderson TO, Mayer DK, Moskowitz CS, Paskett ED et al. Systematic Review of the Impact of Cancer Survivorship Care Plans on Health Outcomes and Health Care Delivery. *Journal of Clinical Oncology* 2018 Jul; 36:2088–100. DOI: 10.1200/jco.2018.77.7482. Available from: <https://doi.org/10.1200/jco.2018.77.7482>
41. Grunfeld E. Survivorship 2.0. *Journal of Clinical Oncology* 2019 Dec; 37:3179–82. DOI: 10.1200/jco.19.01098. Available from: <https://doi.org/10.1200/jco.19.01098>
42. Kenyon M, Mayer DK and Owens AK. Late and Long-Term Effects of Breast Cancer Treatment and Surveillance Management for the General Practitioner. *Journal of Obstetric, Gynecologic*

and Neonatal Nursing 2014 May; 43:382–98. DOI: 10.1111/1552-6909.12300. Available from: <https://doi.org/10.1111/1552-6909.12300>

43. Medisch Contact. Laagdrempelige nazorg na kanker is een onbenut potentieel [Internet]. Available from: <https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/laagdrempelige-nazorg-na-kanker-is-een-onbenut-potentieel#reacties> [Accessed on: 2023 Feb 24]
44. Hesselink A and Martens M. Behoefteteonderzoek inloophuizen onder mensen die kanker hebben (gehad) en hun naasten die (nog) geen gebruik maken van een inloophuis. ResCon. 2014 May. Available from: <https://ipso.nl/wp-content/uploads/2020/03/IPS0-ResCon-Behoefteteonderzoek-inloophuizen.pdf>
45. Belgraver V, Broekhuizen J and Roest-Boers N. Effectonderzoek. De maatschappelijke waarde van IPSO inloophuizen. In order of KWF Kankerbestrijding, in association with IPSO, and carried out by Sinzer BV. 2018 Dec. Available from: <https://ipso.nl/wp-content/uploads/2020/03/IPS0-Sinzer-Effectonderzoek-Maatschappelijke-waarde-IPSO-inloophuizen.pdf>
46. Jefford M, Karahalios E, Pollard A, Baravelli C, Carey M, Franklin J et al. Survivorship issues following treatment completion: results from focus groups with Australian cancer survivors and health professionals. Journal of Cancer Survivorship 2008 Jan; 2:20–32. DOI: 10.1007/s11764-008-0043-4. Available from: <https://doi.org/10.1007/s11764-008-0043-4>
47. Zegers AD, Coenen P, Belzen M, Engelen V, Richel C, Dona DJS et al. Cancer survivors experiences with conversations about work-related issues in the hospital setting. Psycho-Oncology 2020 Oct; 30:27–34. DOI: 10.1002/pon.5529. Available from: <https://doi.org/10.1002/pon.5529>
48. From Cancer Patient to Cancer Survivor. National Academies Press, 2005 Oct :4–8. DOI: 10.17226/11468. Available from: <https://doi.org/10.17226/11468>
49. Nekhlyudov L, Ganz PA, Arora NK and Rowland JH. Going Beyond Being Lost in Transition: A Decade of Progress in Cancer Survivorship. Journal of Clinical Oncology 2017 Jun; 35:1978–81. DOI: 10.1200/jco.2016.72.1373. Available from: <https://doi.org/10.1200/jco.2016.72.1373>
50. Cheung WY, Neville BA, Cameron DB, Cook EF and Earle CC. Comparisons of Patient and Physician Expectations for Cancer Survivorship Care. Journal of Clinical Oncology 2009 May; 27:2489–95. DOI: 10.1200/jco.2008.20.3232. Available from: <https://doi.org/10.1200/jco.2008.20.3232>
51. Sisler JJ Brown JB SM. Family physicians' roles in cancer care. Survey of patients on a provincial cancer registry. Can Fam Physician 2004 Jun; 50:889–96

52. Padova SD, Rosti G, Scarpi E, Salvioni R, Amadori D and Giorgi UD. Expectations of survivors, caregivers and healthcare providers for testicular cancer survivorship and quality of life. *Tumori Journal* 2011 May; 97:367–73. DOI: 10.1177/030089161109700319. Available from: <https://doi.org/10.1177/030089161109700319>
53. *From Cancer Patient to Cancer Survivor*. National Academies Press, 2005 Oct. DOI: 10.17226/11468. Available from: <https://doi.org/10.17226/11468>
54. Cocchiara R, Sciarra I, D'Egidio V, Sestili C, Mancino M, Backhaus I et al. Returning to work after breast cancer: A systematic review of reviews. *Work* 2018 Dec; 61:463–76. DOI: 10.3233/wor-182810. Available from: <https://doi.org/10.3233/wor-182810>
55. European Commission. Treating cancer is only part of the journey': the overlooked needs of cancer survivors [Internet]. Available from: <https://ec.europa.eu/research-and-innovation/en/horizon-magazine/treating-cancer-only-part-journey-overlooked-needs-cancer-survivors> [Accessed on: 2022 Nov 2]
56. The Economist-Intelligence Unit. THE ROAD TO A BETTER NORMAL: Breast cancer patients and survivors in the EU workforce [Internet]. Available from: <https://impact.economist.com/perspectives/health/road-better-normal-breast-cancer-patients-and-survivors-eu-workforce/white-paper/road-better-normal-breast-cancer-patients-and-survivors-eu-workforce> [Accessed on: 2023 Feb 3]
57. Thewes B, Butow P, Girgis A and Pendlebury S. The psychosocial needs of breast cancer survivors. A qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology* 2004 Mar; 13:177–89. DOI: 10.1002/pon.710. Available from: <https://doi.org/10.1002/pon.710>
58. Congard A, Christophe V, Duprez C, Baudry AS, Antoine P, Lesur A et al. The self-reported perceptions of the repercussions of the disease and its treatments on daily life for young women with breast cancer and their partners. *Journal of Psychosocial Oncology* 2018 Oct; 37:50–68. DOI: 10.1080/07347332.2018.1479326. Available from: <https://doi.org/10.1080/07347332.2018.1479326>
59. Lewis J, Mackenzie L and Black D. Workforce participation of Australian women with breast cancer. *Psycho-Oncology* 2020 Apr; 29:1156–64. DOI: 10.1002/pon.5392. Available from: <https://doi.org/10.1002/pon.5392>
60. Yen L, McRae I, Jeon YH, Essue B and Herath P. The impact of chronic illness on workforce participation and the need for assistance with household tasks and personal care by older Australians. *Health and Social Care in the Community* 2011 Apr; 19:485–94. DOI: 10.1111/j.

1365-2524.2011.00994.x. Available from: <https://doi.org/10.1111/j.1365-2524.2011.00994.x>

61. Frederix GW, Quadri N, Hovels AM, Wetering FT van de, Tamminga H, Schellens JH et al. Utility and Work Productivity Data for Economic Evaluation of Breast Cancer Therapies in the Netherlands and Sweden. *Clinical Therapeutics* 2013 Apr; 35:e1–e7. DOI: 10.1016/j.clinthera.2013.03.009. Available from: <https://doi.org/10.1016/j.clinthera.2013.03.009>
62. Gilchrist LS, Galantino ML, Wampler M, Marchese VG, Morris GS and Ness KK. A Framework for Assessment in Oncology Rehabilitation. *Physical Therapy* 2009 Mar; 89:286–306. DOI: 10.2522/ptj.20070309. Available from: <https://doi.org/10.2522/ptj.20070309>
63. Andersen BL, DeRubeis RJ, Berman BS, Gruman J, Champion VL, Massie MJ et al. Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation. *Journal of Clinical Oncology* 2014 May; 32:1605–19. DOI: 10.1200/jco.2013.52.4611. Available from: <https://doi.org/10.1200/jco.2013.52.4611>
64. Amatya B, Khan F and Galea M. Optimizing post-acute care in breast cancer survivors: a rehabilitation perspective. *Journal of Multidisciplinary Healthcare* 2017 Aug; Volume 10:347–57. DOI: 10.2147/jmdh.s117362. Available from: <https://doi.org/10.2147/jmdh.s117362>
65. Colorafi KJ and Evans B. Qualitative Descriptive Methods in Health Science Research. *HERD* 2016 Jan; 9:16–25. DOI: 10.1177/1937586715614171. Available from: <https://doi.org/10.1177/1937586715614171>
66. H. B. Analysis in Qualitative Research. first ed. London: SAGE, 2010
67. JW. C and CN. P. Qualitative Inquiry And Research Design: Choosing Among Five Approaches. Fourth ed. Thousand Oaks: SAGE, 2018
68. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research COREQ: a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007 Sep; 19:349–57. DOI: 10.1093/intqhc/mzm042. Available from: <https://doi.org/10.1093/intqhc/mzm042>
69. Spaniol L, Wewiorski NJ, Gagne C and Anthony WA. The process of recovery from schizophrenia. *International Review of Psychiatry* 2002 Jan; 14:327–36. DOI: 10.1080/0954026021000016978. Available from: <https://doi.org/10.1080/0954026021000016978>
70. Centraal Bureau voor de Statistiek. Werkenden [Internet]. Available from: <https://www.cbs.nl/nl-nl/visualisaties/dashboard-arbeidsmarkt/werkenden> [Accessed on: 2022 Nov 10]

71. Kwan ML, Cheng RK, Iribarren C, Neugebauer R, Rana JS, Nguyen-Huynh M et al. Risk of Cardiometabolic Risk Factors in Women With and Without a History of Breast Cancer: The Pathways Heart Study. *Journal of Clinical Oncology* 2022 May; 40:1635–46. DOI: 10.1200/jco.21.01738. Available from: <https://doi.org/10.1200/jco.21.01738>
72. Guest G, Bunce A and Johnson L. How Many Interviews Are Enough? *Field Methods* 2006 Feb; 18:59–82. DOI: 10.1177/1525822x05279903. Available from: <https://doi.org/10.1177/1525822x05279903>
73. Ando H, Cousins R and Young C. Achieving Saturation in Thematic Analysis: Development and Refinement of a Codebook. *Comprehensive Psychology* 2014 Jan; 3:03.CP.3.4. DOI: 10.2466/03.cp.3.4. Available from: <https://doi.org/10.2466/03.cp.3.4>
74. Britten N. Qualitative Research: Qualitative interviews in medical research. *BMJ* 1995 Jul; 311:251–3. DOI: 10.1136/bmj.311.6999.251. Available from: <https://doi.org/10.1136/bmj.311.6999.251>
75. McGrath C, Palmgren PJ and Liljedahl M. Twelve tips for conducting qualitative research interviews. *Medical Teacher* 2018 Sep; 41:1002–6. DOI: 10.1080/0142159x.2018.1497149. Available from: <https://doi.org/10.1080/0142159x.2018.1497149>
76. Majid MAA, Othman M, Mohamad SF, Lim SAH and Yusof A. Piloting for Interviews in Qualitative Research: Operationalization and Lessons Learnt. *International Journal of Academic Research in Business and Social Scnces* 2017 May; 7. DOI: 10.6007/ijarbss/v7-i4/2916. Available from: <https://doi.org/10.6007/ijarbss/v7-i4/2916>
77. Universiteit Utrecht. Tools to transcribe audio data [Internet]. Available from: <https://www.uu.nl/en/research/research-data-management/tools-services/tools-to-transcribe-audio-data> [Accessed on: 2022 Nov 4]
78. Microsoft Teams 1.4.00.22472 ; Microsoft Windows) [Internet]. Available from: <https://www.microsoft.com/nl-nl/microsoft-teams/group-chat-software> [Accessed on: 2022 Dec 18]
79. ATLAS.ti. Scientific Software Development GmbH [ATLAS.ti 22 Mac] (2022) [Internet]. Available from: <https://atlasti.com> [Accessed on: 2022 Nov 3]
80. Braun V and Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006 Jan; 3:77–101. DOI: 10.1191/1478088706qp063oa. Available from: <https://doi.org/10.1191/1478088706qp063oa>
81. World Medical Association Declaration of Helsinki. *JAMA* 2013 Nov; 310:2191. DOI: 10.1001/jama.2013.281053. Available from: <https://doi.org/10.1001/jama.2013.281053>
82. General Data Protection Regulation GDPR. Regulation (EU) 2016/679 [Internet]. Available from: <https://gdpr-info.eu> [Accessed on: 2022 Nov 7]

83. Hogeschool Utrecht Bibliotheek. Wetenschappelijke integriteit [Internet]. Available from: <https://bibliotheek.hu.nl/onderzoekers/wetenschappelijke-integriteit/> [Accessed on: 2022 Nov 7]
84. Lincoln YS, Guba EG and Pilotta JJ. Naturalistic inquiry. *International Journal of Intercultural Relations* 1985 Jan; 9:438–9. DOI: 10.1016/0147-1767(85)90062-8. Available from: [https://doi.org/10.1016/0147-1767\(85\)90062-8](https://doi.org/10.1016/0147-1767(85)90062-8)
85. Frambach JM, Vleuten CP and Durning SJ. AM Last Page. Quality criteria in qualitative and quantitative research. *Academic Medicine* 2013 Apr; 88:737. DOI: 10.1097/acm.0b013e31828abf7f. Available from: <https://doi.org/10.1097/acm.0b013e31828abf7f>
86. Fitch MI, Nicoll I and Lockwood G. Cancer survivor's perspectives on the major challenge in the transition to survivorship. *Patient Education and Counseling* 2020 Nov; 103:2361–7. DOI: 10.1016/j.pec.2020.04.018. Available from: <https://doi.org/10.1016/j.pec.2020.04.018>
87. Yang EJ, Chung SH, Jeon JY, Seo KS, Shin HI, Hwang JH et al. Current Practice and Barriers in Cancer Rehabilitation: Perspectives of Korean Psychiatrists. *Cancer Research and Treatment* 2015 Jan; 47:370–8. DOI: 10.4143/crt.2014.084. Available from: <https://doi.org/10.4143/crt.2014.084>
88. Garmy P and Jakobsson L. Experiences of cancer rehabilitation: A cross-sectional study. *Journal of Clinical Nursing* 2018 May; 27:2014–21. DOI: 10.1111/jocn.14321. Available from: <https://doi.org/10.1111/jocn.14321>
89. Gupta E, Ng AH, Fu JB, Yadav R, Ngo-Huang A, Bansal S et al. Cancer Rehabilitation Providers and Oncology Patient Expectations for Functional Outcomes after Inpatient Rehabilitation. *PM R*. 2020 Oct; 13:729–36. DOI: 10.1002/pmrj.12473. Available from: <https://doi.org/10.1002/pmrj.12473>
90. Larsen EH, Mellblom AV, Ruud E, Wahl AK and Lie HC. Prepared for survivorship? Multidisciplinary healthcare professionals' experiences with adolescents' transition off cancer treatment: A focus group study. *European Journal of Oncology Nursing* 2022 Jun; 58:102150. DOI: 10.1016/j.ejon.2022.102150. Available from: <https://doi.org/10.1016/j.ejon.2022.102150>
91. Yagil D, Eshed-Lavi N, Carel R and Cohen M. Health care professionals' perspective on return to work in cancer survivors. *Psycho-Oncology* 2018 Feb; 27:1206–12. DOI: 10.1002/pon.4649. Available from: <https://doi.org/10.1002/pon.4649>
92. Ijsbrandy C, Harten WH van, Gerritsen WR, Hermens RP and Ottevanger PB. Healthcare professionals' perspectives of barriers and facilitators in implementing physical activity programmes delivered to cancer survivors in a shared-care model: a qualitative study. *Supportive Care in*

Cancer 2019 Dec; 28:3429–40. DOI: 10.1007/s00520-019-05108-1. Available from: <https://doi.org/10.1007/s00520-019-05108-1>

93. Raque-Bogdan TL, Lamphere B, Kostiuk M, Gissen M and Beranek M. Unpacking the layers: a meta-ethnography of cancer survivors' loneliness. *Journal of Cancer Survivorship* 2018 Nov; 13:21–33. DOI: 10.1007/s11764-018-0724-6. Available from: <https://doi.org/10.1007/s11764-018-0724-6>
94. Cheng K, Cheng H, Wong W and Koh C. A mixed-methods study to explore the supportive care needs of breast cancer survivors. *Psycho-Oncology* 2017 Aug; 27:265–71. DOI: 10.1002/pon.4503. Available from: <https://doi.org/10.1002/pon.4503>
95. Sun Y, Shigaki CL and Armer JM. Return to work among breast cancer survivors: A literature review. *Supportive Care in Cancer* 2016 Nov; 25:709–18. DOI: 10.1007/s00520-016-3446-1. Available from: <https://doi.org/10.1007/s00520-016-3446-1>
96. Sofaer S. Qualitative methods: what are they and why use them? *Health Serv. Res.* 1999 Dec; 34:1101–18
97. Thompson C. If you could just provide me with a sample: examining sampling in qualitative and quantitative research papers. *Evidence-Based Nursing* 1999 Jul; 2:68–70. DOI: 10.1136/ebn.2.3.68. Available from: <https://doi.org/10.1136/ebn.2.3.68>
98. Self B. Conducting Interviews During the COVID-19 Pandemic and Beyond. en. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* 2021 :Vol. 22 No. 3 (2021): The Refiguration of Spaces and Cross–Cultural Comparison II. DOI: 10.17169/FQS-22.3.3741. Available from: <https://www.qualitative-research.net/index.php/fqs/article/view/3741>
99. World Health Organization. WHO remains firmly committed to the principles set out in the preamble to the Constitution [Internet]. Available from: <https://www.who.int/about/governance/constitution> [Accessed on: 2022 Nov 10]

A. Completed COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	11,46
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	46
Occupation	3	What was their occupation at the time of the study?	46
Gender	4	Was the researcher male or female?	46
Experience and training	5	What experience or training did the researcher have?	11
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	12
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	43
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	46
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	10
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	10
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	10
Sample size	12	How many participants were in the study?	11,13
Non-participation	13	How many people refused to participate or dropped out? Reasons?	10
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	10
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	10
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	13
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	11
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	11
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	11
Field notes	20	Were field notes made during and/or after the inter view or focus group?	11
Duration	21	What was the duration of the inter views or focus group?	11
Data saturation	22	Was data saturation discussed?	12,14
Transcripts returned	23	Were transcripts returned to participants for comment and/or	11,12

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	11,46
Description of the coding tree	25	Did authors provide a description of the coding tree?	14
Derivation of themes	26	Were themes identified in advance or derived from the data?	11,46
Software	27	What software, if applicable, was used to manage the data?	11
Participant checking	28	Did participants provide feedback on the findings?	11
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	16-24
Data and findings consistent	30	Was there consistency between the data presented and the findings?	12
Clarity of major themes	31	Were major themes clearly presented in the findings?	14
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	15,18,21

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

B. Substantiation Topic list

Experiences regarding personal recovery

- Van der Stel has defined “recovery” into four types, in which “personal recovery” is an umbrella form that covers the other types of recovery: clinical/medical recovery (absence of mental and physical symptoms of illness), functional recovery (fulfilling roles in daily life that are relevant to the concerned person) and social recovery (improvements of work, housing, income and social contact with others)²⁶.
- Perceived health can be divided into multiple domains, such as the domains of Positive health defined by Huber. Positive health is based on six domains: “bodily functions, mental well-being, meaningfulness, quality of life, participation, and daily functioning”. These domains can be used to determine how people experience their health^{29,30,99}.

Topic 2: Experiences regarding recovery care

- Recovery care refers to supportive care in the recovery of someone’s clinical recovery, personal recovery, social recovery, and functional recovery.
- Various literature emphasises that current care does not meet the needs of BC survivors^{25,47–52}.
- According to research, peer support clinics in the Netherlands, where cancer survivors/patients can talk to fellow cancer survivors/patients and participate in activities, are an unexploited potential in improving recovery care. This idea is substantiated by a preliminary study within this Seed Money project, which has shown that many cancer survivors do not use the current available recovery care^{43–45}.

Topic 3: Recovery (care) needs, gaps, and obstacles

- Needs refer to the required care or support of participants to achieve clinical (both physical and mental), social, and personal recovery)²⁶.
- Gaps refer to the differences between currently available care and needed care. This mainly revolves around additional components within the existing healthcare.
- Obstacles refer to the barriers participants encounter whilst transitioning to the final stages of recovery, (living with the condition and living beyond the condition), according to Spaniol et al⁶⁹.
- In order to improve recovery care, it is essential to properly identify the specific needs, gaps, and obstacles BC survivors of working age experience during recovery^{27–31,39,55,62–64}.

C. Onderbouwing topic lijst

Topic 1: Ervaring persoonlijk herstel

- Van der Stel heeft “herstel” gedefinieerd in vier soorten, waarbij “persoonlijk herstel” (het herstel zoals de persoon het zelf ervaart) een overkoepelende vorm is die over de overige drie vormen van herstel gaat. Klinisch/medisch herstel (afwezigheid van mentale en fysieke ziekteverschijnselen, functioneel herstel (het uit kunnen voeren van handelingen en zelfredzaamheid), sociaal en maatschappelijk herstel (verbeteringen op het gebied van wonen, werk, inkomen en sociale contacten)²⁶.
- Ervaren gezondheid is in te delen in zes dimensies, zoals gedefinieerd door Huber: lichaamsfuncties, mentaal welbevinden, zingeving, kwaliteit van leven, meedoen en dagelijks functioneren. Hiermee kan in kaart worden gebracht hoe patiënten hun gezondheid ervaren en hun vermogen om met fysieke, emotionele en sociale uitdagingen in het leven om te gaan^{29,30}.

Topic 2: Ervaring herstelondersteuning

- Diverse literatuur benadrukt dat de huidige herstellzorg niet aan behoeften van borstkanker patiënten voldoet^{25,47-52}.
- Volgens effectonderzoek vormen inloophuizen in Nederland, waar patiënten kunnen praten met lotgenoten en kunnen deelnemen aan activiteiten, een onbenut potentieel om de herstellzorg te verbeteren. Dit idee wordt onderbouwd door een vooronderzoek binnen dit Seed Money project, waaruit is gebleken dat veel kankerpatiënten geen gebruik maken van de huidige beschikbare herstellzorg⁴³⁻⁴⁵.

Topic 3: Behoeften, hiaten en obstructies herstel(ondersteuning)

- Behoeften hebben betrekking op de benodigde zorg en ondersteuning van participanten om klinisch (zowel fysiek als mentaal), sociaal en persoonlijk herstel te bereiken)²⁶.
- Hiaten verwijzen naar de verschillen tussen huidige zorg en benodigde zorg. Hierbij gaat het voornamelijk over aanvullingen op de huidige zorg.
- Obstructies verwijzen naar de barrières die participanten tegenkomen tijdens de transitie naar de laatste stadia van herstel (leven met de aandoening en leven voorbij de aandoening), volgens Spaniol et al⁶⁹.
- Om de huidige zorg te kunnen verbeteren moeten de behoeften, hiaten en obstructies uitgevraagd worden^{27-31,39,55,62-64}.

D. Interview guide

Table 6: Interviewguide

Introductie interview	
Intro	Hallo ik ben Elmy, masterstudent gezondheidswetenschappen en mondhygiënist. Ik ben blij dat u deel wilt nemen aan mijn onderzoek en hiervoor de tijd wilt nemen. Als het goed is heeft u een informatiebrief ontvangen, heeft u hier nog vragen over?
Topics	Dit gesprek zal gaan over uw ervaringen met betrekking tot herstel en herstellzorg na uw borstkanker behandelingen. Hierbij gaat het om verschillende vormen van herstel: <ul style="list-style-type: none"> • persoonlijk herstel (herstel zoals u dat zelf ervaart). • klinisch/medisch herstel: afwezigheid van (mentale en fysieke) ziekteverschijnselen. • functioneel herstel: het uit kunnen voeren van taken/handelingen en voor uzelf kunnen zorgen. • sociaal/maatschappelijk herstel: verbeteringen op het gebied van wonen, werk, inkomen en sociale contacten.
Onderzoeksdoel	Deze interviews worden bij meer ex-borst kankerpatiënten gehouden. Met behulp van dit onderzoek wordt gekeken naar hoe herstellzorg na borstkanker verbeterd kan worden. Dit onderzoek maakt deel uit van een onderzoek naar herstellzorg na medische episode in de regio Utrecht, om meer betekenisvol zorg- en onderwijsaanbod te ontwikkelen.
Anonimiteit en vertrouwelijkheid gegevens	Bij het uitwerken van de gegevens wordt uw naam niet genoemd, zo kan niemand straks achterhalen wat u precies heeft gezegd. De dingen die u mij vertelt zullen alleen voor dit onderzoek gebruikt worden en zijn dus niet naar u herleidbaar.
Als u wilt stoppen	Als u tijdens het interview besluit dat u wilt stoppen, kunt u dat aangeven en dan stoppen we met het interview.
Tijd	Het interview duurt één tot anderhalf uur.
Gesprek opnemen	Ik neem het gesprek op, dit zorgt ervoor dat ik tijdens het interview niet veel hoef te schrijven en alle aandacht kan vestigen op het luisteren naar u. Ons gesprek wordt later uitgeschreven. Vanuit de wet is voorgeschreven dat ik uw toestemming moeten vragen als we gebruik maken van een opname, daarom vraag ik u zo meteen als de recorder loopt of u toestemming geeft dat dit gesprek wordt opgenomen.

Tijdens het interview		
Uitvragen demografische gegevens	Leeftijd, geslacht, arbeidsstatus, woon provincie, tijd sinds behandelingen, type borstkanker, type behandelingen	
Toestemming gesprek opnemen	Geeft u toestemming om dit gesprek op te nemen? *start opname*	
Topic	Voorbeeldvraag	Uitleg
Ervaring persoonlijk herstel	<ul style="list-style-type: none"> • U heeft met borstkanker te maken gehad. Hoe gaat het nu met u? • Hoe is dit veranderd ten opzichte van toen u net klaar was / hoe heeft u uw herstel (tot nu toe) ervaren? • Wat heeft of had u nodig voor een goed herstel? 	<p>Denk aan: fysieke en mentale gezondheid, zingeving, kwaliteit van leven, meedoen, dagelijks functioneren.</p> <p>Wat was positief, wat was lastig?</p> <p>Ervaringen positief/negatief, hersteld naar eigen beleving.</p>
Ervaring over herstel-ondersteuning	<ul style="list-style-type: none"> • Wat voor ondersteuning heeft u gekregen bij uw herstel, van wie, en hoe heeft u die ondersteuning ervaren? • Hoe kwam u terecht bij (eventuele) professionele ondersteuning? • Hoe kijkt u terug op de periode na uw borstkanker behandelingen? 	<p>Denk aan hulp voor: fysiek en mentaal herstel, zingeving, kwaliteit van leven, meedoen (sociale contacten met anderen), dagelijks functioneren.</p> <p>Huisarts, ziekenhuis, lotgenoten, internet, kennissen, zorg- of arbeidsongeschiktheidsverzekering.</p> <p>Ervaringen positief/negatief, hersteld naar eigen beleving. hiaten (wat ontbreekt), obstructies (tegenaanlopen), ervaringen positief/negatief.</p>
Behoeften herstel-ondersteuning	<ul style="list-style-type: none"> • Wat voor hulp heeft u NU nodig? • Is er iets wat zou u willen adviseren aan zorgprofessionals/instellingen met betrekking tot het verlenen van herstelondersteuning? • Heeft u nog iets toe te voegen wat nog niet besproken is? 	(Kan een herhaling zijn)
Afsluiting	<ul style="list-style-type: none"> • Weet u nog iemand die ik zou kunnen benaderen? • Wat vond u van het interview? 	

Afsluiting	
Membercheck	Het interview zal worden uitgewerkt. U kunt hier een uitdraai van ontvangen.
Uitleg vervolgstappen	Ik typ het interview letterlijk uit. Belangrijke punten/onderwerpen vergelijk ik met andere interviews. De bevonden resultaten en conclusies beschrijf ik in mijn masterthesis.
Bedanken	Hartelijk bedankt voor uw tijd en deelname. Ik hoop dat u het gevoel heeft dat u uw verhaal en ervaring kon vertellen.
Contact	Als er nog vragen zijn kunt u me contacteren via de mail.

E. Phases of thematic analysis

Table 7: Phases of thematic analysis

Nr.	Phase	Description of process and conducted analysis	Involved researchers
1	Familiarising with the data	Transcribing the data, reading the data, and rereading the data line by line. Noting down initial ideas and codes.	EM
2	Generating initial codes	Coding interesting features of the data systematically across the entire data set. Collecting data relevant to each code.	EM
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.	EM, WB
4	Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire dataset; generating a thematic 'map' of the analysis.	EM, GV, MR, LH
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story told by the analysis; generating clear definitions and names for each theme.	EM
6	Producing the report	Selection of vivid extract examples and final analysis of selected extracts; relating back to the analysis to the research question and literature, producing a scholarly report of the analysis.	EM, LH, WB

EM: E.C.A. Maas. Principal investigator (PI), dental hygienist and master student Clinical Sciences for Health Professionals, program in Clinical Health Sciences, University Medical Center Utrecht, Utrecht University, The Netherlands. The principal investigator is a Dutch woman who is likely to approach the subject with an open mind, due to her limited prior knowledge, as BC is not commonly encountered in her primary social network.

WB: W. van Boxtel, MSc. PhD candidate Amsterdam UMC and researcher, Research Group Innovations in Preventive Health Care, HU University of Applied Sciences, Utrecht, The Netherlands.

GV: G. Vujevich. Skin therapist and master student Clinical Sciences for Health Professionals, program in Clinical Health Sciences, University Medical Center Utrecht, Utrecht University, The Netherlands.

MR: M. van Rossum, Dietitian and master student Clinical Sciences for Health Professionals, program in Clinical Health Sciences, University Medical Center Utrecht, Utrecht University, The Netherlands.

LH: E.B. Haverkort, PhD. Supervisor and senior researcher, Research Group Innovations in Preventive Health Care, HU University of Applied Sciences, Utrecht, The Netherlands.