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Optimizing cancer care through e-health: status, potential, and adoption

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Chapter 5

What is needed for improved uptake and adoption of digital aftercare programs by cancer survivors: a mixed methods study applying the COM-B model

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Abstract

Introduction

Cancer survivors face physical, lifestyle, psychological, and psychosocial challenges. Despite the availability of aftercare services, survivors still have unmet needs. Digital aftercare programs may offer support, but their use is limited. This study aimed to examine what is needed to improve uptake and adoption of these programs. Additionally, it explored sociodemographic and clinical variables that may influence these needs.

Methods

A mixed-methods approach was used, involving qualitative interviews, and a questionnaire. The research was guided by the COM-B model of behavior, which considers capability, opportunity, and motivation crucial for behavior. Qualitative analysis was performed using the framework method. Statistical analyses involved descriptive statistics and regression analysis.

Results

Fourteen cancer survivors were interviewed, and 213 participants completed the questionnaire. Findings indicated that most respondents had a positive or neutral attitude towards digital aftercare programs, believing these could address their cancer-related challenges. Still, only a small percentage had experience with them, and most were unaware of their existence. Many expressed a desire to be informed about them. Some were uncertain about their effectiveness. Others were concerned about the lack of reimbursement. No significant influence of the sociodemographic and clinical variables was found.

Conclusion

Cancer survivors are generally positive about digital aftercare programs but are often unaware of their availability. Raising awareness, clarifying their value, and providing support and reimbursement could enhance uptake and adoption. The current insights can contribute to better engagement with digital aftercare programs, which may ultimately foster enhanced health, well-being, and quality of life.

Introduction

Cancer diagnoses have been on the rise in recent years. In the Netherlands, the number of patients receiving a cancer diagnosis has increased from 74,500 twenty years ago to 124,100 in 2022 [1]. Worldwide, there is a 20% chance of developing cancer before the age of 75 [2]. Approximately 70% of adult male cancer patients and 66% of adult female cancer patients survive for at least five years after diagnosis [3]. Cancer survivors often experience physical, lifestyle, psychological, and psychosocial challenges after treatment. Examples of these challenges are fatigue, fear of recurrence, cognitive limitations, sexual dysfunction [4-9], and community reintegration problems, which include cancer-related financial and employment issues and issues relating to friends and family members [10-12]. These challenges vary depending on the type of cancer and treatment and can persist long after treatment completion [13-15].

Previous research showed that 63% of cancer survivors have unmet needs after treatment. These needs are mainly related to emotional and social support, managing side effects, coping with the fear of recurrence, accessing up-to-date information, work support, and smoking cessation support [13]. As a result, addressing the needs of cancer survivors extends beyond the realm of medical care, requiring a broader commitment at the societal level.

The Health Council defines aftercare as an essential part of individual patient care after cancer treatment [16], which includes providing information and guidance, addressing complaints and symptoms, assessing direct or late effects (i.e., those consequences that do not yet exist, or at least do not present complaints at the end of treatment) of disease and treatment, and attention to social consequences [16]. Cancer survivors' health, well-being, and quality of life benefit significantly from proper aftercare [17-19]. For example, nurse-led survivorship care has been shown to have positive patient-reported outcomes in areas such as cognitive and social functioning and fatigue [20].

In Dutch hospitals, cancer care regularly focuses mainly on the medical treatment provided by specialists, with little emphasis on psycho-social aftercare [21]. Additionally, general practitioners and specialist nurses often face difficulties in delivering existing aftercare due to time, resources, and knowledge constraints [10]. Other healthcare providers (HCPs), such as paramedics, psychologists, and informal caregivers from cancer meeting centers, can offer support on psychosocial issues. However, a large proportion of cancer survivors still do not receive appropriate care and support aimed at dealing with the (late) consequences of cancer (treatment) [22].

Digital self-management programs can be a helpful and accessible way to provide aftercare. Typically accessed through web or mobile applications, these programs cater to individual needs.

For instance, a digital aftercare program may commence with users logging into a website and completing a questionnaire detailing their symptoms and challenges. Subsequently, a personalized program is curated based on these responses. This tailored approach encompasses various elements such as informational resources, expert advice, shared experiences from fellow cancer survivors, and interactive assignments on topics such as fatigue, fear of cancer recurrence, and lifestyle [23-33]. For instance, one assignment might involve maintaining an activity diary to discern which activities drain energy and which replenish it for the individual.

Digital self-management programs can alleviate the strain on care for cancer survivors and help survivors develop self-management skills. A recent systematic review in the Netherlands found that several initiatives have been developed and scientifically examined, demonstrating promising results [34]. For instance, these initiatives have shown to be effective in improving physical activity and sleep quality, as well as reducing depressive symptoms [34-36].

Despite the benefits of digital interventions that address cancer-related issues, their impact is often limited due to their restricted reach [37, 38]. Studies have shown that the uptake and adoption of such interventions is hindered by several factors, including limited perceived usefulness and usability, technical difficulties, and lack of time, motivation, and familiarity among users [39-42].

To better understand the factors that affect the use of digital aftercare programs in cancer care, the current study aims to answer the following research question: What do cancer survivors need for improved uptake and adoption of digital aftercare programs? To examine this, the Capability, Opportunity, Motivation - Behaviour (COM-B) model was used as a framework [43]. This model is a widely used behavioural change model in digital health intervention research [44, 45]. According to this model, individuals can only engage in a specific behaviour, such as using digital aftercare programs, if they have the capability, opportunity, and motivation to do so [46].

Research has shown that certain sociodemographic factors, such as age, income, and education level, can affect the use of digital applications. Specifically, individuals who are older, or have lower income or educational levels, tend to use these applications less often [47-49]. This indicates that the extent to which people use digital applications varies. Additionally, research has indicated that clinical factors, such as cancer type and time elapsed since treatment, can influence the challenges experienced after treatment [13-15, 50], which may affect the need for (digital) aftercare. However, it remains unclear whether there are any variations in what is required to encourage the uptake and adoption of online aftercare programs, particularly for cancer survivors. Therefore, the second research question aims to address this gap: Are there

any sociodemographic or clinical variables that influence cancer survivors' needs regarding the uptake and adoption of digital aftercare programs?

There has been little research conducted on the uptake of digital aftercare interventions for cancer survivors. The current study contributes to this field of research and takes a new approach by being the first to use the COM-B model to study the factors that influence survivors' participation in digital aftercare programs. Additionally, this study contributes to the existing literature by exploring bottom-up the needs of cancer survivors regarding the uptake and adoption of digital programs, followed by surveying a broad (more representative) group about these needs. This comprehensive approach enhances the reliability of findings. Additionally, this study examines the specific needs of diverse groups of cancer survivors, considering sociodemographic and clinical factors. Together, this presents a thorough overview of needs, to understand and improve the utilization of digital aftercare programs in specific populations.

Methods

Study design

This study employed a mixed-methods design, using semi-structured interviews and a self-constructed questionnaire to gain a comprehensive understanding of the subject through methodological triangulation [51]. The first research question was answered by conducting interviews to identify themes and gain context, followed by a questionnaire to verify the consistency of information among a larger and more diverse group of cancer survivors. To enhance accessibility and convenience, interviews were conducted online via videoconference and the questionnaire was distributed digitally. This approach may introduce a response bias, as individuals who are more likely to engage with online resources are also the ones providing data on their needs for digital programs. However, considering that this demographic constitutes the primary target group, this method was selected to facilitate their participation as much as possible.

For the second research question, exploratory analyses were performed on the questionnaire data to determine whether sociodemographic or clinical variables influenced the needs of survivors for the uptake and adoption of digital aftercare programs.

Conceptual framework

The qualitative interviews, the questionnaire, and the data analyses were based on the COM-B model of behaviour [43], a widely used approach to understanding behaviour and behavioural change in the context of health. The model is instrumental in designing behavioural interventions or approaches that effectively target specific factors influencing behaviour. The COM-B model

identifies three key factors for a behaviour: capability, opportunity, and motivation [52]. Capability refers to an individual's psychological and physical ability (i.e., knowledge, skills, and abilities) to engage in the behaviour. Opportunity encompasses external factors that enable or prompt the behaviour, such as social and physical circumstances. Motivation encompasses conscious and unconscious processes that drive behaviour, including emotion and impulse [52]. The interviews and questionnaire included questions to measure cancer survivors' capability, opportunity, and motivation to utilize digital aftercare programs. Furthermore, the data were analyzed using the COM-B model as a framework for the coding scheme.

Sampling and recruitment

Participants were recruited for the interviews through Kanker.nl (Cancer.nl); a national online platform for cancer survivors and their relatives [53]. Relevant users on this platform who had given permission to be approached for scientific research, received an email invitation. The invitation contained a sign-up link that directed them to a short online questionnaire to determine their eligibility for the study. Participants were eligible for this study if they had been diagnosed with cancer and completed treatment within the past five years and were proficient in Dutch. In addition, they had to report a need for support or information during the aftercare phase, as the study aimed to investigate the motivations and factors specifically related to the adoption and uptake of digital aftercare programs, rather than broader considerations regarding the need for aftercare itself. As a token of appreciation for their participation, respondents received a €25 gift voucher, which was communicated during recruitment.

A purposive sampling method [54] was used to select participants from the list of applicants to ensure diversity in demographics (age, gender, and education), cancer type, and duration since treatment completion. The sample size was not predetermined, and interviews were conducted until data saturation was reached. Out of forty-six applicants who met the eligibility criteria, sixteen were invited for an interview. However, two of them withdrew from participation, which resulted in a total of fourteen participants. All participants provided written consent and were fully informed about the objectives and characteristics of the study.

To gather respondents for the questionnaire, invitations containing the link to the questionnaire were emailed to the same group of Kanker.nl users who were approached for interviews. Respondents were also recruited through the LinkedIn pages of the researchers and their organizations and by posting invitations to Dutch Facebook groups for cancer survivors. Three €50 gift vouchers were raffled among the respondents, as communicated in the recruitment messages.

Before starting the questionnaire, all respondents received written information detailing the study's objectives and procedures. Respondents were required to confirm that they had read,

understood, and agreed to the goals and procedures of the study, as well as their rights as respondents.

Data collection

The online interviews were conducted in April and May 2023 in Dutch by two female researchers with a background in psychology and trained in interview techniques (authors LvD, MSc and RvdV, PhD). A semi-structured protocol, which consisted of open-ended questions and probes, was used during the interviews. This allowed the interviewers to adjust the order of questions or clarify them when necessary [55]. The protocol was pilot tested with a cancer survivor before the study began, resulting in minor adjustments.

At the start of the interview, each participant was presented with a hypothetical example of a digital aftercare program based on existing programs (Supplementary File 1). The design of the hypothetical program included a personalized questionnaire to determine which modules would be most relevant to the participant, followed by several modules providing information, videos from cancer survivors and HCPs, and assignments. The program would address topics such as fear of cancer recurrence, physical activity, and fatigue.

All components of the COM-B model were covered in the interview. The questions were based on sample questions developed by the University College London Centre for Behaviour Change [56], tailored to the context and method of this study. Some examples of the resulting questions were: 1. Have you ever used online aftercare programs? If so, what did you like, and what did you miss? (behaviour); 2. Can you tell us how familiar you were with online aftercare programs before this conversation? What do you know about them? (opportunity); 3. What advantages do you perceive to gain from using online aftercare programs? (motivation); 4. How easy or difficult do you think using online aftercare programs would be for you? What could make it easier for you? (capability). The complete interview guide can be found in Supplementary File 2.

The interviews, which were video recorded and transcribed verbatim, lasted approximately one hour. Data saturation was achieved for the identified themes after fourteen interviews.

The questionnaire was launched in July 2023 and could be filled out by respondents until September 2023. The questionnaire had forty-nine questions based on the COM-B model and the interview results. The interview results were used to select and operationalize the relevant themes related to the COM-B concepts to be included in the questionnaire. The questionnaire started with an assessment of demographics. Then, it continued with questions about each COM-B category, addressing current usage, motivation, capability, and opportunity for the adoption and uptake of digital aftercare programs. A video was created to explain the concept

of digital aftercare programs, which respondents were instructed to watch before completing the questionnaire. The video was based on the hypothetical example of a digital aftercare program given during the interviews. The questionnaire was hosted on Formdesk, which is a web-based survey platform [57]. It took about fifteen minutes to complete. The questionnaire can be found in Supplementary File 3.

Data analysis

The interviews were analyzed using MAXQDA 2022 software [58]. The analysis process was deductive, using the conceptual categories from the COM-B model as a framework [46], and inductive, adding new categories deriving from the data. The framework method [59] was used for data analysis, which is a qualitative content analysis approach adaptable for generating themes. Two researchers, LvD and RvdV, independently coded the first three interviews, after which the researchers collaborated to create a common coding framework for all the data. The coding framework was refined through continued collaboration and discussions to resolve discrepancies during the coding of all subsequent interviews. A framework matrix was created to summarize the data from each interview, and finally, the data was interpreted. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to ensure research quality (Supplementary File 4) [60]. Illustrative quotes were translated into English and the following information was added: participant number, gender, and age in years.

The IBM SPSS Statistics version 28 was used to analyze the data of the questionnaire [61]. Descriptive statistics were used to summarize the questionnaire items (Supplementary File 5). Exploratory regression analyses were conducted to examine whether sociodemographic or clinical variables influenced the needs of cancer survivors for the uptake and adoption of digital aftercare programs (Supplementary File 6). Four sociodemographic variables were analyzed: age, educational level, income, and marital status, as well as two clinical variables: type of cancer and duration since treatment completion. The exploratory analyses were conducted on four questions from the questionnaire designed to measure the main components of the COM-B model. For questions requiring respondents to choose one or multiple options, only those selected by at least 15% of the respondents were included in the analyses. The data was analyzed using binary logistic and ordinal regression analyses, as appropriate. Due to the large number of tests conducted, the Benjamin Hochberg FDR correction [62] was applied to correct for multiple testing.

Results

Characteristics of interview participants and questionnaire respondents

Interviews were held with fourteen participants: seven men and seven women. Six individuals completed secondary vocational education (42.9%), three completed post-secondary vocational education (21.4%), and five completed higher professional or academic education (35.7%). Most participants were diagnosed with either breast ($n=4$; 28.6%), skin ($n=3$; 21.4%), or bladder ($n=2$; 14.3%) cancer. The majority finished treatment either less than one year ago ($n=3$; 21.4%), one to two years ago ($n=5$; 35.7%), or three to four years ago ($n=4$; 28.6%). More information on interview participants' characteristics can be found in Supplementary File 7.

In the study, a total of 282 individuals responded to the questionnaire. Out of these, sixty-nine individuals were excluded from the analysis as they did not meet the inclusion criteria for participation. This was because they stated they did not require assistance with their challenges and complaints. The remaining 213 individuals' data were used for the analyses. Table 1 provides an overview of the characteristics of these respondents. For more information on the respondents' characteristics, please refer to Supplementary File 5.

Table 1. Questionnaire respondents' characteristics (N = 213)

Characteristics	n	%
Gender		
Male	70	32.9
Female	141	66.2
Non-binary	2	.9
Age		
Mean (SD, min-max)	71 (10.6, 23 – 94)	
Marital status¹		
With partner	154	72.3
Without partner	58	27.2
Educational level		
Secondary (vocational) education	43	20.2
Post-secondary vocational education	52	24.4
Higher professional education or academic education	118	55.4
Difficulty making ends meet from household income in the past twelve months²		
Yes	48	22.5
No	164	77.0
Cancer type³		
Breast cancer	51	23.9
Colorectal cancer	22	10.3
Bladder cancer	20	9.4
Prostate cancer	16	7.5
Throat or laryngeal cancer	13	6.1
Esophageal cancer	11	5.2
Ovarian cancer	8	3.8
Skin cancer	8	3.8
Multiple types of cancer	8	3.8
Uterine or cervical cancer	7	3.3
Lymph node cancer	7	3.3
Lung cancer	6	2.8
Brain tumour	5	2.3
Other types	31	14.5
Time since treatment completion⁴		
Currently undergoing treatment	34	16.0
Less than one year ago	46	21.6
One to two years ago	53	24.9
Three years or longer ago	80	37.6

¹With partner: married or registered partnership (n=123, 57.7%); in a relationship (not married or in a registered partnership) (n=31, 14.6%). Without partner: single (n=29, 13.6%); divorced (n=15, 7.0%); widow(er) (n=14, 6.4%). Other (n=1, 0.5%); ²Yes: significant difficulty (n=10, 4.7%); some difficulty (n=38, 17.8%). No: no difficulty, but I need to watch my expenses (n=78, 36.6%); no difficulty (n=86, 40.4%). I would rather not say (n=1, .5%); ^{3,4}An overview of the other types of cancer and data on the duration since treatment is completed can be found in Supplementary File 5.

The results of the qualitative analyses of the interviews and the descriptive analyses of the questionnaire data are presented below. Additional details on these results can be found in Supplementary File 5.

Behaviour – experiences with the (digital) aftercare interventions

All interview participants experienced challenges and complaints after treatment completion, as this was an inclusion criterion to participate in the interviews. They frequently mentioned fatigue, fear of recurrence, and difficulty in processing their experiences with the disease and the treatment. Pain, nutrition, and exercise were also mentioned.

Participants were asked about their current in-person and digital aftercare usage. A small group of participants had in-person contact with HCPs such as physiotherapists, psychologists, or dieticians. Some sought information from patient associations or walk-in centers. Half of those interviewed used online opportunities to connect with peers, for example, through social media. No interviewee utilized stand-alone digital aftercare programs as outlined by the researchers in the hypothetical example. Two individuals participated in blended aftercare programs that combined online conversations or modules with in-person consultations with a psychologist.

“An online aftercare program would definitely be something that appeals to me, at least. There was a point when I really felt the need for it and even looked for it, but I didn’t find anything suitable.”
[Interview 3, woman, 62 years old]

The questionnaire respondents reported facing various challenges and complaints after treatment. The most commonly listed were fatigue ($n=162$; 76.1%), fear of cancer recurrence ($n=119$; 55.9%), concentration problems ($n=102$; 47.9%), and pain ($n=100$; 46.9%). Almost all respondents agreed (completely) with the following statement: “I think it is important to address my complaints or challenges to alleviate the resulting stress” ($n=196$; 92%). Participants sought help from various sources, which included visiting a general practitioner ($n=108$; 50.7%), a physiotherapist ($n=130$; 61%), or a psychologist ($n=91$, 42.7%). In addition, over two thirds of the participants searched for information online ($n=143$; 67.1%). Some sought digital peer support, for example, via Kanker.nl ($n=96$; 45.1%). Only a small percentage of respondents had used digital aftercare programs before ($n=21$; 9.9%).

Capability – knowledge, skills, and ability to use digital programs

Digital aftercare programs were largely unknown among the interview participants; only one person was familiar with them. Numerous participants have expressed their desire to be informed about the available programs. After completing their treatment, a substantial number of participants felt unsupported and left to fend for themselves. They believed that digital aftercare programs could have been helpful during this phase.

“Yes, awareness is the most important thing. That people know there is more help available than just the hospital.” [Interview 14, woman, 56 years old]

Participants had varying opinions on who should inform them about digital aftercare programs. While most participants believed that the hospital should facilitate this, specifically the doctor or nurse, some preferred to be informed through their general practitioner or notified through social media. Most participants did not have a specific preference about the timing of when they should receive this information during their treatment process. Half of the participants expressed confidence in their ability to use digital aftercare programs, believing that they could easily navigate them. Others stated that they could use the programs but emphasized the need for accessible, and user-friendly design. A small group of participants felt that they lacked sufficient digital skills and needed to improve them to use the programs effectively. Participants suggested a clear explanation of the program, IT help desks and support websites to support those with less digital literacy skills. Furthermore, they mentioned that senior citizens' associations, domiciliary care, libraries, and individuals' social networks could serve as potential support providers.

“I spoke with a 74-year-old woman with breast cancer, and she feels completely abandoned. But she also doesn't seek help herself because she's not from the generation that uses computers.” [Interview 7, woman, 49 years old]

The questionnaire results showed as well that most respondents ($n=180$; 84.5%) were unfamiliar with digital aftercare programs, as explained in the video before filling out the questionnaire. Of the 33 respondents who had heard of it (15.5%), most were informed by their oncological nurse ($n=8$; 24.2%) or the Kanker.nl website ($n=11$; 33.3%). Of the 21 respondents (9.9%) with prior experience using digital aftercare programs, 47.6% ($n=10$) (completely) agreed that they addressed their challenges, 38.1% ($n=8$) had no opinion, and 14.3% ($n=3$) (completely) disagreed.

Most respondents would have liked to have been informed about the existence of digital aftercare programs ($n=205$; 96.3%), which should be done preferably during ($n=93$; 43.7%) or immediately after completing treatment ($n=115$; 54.0%). Respondents preferred to hear about it from HCPs such as their medical specialist ($n=131$; 61.5%), (oncological) nurse ($n=127$; 59.6%), or general practitioner ($n=99$; 46.5%). Other frequently listed sources were the website Kanker.nl ($n=84$; 39.4%) and patient associations ($n=52$; 24.4%).

Most respondents agreed with the statement that they possessed sufficient digital skills to use digital aftercare programs ($n=189$; 88.7%). However, almost half of them ($n=100$; 46.9%) still expressed the need for further assistance, such as through a digital helpdesk ($n=60$; 28.2%), a phone number to call ($n=35$; 16.4%), or a program tutorial ($n=30$; 14.1%). About forty percent of the respondents ($n=85$; 39.9%) reported they did not require any help using the programs,

and 13.1% did not know ($n=28$). Apart from digital skills, other factors that could hinder respondents from using digital aftercare programs were a lack of energy ($n=58$; 27.2%) and concentration ($n=48$; 22.5%).

Opportunity – external factors that enable or prompt the use of digital programs

Related costs and reimbursement were external factors influencing the opportunity to use the programs among interview participants. Participants expressed varying opinions regarding their willingness to pay for digital aftercare programs. Many could pay for such programs but would only be willing if they were proven effective. On the other hand, some participants stated that they were not willing to spend money on digital aftercare programs. Some reasons for this included limited funds and the belief that health insurance should cover aftercare. Some participants mentioned that offering programs for free would make them more accessible.

“I do think it should be covered. Because it's not for everyone, it's for specific groups. There are already so many cutbacks, and you already have to pay for so much yourself. I think these kinds of things should just be taken care of by health insurance.” [Interview 10, man, 42 years old]

The participants did not experience any major obstacles due to the absence of information and communication technology (ICT) resources, as most of them possessed the necessary equipment. They also expressed that they would be able to manage their time effectively to use the digital programs. Furthermore, the participants reported that their immediate social environment supported their recovery. However, their support would not be a decisive factor in the participants' decision to use digital aftercare programs.

According to the questionnaire results, several external factors may hinder respondents from using digital aftercare programs. A crucial factor was the payment for digital aftercare programs. Some participants indicated they had little money to purchase a digital aftercare program ($n=26$; 12.2%). Most respondents did not want to pay anything for the use of the program ($n=166$; 77.9%). Of those willing to pay ($n=47$; 22.1%), the average amount they wanted to pay would be 48.8 euros ($SD = 36.6$; range: 10–150). For 60.1% of respondents ($n=128$), it was crucial that their health insurance entirely financed the program. Other relevant factors influencing the use of digital aftercare programs were doubts about their effectiveness ($n=64$; 30.0%) and reliability ($n=29$; 13.6%) and concerns about privacy ($n=32$; 15.0%). However, about a quarter of the respondents ($n=56$; 26.3%) did not believe any factor could prevent them from using a digital aftercare program.

In terms of the role of the social environment, respondents generally expected their social environments, such as friends, family, and colleagues, to have a (very) positive ($n=99$; 46.5%) or neutral ($n=68$; 31.9%) attitude towards digital aftercare programs. Part of the respondents did

not know the opinion of their social environment on the matter ($n=43$; 20.2%). Most respondents (completely) disagreed with the statement: “The opinion of the people in my surroundings would influence my decision to use digital aftercare programs” ($n=144$; 67.6%), while 26.8% ($n=57$) neither agreed nor disagreed, and 35.7% ($n=76$) (completely) agreed. Only a few respondents had someone in their social surroundings using digital aftercare programs ($n=12$; 5.6%). Most respondents believed that their HCPs would have a (very) positive ($n=123$; 57.8%) or neutral ($n=43$; 20.2%) attitude towards digital aftercare programs. Some respondents indicated they did not know their HCPs’ opinions ($n=42$; 19.7%). The respondents held different beliefs regarding whether their healthcare providers’ opinions would affect their decision to use digital aftercare programs. Among them, 37.6% ($n=80$) completely agreed with the statement “The opinion of my healthcare providers would influence my decision to use digital aftercare programs,” while 30.5% ($n=65$) completely disagreed and 25.4% ($n=54$) neither agreed nor disagreed.

Motivation – (un)conscious processes that drive the use of digital programs

Many interview participants expressed their willingness to use digital aftercare programs to address their challenges. They believed that these programs could offer a sense of validation for individuals who feel misunderstood or unsupported by their social environment when they encounter difficulties after treatment has ended.

“And also with those fatigue complaints, if there is a good way to work on that, then I would definitely make use of it.” [Interview 3, woman, 62 years old]

However, some participants expressed uncertainty or skepticism towards digital aftercare and believed that in-person care was superior. During the study, the participants shared their thoughts on the pros and cons of digital aftercare. They mentioned that digital aftercare had several benefits such as being convenient, accessible, and flexible. It also eliminates waiting lists, saves time and costs, can prevent further care, and allows patients to pause the program or revisit information.

“I can set it aside for a moment and think about it. So that’s easier than when you’re talking with someone, because when you’re talking with someone, you want to be able to give an immediate answer, and that just doesn’t always work. Sometimes I just can’t come up with things.” [Interview 14, woman, 56 years old]

However, some participants felt that it could be impersonal and requires a lot of self-discipline to continue. While a few preferred in-person support, most believed that the advantages of digital aftercare outweighed the disadvantages. A few were willing to consider digital aftercare but distrusted commercial programs.

Concerning the program's content, participants desired personalized programs tailored to their needs. They would prefer programs that offer information, tips, and advice on how to deal with various issues and situations. Some participants would like to read about the experiences of peers, while others would appreciate direct contact with fellow sufferers. Assignments would be helpful to some, and others would appreciate references within the program for further information. Almost all participants were motivated to use online programs to reduce the impact of their challenges and complaints on their daily lives. Participants suggested receiving regular reminders and feedback and adjusting the program based on their results to stay motivated. Although not typically part of stand-alone digital aftercare programs, almost half the participants wished to have contact with an HCP or an experienced expert in addition to the program.

"When it comes to fatigue, it's nice to have tips. For example, knowing which exercises you should do, how long you should do them, and perhaps something related to diet. Like saying: well, it's best not to eat too much of this, but make sure you get plenty of fruits and vegetables." [Interview 2, man, 62 years old]

Regarding the questionnaire results, it was observed that most respondents had a positive ($n=133$; 62.4%) or neutral ($n=69$; 32.4%) attitude towards digital aftercare programs. To the statement: "Digital aftercare programs can help me with the complaints or challenges I am experiencing due to cancer or cancer treatment," most respondents (completely) agreed ($n=130$; 61.0%) or neither agreed nor disagreed ($n=50$; 23.5%). When reflecting on their motivation to use digital programs, most respondents believed that the benefits of using a digital aftercare program would outweigh the disadvantages ($n=114$; 53.5%), while some did not know ($n=76$; 35.7%), and only a few did not think the benefits would outweigh the advantages ($n=23$; 10.8%). The most frequently selected advantages (from a list of options) of digital aftercare programs were being in control of when to use it ($n=179$; 79.8%), the option of re-reading information ($n=132$; 62.0%), being able to instantly (without a waiting list) ($n=80$; 37.6%) and independently ($n=75$; 35.2%) work on challenges and complaints, and receiving support in the phase after treatment completion ($n=68$; 31.9%). Out of the options provided, the most common selected drawbacks of the program were the inability to have personal contact ($n=133$; 62.4%), the absence of opportunity to ask questions ($n=106$; 49.8%), and the fact that it takes effort to continue using the program ($n=76$; 35.7%). Out of all respondents, 30.0% expressed doubts about the effectiveness of digital aftercare programs ($n=64$), while 13.6% had concerns about their reliability ($n=29$).

Regarding staying motivated to use digital programs for a more extended period, part of the respondents would find it (very) difficult to consistently use a digital aftercare program a few times a week ($n=42$, 20.6%). A larger group neither would find it hard nor easy ($n=78$; 36.6%), while other respondents would find it (very) easy ($n=70$; 32.9%), and 9.9% did not know ($n=21$).

The questionnaire results indicate that the factors that would encourage people to use these programs frequently include personalized tailoring of the program to their situation ($n=134$; 62.9%), providing insight into the duration and the completed parts of the program ($n=124$; 58.2%), and providing feedback based on their activities ($n=91$; 42.7%). In addition, respondents expressed interest in having digital contact with an HCP or coach ($n=87$; 40.8%) and receiving regular reminders ($n=73$; 34.3%).

Exploratory analyses regarding possible influencing variables

Supplementary File 6 contains the output of the exploratory analyses regarding possible influencing variables on four questions representing the main components of the COM-B model. The first question assessed respondents' familiarity with digital aftercare programs. Binary logistic regression analysis revealed no significant associations between the sociodemographic and clinical variables and respondents' responses to this question. The second question explored possible differences in respondents' preferences of how to be informed about digital aftercare programs. Separate binary logistic regression analyses were conducted for each answer option selected by at least 15% of respondents. Initially, the results showed significant associations between the variables "Age" and "Type of cancer" and the answer option "through the medical specialist" ($p = .006$; $p = .004$, respectively). A significant association was also found between the variable "Educational level" and the answer option "through the nurse" ($p = .006$). However, after applying the Benjamin Hochberg False Discovery Rate (FDR) correction, these three associations were no longer significant ($p = .18$; $p = .18$; $p = .18$ respectively). The third question investigated factors that could deter respondents from using digital aftercare programs. Initially, the results revealed significant associations between the variable "Age" and the answer option "Difficulty concentrating" ($p = .029$), and the variable "Type of cancer" and the answer option "no factors" ($p = .02$), but after applying the Benjamin Hochberg FDR correction, these associations lost their significance ($p = .44$; $p = .40$ respectively). The fourth question assessed respondents' agreement with the statement, "I would like to address my complaints or challenges independently and online." An ordinal regression analysis initially found one significant association for the variable "Time Since Treatment Completed" ($p = .009$). This association was no longer significant after applying the Benjamin Hochberg FDR correction ($p = .20$).

Discussion

The primary research question of this mixed-methods study was: what is needed for improved uptake and adoption of digital aftercare programs by cancer survivors? The study's findings suggest that cancer survivors are generally positive about using digital aftercare programs. They value the possibility to use these programs independently and on their own terms. They recognize the potential of such programs in addressing various challenges they face, such as fatigue, fear

of recurrence, coping with illness, and pain. Other studies have also found positive attitudes among cancer survivors towards digital aftercare programs. For instance, a study by Melhem et al. (2023) found that many cancer survivors are interested in using mobile applications to access cancer-related information during survivorship [47], while another study by Vogel et al. (2021) found that 68.7% of cancer survivors believed that an app would be an ideal complement to standard follow-up [63]. However, despite this positive attitude, the current study also found that usage of digital aftercare programs among cancer survivors is very low, which is consistent with previous research that found low adoption rates of mobile technologies among cancer survivors [64].

During the study, several key factors were identified that could potentially enhance the uptake and adoption of digital care programs among cancer survivors. Notably, it was observed that many survivors are often unaware of the existence of these programs, despite two-thirds of questionnaire participants indicating they searched for information on complaints and challenges related to their cancer or cancer treatment online. This finding aligns with previous research indicating that patients often lack knowledge about their e-health options, resulting in the underutilization of such programs [65]. The low discoverability of digital care resources underscores the need for improved visibility and accessibility to ensure that survivors can easily find these programs and benefit from them.

Survivors would appreciate being actively informed about the programs, preferably by their medical specialist or nurse. Although the social environment doesn't seem to influence survivors' decision to use digital aftercare programs, healthcare professionals' opinions are very important for some survivors. Therefore, it is important for healthcare professionals to inform their patients about the available programs, their effectiveness based on evidence, and the possible benefits that the programs can provide for the patient. It is crucial to understand the preconditions and needs of healthcare professionals to effectively perform their role as a referrer. Therefore, it is essential to determine if healthcare professionals are familiar and willing to recommend such programs. Incorporating information about online aftercare programs into HCP educational programs can be beneficial, enabling them to know the options, which ones have been proven effective, and which ones they can confidently recommend.

Additionally, some survivors have doubts about the effectiveness of digital aftercare programs, and some considered traditional in-person care to be superior. These doubts may limit their willingness to use such programs and hinder their ability to benefit from them [66]. In these cases, a blended approach, combining online components through digital aftercare programs with face-to-face interaction with human care providers, could be an adequate solution [67]. This blended care approach is commonly used in e-health and could overcome the limitations of digital programs, although it introduces its own set of challenges [67-70]. In fact, our study

found that many respondents would prefer a combination of a digital aftercare program with (digital) contact with a healthcare provider.

Furthermore, our study discovered that certain design elements of digital aftercare programs are vital to motivate survivors to use them consistently. Personalized programs that provide feedback on the progress made, by offering insights into their activities, were found to be more engaging for survivors. Therefore, tailoring information, advice, and support to the individual's use and needs can enhance digital aftercare programs. Evidence has shown that tailored web-based interventions on health behaviors are more effective than non-tailored interventions in affecting health outcomes [71]. For example, a meta-analysis by Lustria et al. (2013) demonstrated the effectiveness of tailored web-based approaches to health interventions [72].

Finally, the availability of free digital aftercare programs significantly impacts their uptake and adoption by cancer survivors. Currently, the provision of these programs varies. Some are offered by healthcare institutions, such as general practitioners, mental healthcare organizations, or hospitals. Others are provided for free by private organizations or patient organizations. Finally, some programs must be purchased by patients. Many survivors hesitate to pay for these programs out of pocket and would prefer their healthcare insurer to cover the costs. Thus, it is crucial to organize these programs, so they are included in the reimbursed care package. To address the issues of availability and accessibility, a Dutch initiative called the Cancer.nl OncoAppstore was recently launched [73, 74]. The OncoAppstore, financed by the Dutch Cancer Society, is a central landing page via a reliable source. Currently, cancer survivors can receive a digital budget of one hundred euros via the website. This budget enables them to access interventions that have been labeled evidence-based and user-friendly based on the test method of the Dutch Public Health Service [75]. Also, healthcare professionals and other relevant parties could use the OncoAppstore to easily refer patients to digital aftercare programs.

Another strategy that could be used to increase awareness of the possibilities of digital programs among cancer survivors is using public health campaigns via social media, which has been successfully done to improve knowledge and attitudes towards cancer prevention [74]. Additionally, community-based outreach programs can be applied to reach cancer survivors in diverse populations [76]. Research is needed to examine whether these approaches encourage more survivors to uptake and adopt these programs.

The study's second research question was whether certain sociodemographic and clinical variables influence the needs for the uptake and adoption of digital aftercare programs. However, based on the current exploratory analyses, there was insufficient data to demonstrate the possible influence of the studied variables. Therefore, additional analyses should be conducted

using larger datasets to examine these and other variables to enhance the generalizability of the findings.

This study had several strengths, one of which was the use of a mixed-methods approach. This approach made it possible to cross-verify findings, increasing the overall validity and reliability of the results. Additionally, the use of the COM-B model provided a structured theory-based approach to understand the complex interplay of several factors. However, there were some limitations that need to be acknowledged [77]. First, the study relied on convenience samples and self-reported data, which may have led to a selection and response bias [78]. Additionally, since the interviews and the questionnaire were conducted and distributed digitally, individuals with digital skills are likely overrepresented. However, given the large group that needs additional support while relatively few make use of digital programs, it provides valuable insight to start with those who are already using the internet. They are the primary target for broader outreach with this type of intervention. Finally, the data was cross-sectional, which limits the ability to establish causal relationships and observe temporal changes [79].

Conclusion

In this mixed-methods study, guided by the COM-B model, we integrated qualitative and quantitative approaches to gain valuable insights into cancer survivors' views on what is needed for their improved uptake and adoption of digital aftercare programs. The study showed that cancer survivors are generally positive about using digital aftercare programs and recognize their numerous benefits. However, many survivors are unaware of the existence of these programs. For the uptake and adoption of digital aftercare programs, it is essential to raise awareness, clarify their value, and ensure that funding and support are available for survivors. The results of this study can be used to improve survivors' access to and utilization of digital aftercare programs, which may ultimately foster post-treatment outcomes.

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Declarations

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Conflict of Interest

The authors declare no competing interests.

Authors' Contributions

LvD, JJA, and RvdV conceptualized the study idea and objectives and designed the codebook. LvD and RvdV conducted the data collection, analysis, and interpretation. LvD wrote the manuscript. RvdV, JJA, and NHC critically revised the manuscript. All authors read and approved the definitive version of the manuscript for submission and publication in this journal.

Data availability

The authors confirm that the data supporting the findings of this study are available within the article and its Supplementary Files. Raw data that support the findings of this study are available from the corresponding author; upon reasonable request.

Ethics approval

The study was declared to not fall within the scope of the Dutch Medical Research Involving Human Subjects Act by the clinical expertise center of the Dutch National Institute for Public Health and the Environment (VPZ-612).

Consent to participate

All interviewees and questionnaire respondents have provided written informed consent to participate.

Consent for publication

Not applicable.

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Supplementary File 1.

Illustration of a digital aftercare program



Figure 1. Illustration of a digital aftercare program

Supplementary File 2.

Interview guide

Introduction and Context [introduction slide]

First of all, thank you very much for agreeing to participate in this conversation. I would like to start this conversation by introducing myself and explaining the purpose and context of the research. After that, I would like to hear more about you. My name is [name of the interviewer], and I work as a researcher for the E-health Monitor. The E-health Monitor is a collaborative project of the RIVM, NeLL, and Nivel, all organizations that conduct national research on healthcare. We started this project in 2021, commissioned by the Ministry of Health, Welfare, and Sport. The goal of this project is to assess the use of digital healthcare and learn how digital healthcare can contribute to improving healthcare. By digital healthcare, we mean the use of ICT in healthcare, such as video calling or the use of a patient portal. In this conversation, we will focus on a specific form of digital healthcare, namely online aftercare, which I will discuss later. It's important to note that digital healthcare is not an end in itself - it is a means to offer healthcare differently. This can have various benefits, such as reducing travel time, easing the

workload of healthcare providers, or improving the quality of care. However, it can also have drawbacks, as not everyone is equally comfortable using a computer or smartphone, and it may lead to less personal contact.

Agreement on Recording - I would like to record this conversation. Is that okay with you?

Introduction of participant - Now, I'm interested in learning more about you. Could you briefly tell me who you are, and could you share something about where you are in the disease process?

Urgency of Care [Slide 2: Headlines]

I'd like to start with some general questions about the current state of healthcare. I will show you a slide now. As you can see, staff shortages, rising costs...

1. Do you recognize this news? Do you believe that something really needs to change in healthcare to continue providing good care to all Dutch citizens, or do you think it will be fine as it is?

As the slide already indicates, Dutch healthcare is under pressure. This means that healthcare costs are rising, and staff shortages are growing. As a result, there is a need to think about how we can organize healthcare more efficiently while maintaining the quality of care.

The way healthcare is delivered needs to change. For example, by implementing digital healthcare. It also requires something from patients; they are expected to take more control of their own care, for instance, by being more self-sufficient in their recovery during the aftercare phase following treatment.

2. What do you think of the idea that patients should have more control or should take more control over a part of their disease process?

Prompt: What do you observe in your own environment?

Now, I would like to talk about your situation as a patient. From previous research, we know that many people with cancer have a strong need for more support after treatment, especially during aftercare, and that this can be effectively provided through online aftercare programs. In this conversation, we would like to discuss with you how you view the use of online aftercare and what could either help or hinder you from using these programs.

Case [Slide 3: Case]

To give you an idea of what online aftercare programs can entail, we'll provide an example of such a program: Through an online aftercare program, people who have completed their cancer treatment can fill out a brief questionnaire on a website to assess how they are doing. This way,

it can be determined what is going well and where they still need help or are experiencing difficulties. For example, based on the questionnaire, it might be identified that someone is still suffering from fatigue. The program covers topics such as returning to work, relationships with others (including sexuality and intimacy), anxiety and depressive feelings, dealing with pain, exercise, nutrition, and smoking cessation. Based on the questionnaire, the program provides advice on which modules would be most valuable for a participant. If someone is experiencing fatigue, they can follow the fatigue module. This module includes:

- Information on how to deal with fatigue, sleep-wake rhythms, and thoughts about fatigue.
- Videos featuring the experiences of people with cancer on this topic, as well as advice from a clinical psychologist.
- Assignments, such as daily tracking of an activity diary to gain insight into which activities are tiring or relaxing.

Now, I would like to discuss online aftercare in detail with you, how you feel about it, and what could help or hinder you in using it. You can keep the example program in mind.

Goal Behavior: Use of Online Aftercare

First, I am curious about:

1. You indicated when you signed up for this conversation that you have a need, or had a need, for support in your recovery and well-being during the aftercare phase. Can you specify in what areas that need lies?
2. To get a general impression of your experience, I would like to know to what extent you are already using online aftercare programs.
<If someone already has experience with this>
 - What do you like about these programs?
 - What do you miss or what would you like to see differently?

B. Psychological Capability - Knowledge, Memory, Attention, Decision Processes, Behavior Regulation

Now, I would like to talk to you about how familiar you are with specific online aftercare programs.

1. Can you tell me to what extent you were already familiar with online aftercare programs before this conversation? What do you know about them?
2. What (digital) options do you know to actively work on your well-being and recovery?
3. To what extent do you know where to find these programs? If not, how would you like to be informed about these opportunities?
Prompt: e.g., through an oncologist, a general practitioner, social media, etc.
Prompt: You mentioned earlier that you have already used X, how did you come across it?
4. Have others pointed out the possibilities of digital support in your recovery during aftercare?

Prompt: Did your healthcare providers discuss it?

Prompt: Or fellow patients?

<If the answer to question 4 is "no">

5. From whom would you like to receive this information, so you would actually use online aftercare? And at what point would you like to receive this information?

Prompt: Timing; when in the process would you like to receive this information?

A. Reflective Motivation - Beliefs about Capabilities and Consequences, Roles, Identity, Intentions, Goals, Optimism

I would now like to talk to you about your willingness and motivation to use online aftercare for your well-being and recovery.

1. You mentioned earlier that you mainly need [answer to question 1] in terms of aftercare. Do you think an online aftercare program can help you with this, or that you need it? If so, in what ways can it help you?

Prompt: Do you feel like you should use it?

Prompt: Does it contribute to your recovery and well-being?

Prompt: Do you think an online aftercare program suits you?

Prompt: Would you be open to using online aftercare?

2. Is using online aftercare programs something normal or common for you? Why or why not?
3. What benefits do you see in using online aftercare programs?
4. What disadvantages do you see in using online aftercare programs? Do the benefits outweigh the disadvantages for you?

Prompt: What would happen if you did not use (online) aftercare programs?

Prompt: disadvantages compared to offline aftercare programs

5. How do you think you would feel when using online aftercare programs?

Prompt: For example, feeling abandoned or empowered

Prompt: what emotions might they trigger?

C. Physical Competence - Skills, Abilities, or Capabilities Acquired through Practice

Not everyone can easily use online aftercare programs. Certain skills and abilities are required, and you must also be physically capable.

1. How easy or difficult do you think it would be for you to use online aftercare programs?

Prompt: Digital skills (how easy do you find it to log in to websites, such as online banking)?

Prompt: What would help you in this regard?

2. Do you need assistance with this?
3. Do you believe you are physically capable of using online aftercare?

Prompt: For example, do you have enough energy, endurance, and concentration during your

treatment recovery to use it?

4. What would help you in this regard?

D. Physical Possibilities - Environmental Context and Resources

In addition to skills, the use of online aftercare programs also requires certain things from patients. You need to engage with it on your own time and require specific resources, such as a computer and reliable Wi-Fi. I would like to discuss this with you now.

1. Do you have the time to use online aftercare programs?
2. Are you willing to pay for it yourself, or do you think an online aftercare program should be (partially) financed for you?
3. Do you have the necessary equipment and facilities to use online aftercare programs?

Prompt: ICT; stable Wi-Fi

4. Are there other factors in your environment that could help or hinder you from using online aftercare programs?

Prompt: For example, automated reminders

5. Do you have confidence that something can be done to address your obstacles?

E. Social Opportunities - Social Influences such as Social Norms, Pressure, Conformity, Comparisons

Now, I would like to continue talking with you about how your environment views the use of online aftercare. By your environment, I mean both your family and friends and the healthcare providers you have (or have had) for your treatment.

1. How does your environment view the use of online aftercare programs (as you estimate)?

Prompt: e.g., healthcare providers, family/friends

2. To what extent does this influence your decision to use or not use online aftercare programs? How does your environment view your recovery and well-being?

Prompt: Do you discuss this? Do they support you in this?

To what extent do you think your environment would help/support you in applying the lessons learned from an online aftercare program?

Prompt: Can you discuss it with them? Would they remind you?

3. Do you know other people who use online aftercare programs?

F. Automatic Motivation - Emotions, Reinforcements such as Rewards, Punishments, Incentives

Finally, I would like to discuss how an online aftercare program would need to be designed for you to use it effectively.

1. What aspects of the design of an online aftercare program would help you to use it?

Prompt: For example, in terms of design, certain rewards for using it, or ways to remind you to use it?

2. Do you think you could make a habit of using online aftercare programs? What could help you with this?
Prompt: To what extent do you think you would remember to use online aftercare programs in your daily life?
3. What do you need to integrate it into your daily life?

Priorities

I would like to conclude the conversation now. Finally, looking back on this conversation, if you had to identify the 2-3 most important things for you to use online aftercare, what would those be?

Prompt: Of course, you've mentioned many things, but what are the top 2 most important things?

Conclusion

Thank you very much for the conversation. We will process and analyze the conversations anonymously. The results will be published in a scientific article. We will send you the gift voucher via email soon. If you have any questions or additional content to add later, please feel free to contact us. You have my email address.

Supplementary File 3.

Questionnaire

Table 1. Questionnaire

Question to respondents	Answer categories	Routing and recoding of answers
Background questions		
1. What is your gender?	1. Male 2. Female 3. Non-binary 4. Prefer not to say	
2. What is your age (in years)?	Open question	
3. What is your marital status?	1. Single (never married or in a registered partnership before) 2. In a relationship (not married and no registered partnership) 3. Married or in a registered partnership 4. Divorced 5. Widow or widower 6. Other, namely	
4. What is your highest completed education?	1. Lower secondary vocational education or special secondary education (in Dutch: Lbo, vso, lts, leao, vbo, huishoudschool, ambachtsschool) 2. Preparatory vocational secondary education or remedial education (in Dutch: Vmbo, lwoo) 3. Middle general secondary education (in Dutch: Mavo, ulo, mulo) 4. Senior general secondary education (in Dutch: Havo, mms) 5. Pre-university education, higher civic school, or lyceum (in Dutch: VWO, gymnasium, atheneum, hbs, lyceum) 6. Post-secondary vocational education (in Dutch: Mbo, mts, meao, middenstandsdiploma, pdb, mba) 7. Higher professional education (in Dutch: Hbo, hts, heao, kweekschool, associate degree) 8. Academic education, including postgraduate programs and doctoral research (in Dutch: WO)	- Secondary (vocational) education if answer category 1, 2, 3, 4 or 5 was checked - Post-secondary vocational education if answer category six was checked - Higher professional education or academic education if answer category 7 or 8 was checked

Question to respondents	Answer categories	Routing and recoding of answers
5. Have you had difficulty making ends meet from your household income in the past 12 months?	1. No difficulty at all 2. No difficulty, but I do need to watch my spending 3. Yes, some difficulty 4. Yes, significant difficulty 5. I do not know 6. Prefer not to say	
6. What type of cancer have you (had)?	1. Pancreatic cancer 2. Bladder cancer 3. Breast cancer 4. Colon cancer 5. Skin cancer 6. Lung cancer 7. Lymph node cancer 8. Kidney cancer 9. Prostate cancer 10. Esophageal cancer 11. Other, namely	
7. In which stage of the illness are you?	1. Undergoing treatment 2. Under control after treatment 3. Chronic phase 4. Cured 5. Palliative phase 6. I do not know 7. Other, namely	
8. How many years ago did you complete the treatment? Follow-up appointments are not included in the treatment period	1. I am currently undergoing treatment 2. Less than one year ago 3. One to two years ago 4. Three to four years ago 5. Five to six years ago 6. Seven to eight years ago 7. More than eight years ago 8. I do not know	

Question to respondents	Answer categories	Routing and recoding of answers
Challenges and complaints		
9. What complaints or challenges are you experiencing as a result of cancer or cancer treatment? (Multiple answers possible)	1. Fatigue 2. Fear of cancer recurrence 3. Mood issues (such as sadness) 4. Dealing with pain (including neuropathy) 5. Coping with the illness and its processing 6. Problems with concentration 7. Relationships with others (including sexuality and intimacy) 8. (Returning to) work 9. Nutrition 10. Physical activity 11. Alcohol consumption 12. Quitting smoking 13. Desire for peer support	
10. To what extent do you agree with the following statement? "I think it is important to address my complaints or challenges to alleviate the resulting stress." If this varies by complaint or challenge, consider the one that is most important to you	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know 7. 8. 9.	
11. What activities have you done to help with the complaints or challenges you are experiencing? (multiple answers possible)	1. Visited a general practitioner (GP) 2. Visited a physiotherapist 3. Visited a psychologist 4. Visited a dietitian 5. Explored alternative therapies (e.g. acupuncture or homeopathy) 6. Attended a physical meeting of a patient association or foundation 7. Engaged in physical peer support (e.g. attended a gathering at a support center) 8. Searched for online information 9. Engaged in digital peer support (e.g. via Kanker.nl) 10. Visited social media platforms like Facebook 11. I have not taken any actions yet for the complaints and challenges I am experiencing	

Question to respondents	Answer categories	Routing and recoding of answers
12. For which complaints or challenges would you like (more) support? (multiple answers possible)	1. Fatigue 2. Fear of cancer recurrence 3. Mood issues (such as sadness) 4. Dealing with pain (including neuropathy) 5. Coping with the illness and its processing 6. Problems with concentration 7. Relationships with others (including sexuality and intimacy) 8. (Returning to) work 9. Nutrition 10. Physical activity 11. Alcohol consumption 12. Quitting smoking 13. Desire for peer support 14. I do not need any support for my complaints or challenges	- The questionnaire ended when answer category fourteen was selected. The participants who selected this answer category were excluded from the analysis.

Familiarity with digital aftercare programs

13. Were you already familiar with digital aftercare programs as explained in the video before starting this questionnaire?	1. Yes 2. No	- If answer category one was selected, question 14 – 16 were shown - If answer category two was selected, questions 14 – 16 were skipped
14. How did you learn about digital aftercare programs? (Multiple answers possible)	1. Through the general practitioner (GP) 2. Through the medical specialist 3. Through the (oncology) nurse 4. Through another healthcare provider 5. Through a patient association or foundation 6. Through Kanker.nl 7. Through social media 8. Through Google or another search engine 9. Through friends / family 10. Through peers 11. Other, namely	

Question to respondents	Answer categories	Routing and recoding of answers
15. Have you ever used a digital aftercare program yourself? If yes, for which complaints or challenges? (Multiple answers possible)	1. No, I have not (yet) used any digital aftercare programs 2. Yes: fatigue 3. Yes: fear of cancer recurrence 4. Yes: mood issues (such as sadness) 5. Yes: dealing with pain (including neuropathy) 6. Yes: coping with the illness and its processing 7. Yes: problems with concentration 8. Yes: relationships with others (including sexuality and intimacy) 9. Yes: (returning to) work 10. Yes: nutrition 11. Yes: physical activity 12. Yes: alcohol consumption 13. Yes: quitting smoking 14. Yes: desire for peer support 15. Yes: for another complaint or challenge, namely	
16. To what extent do you agree with the following statement? "The digital aftercare programs I have used are beneficial for addressing my complaints or challenges".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	
17. To what extent do you agree with the following statement? "I would use digital aftercare programs for the complaints or challenges I am experiencing due to cancer or cancer treatment".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	

Question to respondents	Answer categories	Routing and recoding of answers
18. How would you prefer to hear about digital aftercare programs? (Multiple answers possible)	1. Through the general practitioner (GP) 2. Through the medical specialist 3. Through the (oncology) nurse 4. Through the case manager 5. Through a patient association 6. Through Kanker.nl 7. Through social media such as private Facebook groups 8. Through search engines like Google 9. Through friends or family 10. I do not want to hear about digital aftercare programs 11. I do not know 12. In another way, namely	- If answer category ten was selected, question 19 was not shown.
19. At what point would you have preferred to hear about the existence of digital aftercare programs? (Multiple answers possible)	1. During the diagnosis phase 2. During the treatment 3. Immediately after completing the treatment 4. A few weeks after completing the treatment 5. I do not know 6. At another time, namely	
Attitude towards digital aftercare programs		
20. To what extent do you agree with the following statement? "Digital aftercare programs can help me with the complaints or challenges I am experiencing due to cancer or cancer treatment".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	

Question to respondents	Answer categories	Routing and recoding of answers
21. For which complaints or challenges would you find it useful to use a digital aftercare program? (Multiple answers possible)	1. Fatigue 2. Fear of cancer recurrence 3. Mood issues (such as sadness) 4. Dealing with pain (including neuropathy) 5. Coping with the illness and its processing 6. Problems with concentration 7. Relationships with others (including sexuality and intimacy) 8. (Returning to) work 9. Nutrition 10. Physical activity 11. Alcohol consumption 12. Quitting smoking 13. Desire for peer support 14. I do not know 15. I do not need help or support through a digital aftercare program 16. Another complaint or challenge, namely	
22. Which components of a digital aftercare program would be useful for you? (Multiple answers possible)	1. Information, tips, and advice 2. Experiences of other people who have had cancer 3. Contact with other people who have had cancer 4. Assignments to work on individually 5. Referrals to more information or help 6. I do not know 7. No components 8. Another component, namely	

Question to respondents	Answer categories	Routing and recoding of answers
23. What do you see as the main benefits of using digital aftercare programs compared to physical support? (You can select up to five answers)	1. Being in control of when you use it 2. Being able to pause in between 3. Being able to review information 4. Not having to go to a healthcare provider 5. Saves travel time 6. Saves costs for me as a patient 7. Saves costs for healthcare 8. Provides support in the post-treatment phase 9. Being able to work independently 10. Being able to start immediately (without waiting list) 11. Being able to work anonymously (e.g. with potentially sensitive topics like sexuality) 12. I do not see any benefits 13. I do not know 14. Another benefit, namely	
24. What do you see as the main disadvantages of using digital aftercare compared to physical support? (You can select up to three answers)	1. No possibility of personal contact 2. No possibility of asking questions 3. It takes strength to persist in using the program 4. Need to be tech-savvy 5. Having to work independently on complaints or challenges 6. A healthcare provider could better assist me with my complaints or challenges 7. I do not see any disadvantages 8. I do not know 9. Another disadvantage, namely	
25. Do you think the benefits of using digital aftercare programs would outweigh the disadvantages for you?	1. Yes 2. No 3. I do not know	
26. To what extent do you agree with the following statement? "I would like to address my complaints or challenges independently and online, without the involvement of a healthcare provider or someone else".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	

Question to respondents	Answer categories	Routing and recoding of answers
27. To what extent do you agree with the following statement? "Using digital aftercare programs is a good fit for me as an individual".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	
28. To what extent do you agree with the following statement? "Using digital aftercare programs would be something normal for me".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	

Capability of using digital aftercare programs

- | | |
|--|--|
| 29. To what extent do you agree with the following statement?
"I believe I have sufficient digital skills to use digital aftercare programs". | 1. Completely agree
2. Agree
3. Neither agree nor disagree
4. Disagree
5. Completely disagree
6. I do not know |
| 30. Would you like assistance with using digital aftercare programs? If yes, what kind of assistance? (Multiple answers possible) | 1. No, I do not want any assistance
2. Yes, a digital helpdesk via email or chat
3. Yes, a physical helpdesk at the hospital or with a healthcare provider (e.g. a general practitioner or physiotherapist)
4. Yes, a phone number that I can call
5. Yes, a course on using digital aftercare programs
6. Yes, assistance from people in my surroundings (e.g. family, friends, or colleagues)
7. Yes, assistance via the library
8. Yes, an explanation within the digital aftercare program
9. I do not know
10. Yes, another form of assistance, namely |

Question to respondents	Answer categories	Routing and recoding of answers
31. What factors could prevent you from using digital aftercare programs? (Multiple answers possible)	1. I do not have a good internet connection 2. I do not have a computer, smartphone, or tablet 3. I have little money to purchase a digital aftercare program 4. I have little time 5. I have little energy 6. I have difficulty concentrating 7. Concerns about privacy 8. Doubts about the program's reliability (e.g. information and advice) 9. Doubts about the program's effectiveness 10. Doubts about whether the program aligns with the advice of my healthcare providers 11. There are no factors that would prevent me from using digital aftercare programs 12. Other, namely	
32. How much would you be willing to pay for the use of a digital aftercare program (in euros)? Please enter '0' if you do not want to pay for the use of digital aftercare programs.	Open question	
33. Would it be a requirement for you to have digital aftercare programs fully covered by your health insurance in order for you to use these programs?	1. Yes 2. No 3. I do not know	
Social environment and digital aftercare programs		
34. Do you know other people who use digital aftercare programs?	1. Yes 2. No 3. I do not know	

Question to respondents	Answer categories	Routing and recoding of answers
35. How do you expect your healthcare providers to view the use of digital aftercare programs?	1. Very positively 2. Positively 3. Neutral 4. Negatively 5. Very negatively 6. I do not know	
36. To what extent do you agree with the following statement? "The opinion of my healthcare providers about digital aftercare programs would influence my decision to use digital aftercare programs".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	
37. How do you expect the people in your surroundings (e.g., friends, family, or colleagues) to view the use of digital aftercare programs?	1. Very positively 2. Positively 3. Neutral 4. Negatively 5. Very negatively 6. I do not know	
38. To what extent do you agree with the following statement? "The opinion of the people in my surroundings about digital aftercare programs would influence my decision to use digital aftercare programs".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	
39. To what extent do you concur with the following statement? "I feel the need for support from people around me when applying the insights gained from a digital aftercare program".	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	
40. To what extent do you agree with the following statement? "I expect that the people in my environment can support me in using the things I learn in a digital aftercare program."	1. Completely agree 2. Agree 3. Neither agree nor disagree 4. Disagree 5. Completely disagree 6. I do not know	

Question to respondents	Answer categories	Routing and recoding of answers
Daily use of digital aftercare programs		
41. How easy or difficult would it be for you to regularly use a digital aftercare program and stick to it (e.g., a few times per week)?	1. Very easy 2. Easy 3. Neither easy nor difficult 4. Difficult 5. Very difficult 6. I do not know	
42. What would help you to regularly use and maintain a digital aftercare program (e.g., a few times per week)? (Multiple answers possible)	1. Regular reminders 2. Insight into the duration of the program and which part I have already completed 3. The program provides feedback on my activities (e.g., compliments or tips) 4. The program is tailored to my personal situation (e.g., type of cancer) 5. Ability to set clear goals in the program 6. The program is accessible on both a computer and a tablet or phone 7. Rewards (e.g., earning points) 8. Digital contact with a healthcare provider or coach 9. Digital contact with someone who has also had cancer 10. I do not know 11. Other; namely	
43. What is your view of digital aftercare programs as explained in the video?	1. Very positive 2. Positive 3. Neutral 4. Negative 5. Very negative	

Supplementary File 4.
COREQ checklist

Table 1. COREQ checklist

No. Item	Guide questions/ description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	9
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	9
3. Occupation	What was their occupation at the time of the study?	9
4. Gender	Was the researcher male or female?	9
5. Experience and training	What experience or training did the researcher have?	9
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Supplementary File (SF) 1
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	SF 1
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons, and interests in the research topic	SF 1
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	10
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	8

11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	8
12. Sample size	How many participants were in the study?	8
13. Non-participation	How many people refused to participate or dropped out? Reasons?	8
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	9
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	9
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	11 – 12; SF 6
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	9; SF 1
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	9
20. Field notes	Were field notes made during and/or after the interview or focus group?	No
21. Duration	What was the duration of the interviews or focus group?	10
22. Data saturation	Was data saturation discussed?	10
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	10
25. Description of the coding tree	Did authors provide a description of the coding tree?	No

26. Derivation of themes	Were themes identified in advance or derived from the data?	10
27. Software	What software, if applicable, was used to manage the data?	10
28. Participant checking	Did participants provide feedback on the findings?	No
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	No
30. Data and findings consistent	Was there consistency between the data presented and the findings?	11 – 19
31. Clarity of major themes	Were major themes clearly presented in the findings?	11 – 19
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	11 – 19

Supplementary File 5.
Descriptive analyses

Supplementary File 5 is not included in this dissertation due to its length. It is available online at <https://doi.org/10.1007/s11764-024-01635-x>

Supplementary File 6.

Explorative analyses regarding possible influencing variables as conducted in SPSS

Table 1. Results of the binary regression analysis for predicting answer to the question: “Were you already familiar with digital aftercare programs as explained in the video before starting this questionnaire?” (Yes or No)

Predictor variable ¹	Wald Chi-square statistic	P-value
Marital status	1.05	.31
Age	3.80	.05
Income	0.18	.68
Educational level	4.49	.11
Type of cancer	5.66	.23
Duration since treatment completion	0.70	.88

¹For the explorative analyses, the variables ‘Marital status’; ‘Income’; and ‘Duration since treatment completion’ were recoded. Marital status was recoded into two categories: 1) With partner: married or registered partnership (n=123, 57.7%); in a relationship (not married or in a registered partnership (n=31, 14.6%) and 2) Without partner: single (n=29, 13.6%); divorced (n=15, 7.0%); widow(er) (n=14, 6.4%). Other (n=1, 0.5%); Income was recoded into two categories: 1) Yes: significant difficulty (n= 10, 4.7%); some difficulty (n=38, 17.8%) and 2) No: no difficulty, but I need to watch my expenses (n=78, 36.6%); no difficulty (n=86, 40.4%). I would rather not say (n=1, .5%); Duration since treatment completion was recoded into four categories: 1) Currently undergoing treatment (n=34, 16.0%); 2) Less than one year ago (n=46, 21.6%); 3) One to two years ago (n=53, 24.9%); 4) Three years or more ago (n=80, 37.6%). For the variable ‘Type of cancer’ the following categories were used: breast cancer, colon cancer, bladder cancer, prostate cancer, and esophageal cancer.

Table 2. Results of the binary regression analysis for predicting answers to the question: “How would you prefer to hear about digital aftercare programs?” (Multiple answers possible)

Answer option	Predictor variable	Wald Chi-Square statistic	P-value	Adjusted p-value ¹ (where applicable)
Through the general practitioner	Marital status	0.18	.67	
	Age	0.23	.63	
	Income	0.02	.90	
	Educational level	1.98	.37	
	Type of cancer	3.88	.42	
	Duration since treatment completion	5.57	.13	

Answer option	Predictor variable	Wald Chi-Square statistic	P-value	Adjusted p-value ¹ (where applicable)
Through the medical specialist	Marital status	0.25	.62	
	Age	7.56	.006**	.18
	Income	1.32	.25	
	Educational level	2.48	.29	
	Type of cancer	15.55	.004**	.18
	Duration since treatment completion	1.28	.74	
Through the (oncology) nurse	Marital status	2.72	.10	
	Age	3.53	.06	
	Income	0.41	.52	
	Educational level	10.36	.006**	.18
	Type of cancer	7.29	.12	
	Duration since treatment completion	1.94	.59	
Through the case manager	Marital status	1.82	.18	
	Age	0.13	.72	
	Income	1.98	.16	
	Educational level	0.48	.79	
	Type of cancer	0.89	.93	
	Duration since treatment completion	2.79	.42	
Through a patient association	Marital status	0.09	.77	
	Age	3.52	.06	
	Income	0.00	.10	
	Educational level	4.21	.12	
	Type of cancer	4.66	.32	
	Duration since treatment completion	4.46	.22	
Through Cancer.nl (Kanker.nl)	Marital status	2.27	.13	
	Age	0.15	.70	
	Income	1.24	.27	
	Educational level	2.35	.31	
	Type of cancer	1.40	.84	
	Duration since treatment completion	5.04	.17	

Answer option	Predictor variable	Wald Chi-Square statistic	P-value	Adjusted p-value ¹ (where applicable)
Through social media	Marital status	0.64	.43	
	Age	0.26	.61	
	Income	1.26	.26	
	Educational level	2.51	.29	
	Type of cancer	4.42	.35	
	Duration since treatment completion	3.39	.34	

¹Adjusted p-values after applying the multiple testing correction method (Benjamin Hochberg FDR correction). This correction is only applied to significant p-values. * = $p < .05$; ** = $p < .01$

Table 3. Results of the binary regression analysis for predicting answers to the question: “What factors could prevent you from using digital aftercare programs?” (Multiple answers possible)

Answer option	Predictor variable	Wald Chi-Square statistics	P-value	Adjusted p-value ¹ (where applicable)
I have little energy	Marital status	0.06	.81	
	Age	2.82	.09	
	Income	2.95	.09	
	Educational level	1.48	.48	
	Type of cancer	5.17	.27	
	Duration since treatment completion	0.08	.99	
I have difficulty concentrating	Marital status	0.57	.45	
	Age	4.78	.03*	.44
	Income	0.01	.95	
	Educational level	3.13	.21	
	Type of cancer	7.33	.12	
	Duration since treatment completion	6.24	.10	
Concerns about privacy	Marital status	0.78	.38	
	Age	0.69	.41	
	Income	0.60	.44	
	Educational level	4.66	.10	
	Type of cancer	0.50	.97	
	Duration since treatment completion	3.01	.39	

Answer option	Predictor variable	Wald Chi-Square statistics	P-value	Adjusted p-value ¹ (where applicable)
Doubts about the program's effectiveness	Marital status	1.44	.23	
	Age	3.03	.08	
	Income	0.19	.66	
	Educational level	4.73	.09	
	Type of cancer	1.79	.78	
	Duration since treatment completion	4.62	.20	
There are no factors that would prevent me from using digital aftercare programs	Marital status	3.00	.08	
	Age	0.47	.50	
	Income	1.98	.16	
	Educational level	3.14	.21	
	Type of cancer	11.41	.02*	.40
	Duration since treatment completion	2.07	.56	

¹Adjusted p-values after applying the multiple testing correction method (Benjamin Hochberg FDR correction). This correction is only applied to significant p-values. * = $p < .05$; ** = $p < .01$

Table 4. Results of the ordinal regression analysis for predicting answers to the question: “To what extent do you agree with the following statement? “I would like to address my complaints or challenges independently and online, without the involvement of a healthcare provider or someone else” ((completely) agree, neither agree nor disagree, (completely) disagree)

Predictor variable	Category	Estimate	S.E.	Wald Chi-Square statistic	P-value	Adjusted p-value (where applicable) ¹
Marital status ²	With partner	0.63	.52	1.44	.23	
Age		0.03	.03	1.47	.23	
Income ³	Some or significant difficulty	0.57	.53	1.15	.28	
Educational level ⁴	Post-secondary vocational education	-0.88	.67	1.72	.19	
	Higher professional or academic education	-0.31	.62	0.25	.62	
Type of cancer ⁵	Esophageal cancer	0.29	.84	0.12	.78	
	Prostate cancer	-0.19	.74	0.07	.79	
	Bladder cancer	-0.32	.60	0.28	.60	
	Colorectal cancer	0.53	.58	0.83	.36	
Duration since treatment completion ⁶	Less than one year ago	-1.32	.82	2.58	.11	
	One to eight years ago	-1.86	.71	6.82	.009**	.20
	Longer than eight years ago	-1.47	.98	2.25	.13	

¹Adjusted p-values after applying the multiple testing correction method (Benjamin Hochberg FDR correction). This correction is only applied to significant p-values; ²Reference category (RC) = no difficulty; ³RC = without partner ⁴RC = secondary (vocational) education; ⁵RC = breast cancer; ⁶RC = Currently undergoing treatment; * = $p < .05$; ** = $p < .01$

Supplementary File 7.
Interview participants' characteristics

Table 1. Interview participants' characteristics

Characteristic	n	%
Sex		
Male	7	50.0
Female	7	50.0
Educational level		
Secondary (vocational) education	6	42.9
Post-secondary vocational education	3	21.4
Higher professional education or academic education	5	35.7
Treatment period		
Finished treatment <1 year ago	3	21.4
Finished treatment 1 – 2 years ago	5	35.7
Finished treatment 3 – 4 years ago	4	28.6
Finished treatment 5 – 6 years ago	1	7.1
Finished treatment 7 – 8 years ago	1	7.1
Cancer type		
Breast cancer	4	28.6
Skin cancer	3	21.4
Bladder cancer	2	14.3
Colorectal cancer	1	7.1
Prostate cancer	1	7.1
Lung cancer	1	7.1
Lymph node cancer	1	7.1
Stomach cancer	1	7.1

