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# Patient-centered development of *Embrace Pain*: an online acceptance and commitment therapy intervention for cancer survivors with chronic painful chemotherapy-induced peripheral neuropathy

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## ABSTRACT

**Background:** Around 30% of cancer survivors suffer from chemotherapy-induced peripheral neuropathy (CIPN)  $\geq 6$  months after completion of chemotherapy, which comes with limitations in daily functioning and worsened quality of life (QoL). Treatment options are scarce. Our aim was to develop an online self-help intervention based on Acceptance and Commitment Therapy (ACT) to reduce pain interference in cancer survivors experiencing painful chronic CIPN.

**Material and methods:** This article applied a patient-centered design process using the Center for eHealth Research (CeHRes) roadmap. User needs were examined using online semi-structured interviews with patients and experts ( $N=23$ ). Interviews were transcribed verbatim and analyzed using thematic analysis. Personas were created based on interviews. Intervention content was based on identified user needs and ACT. Content and design were finalized using low-fidelity prototype testing ( $N=5$ ), and high-fidelity prototype testing ( $N=7$ ).

**Results:** Patients appreciated and agreed with the elements of ACT, had varying guidance needs, and wanted to have autonomy (e.g., moment and duration of use). Additionally, it was important to be aware that patients have had a life-threatening disease which directly relates to the symptoms they experience. Patients reported to prefer a user-friendly and accessible intervention. Similar points also emerged in the expert interviews. The final intervention, named *Embrace Pain*, includes six sessions. Session content is based on psychoeducation and all ACT processes. Further interpretation of the intervention (such as quotes, guidance, and multimedia choices) is based on the interviews.

**Conclusion:** This development demonstrated how a patient-centered design process from a theoretical framework can be applied. Theory-driven content was used as the basis of the intervention. Findings show an online ACT intervention designed for cancer survivors with painful chronic CIPN.

## ARTICLE HISTORY

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## KEYWORDS



chemotherapy-induced peripheral neuropathy; cancer survivors; acceptance and commitment therapy; eHealth; online; PROFILES registry

## Background

The incidence of cancer unfortunately is still rising, yet treatment options continue to be improved. As such, the long-term consequences of cancer and its treatment become increasingly relevant [1–6]. A great amount of cancer patients suffer from chemotherapy-induced peripheral neuropathy (CIPN), which is a long-term consequence [7]. Certain chemotherapeutic agents (e.g., taxanes, platinum compounds, and vinca alkaloids) can cause CIPN, which includes symptoms such as tingling, numbness, cramps, and aching or burning pain in hands, feet, arms, and legs and feet [8–11]. One month after chemotherapy CIPN is present in up to

80% of survivors, which decreases to around 30% after 6 months or longer [7,12–17]. CIPN results in decreased quality of life (QoL), specifically in patients with *painful* CIPN [18]. Due to the increasing application of chemotherapy, CIPN is expected to become one of the most prevalent side-effects [19]. However, to date there is only a limited number of treatment options for CIPN [20].

Cognitive behavioral interventions, like acceptance and commitment therapy (ACT), have been shown to improve cancer patients' QoL [21,22]. ACT helps patients toward acceptance and teaches patients how to perform personally valuable activities [23]. It has been shown to be effective in

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chronic pain patients [24]. Interventions are increasingly offered online, bringing benefits regarding costs, accessibility, availability, traveling, stigma, and psychological burden, compared to *face-to-face* interventions [25,26]. Besides, online interventions broaden the scope and diversity of possibilities for different types of interventions for patients, especially for patients who feel more comfortable in an online environment [27]. A study by Knoerl et al. [25] has shown that an online CBT intervention positively influenced pain intensity in patients with chronic painful CIPN, suggesting that an online ACT treatment might also be beneficial to CIPN patients. However, since the nature of ACT (i.e., improving psychological flexibility) appears to better fit the mechanisms of chronic pain compared to CGT, and the intervention by Knoerl et al. [25] was not developed for and with CIPN patients specifically, further research is needed. To the best of our knowledge, development of online ACT interventions for patients with chronic painful CIPN has not yet been undertaken.

When developing online (asynchronous) interventions, several considerations need to be taken into account regarding the main components of the online intervention: program content, multimedia use/choices, interactive online activities, and feedback support provision [27]. These components need to be chosen in a way that they fit the task and serve the end user. To make sure that the technology comes with high usability and utility, a patient-centered design process, a form of user-centered design whereby patients are involved in the choices made in the development process, is advised [28]. In this process, it is crucial to focus on matching the user, task, and technology of the intervention, in which the technology acceptance model (TAM) [29,30] and task-technology fit model (TTF) [31] could serve as appropriate theoretical frameworks. More specifically, TAM shows that use is determined by perceived usefulness and perceived ease of use [29]. The TTF model serves as an appropriate complement, showing that the relationship of task, user and technology determine the task-technology fit, which ultimately determines usage [31]. Both theories show the importance of involving the user in development to align task and technology with them.

The aim of this study is, therefore, to develop an online asynchronous ACT intervention to improve pain interference in cancer survivors with painful chronic CIPN using a patient-centered design process. In addition, this study specifically focuses on matching the user, task, and technology of the intervention, based on TAM [29,30] and TTF [31]. We expect the patient-centered design process to allow for the best possible patients' needs assessment, which will result in optimal development of the online asynchronous ACT.

## Material and methods

### Overview

In this study, the Center for eHealth Research (CeHRes) roadmap, which is a framework for how to develop technology that fits the user and context, has been used to apply a

patient-centered design process [32]. As this practical roadmap aligns well with the theoretical reasoning of TTF and TAM, it was considered an appropriate method for this study, guiding the steps to be taken when developing an eHealth solution. Steps to be taken are described in the following paragraphs. This study was approved by the Ethical Review Board of Tilburg University (School of Social and Behavioral Sciences; #RP284).

### User needs exploration

Semi-structured interviews with patients were conducted to assess online intervention needs. Inclusion criteria were: (1) 18 years or older, (2) having CIPN for at least 3 months, (3) experiencing self-reported interference of CIPN with daily life activities, (4) curative disease phase, and (5) score of 3 or higher on an 11-point Numeric Rating Scale (NRS) to assess pain severity. Patients were recruited by distribution of digital recruitment flyers *via* patient organizations and *Kanker.nl* (i.e., Dutch unified web platform delivering tailored medical information and peer-support for cancer patients and relatives [33]). Patients did not receive financial remuneration incentives for participating. Interviews took place *via* video calling due to COVID-19. The interview scheme was divided into different topics, including perceptions of and experience with online interventions, attitude toward ACT elements, user needs (i.e., amount of time, design, content, and requirements), need for guidance, and importance of comorbidities.

Additionally, semi-structured interviews were conducted with experts from several relevant fields (i.e., oncology, oncology nursing, psychology, and eHealth). This included assessment of experts' perceptions of patients' online intervention needs. Experts were recruited based on their relatedness to the topic. People were considered experts in this context if they had been working in oncology, oncology nursing, psychology, or eHealth for several years. Experts did not receive financial incentives for participating. Interviews took place *via* video calling due to COVID-19. Several topics were included in the interview scheme, including user needs (i.e., amount of time, content, and requirements), need for guidance, and importance of comorbidities. Interviews with psychologists also included questions about patients' willingness to engage in ACT as well. Interviews with eHealth experts were complemented with adherence and engagement questions.

Interviews were transcribed verbatim and analyzed using thematic analysis [34]. Analyses have been performed in Atlas.ti. Interviews were coded, after which themes were created. Also, condensed meaningful units were created for each quote of all code, which reflected the main point of a participant's quote.

Insights from the exploratory interviews were used to create personas. Persona development includes representations of the patient user group, including demographics, behavior, preferences, thoughts, feelings of a fictitious person to enhance an optimal fit between task, technology, and user to improve use [35,36]. Personas were developed for IT

developers and psychologist involved in the development, to inform then about the user group.

## Development

### Intervention content development and low-fidelity prototype testing

Structure and content of the intervention sessions were created by two psychologists specialized in ACT (HT and ABS) and final content edited by a communication and information scientist (DG).

Low-fidelity prototype testing (i.e., iterative evaluation) was applied to evaluate the content of the intervention. Evaluation interviews with patients and experts took place *via* video calling due to COVID-19. The interview structure was created based on items of the Website User Satisfaction Questionnaire (WUSQ) [37], of which the information (e.g., 'The information in the web site is easy to understand') and language customizations (e.g., 'The information is provided in a desired language') subscales were incorporated. Patients were given a plain text version of one of the sessions to review. After this, they were asked their opinion about the session. This resulted in content adjustments on the particular session and on the other sessions for which the feedback was also relevant.

### Software development and high-fidelity prototype testing

Subsequently, high-fidelity prototype testing (i.e., formative evaluation) was applied to evaluate the online environment of the intervention. Evaluation interviews with patients and experts also took place *via* video calling due to COVID-19 using the entire WUSQ. Participants were provided with access to the online intervention and were asked to work

through one of the sessions before providing feedback. Adjustments in the online intervention were then made based on participants' suggestions.

## Results

### User needs exploration

#### Interviews (patients)

Patients with chronic painful CIPN ( $N = 12$ ) participated in individual interviews (Figure 1). Comprehensive patient characteristics are presented in Appendix A (Table A1). Participants included Caucasian patients only. Interviews lasted between 60 and 90 min. Patients had varying ages, cancer diagnoses and time since CIPN onset. In total, 45 codes and 10 themes were defined in the patient interviews; psychosocial aspects, overall intervention need, exercises, content, intervention development, usability, guidance, peer support, comorbidities, and implementation.

Table 1 shows the main results of the interviews, including patients' needs and quotes. Patients supported the development of an online ACT intervention for CIPN, ranging from 'strong need' to 'no need' and appreciated the elements of ACT. Attitudes toward ACT's mindfulness component varied from no interest to high interest. Communication with social environment and psychoeducation were topics that were also strongly encouraged, while opinions about peer support differed, varying from highly interested to not interested. Patients demanded having autonomy in usage (e.g., moment and duration of use). There were many differences in need for guidance or the intensity thereof. Patients reported appreciating doing exercises, and indicated that exercises should be short. Patients preferred a user-friendly and accessible intervention. This specifically applied to this

## Patient-centered development

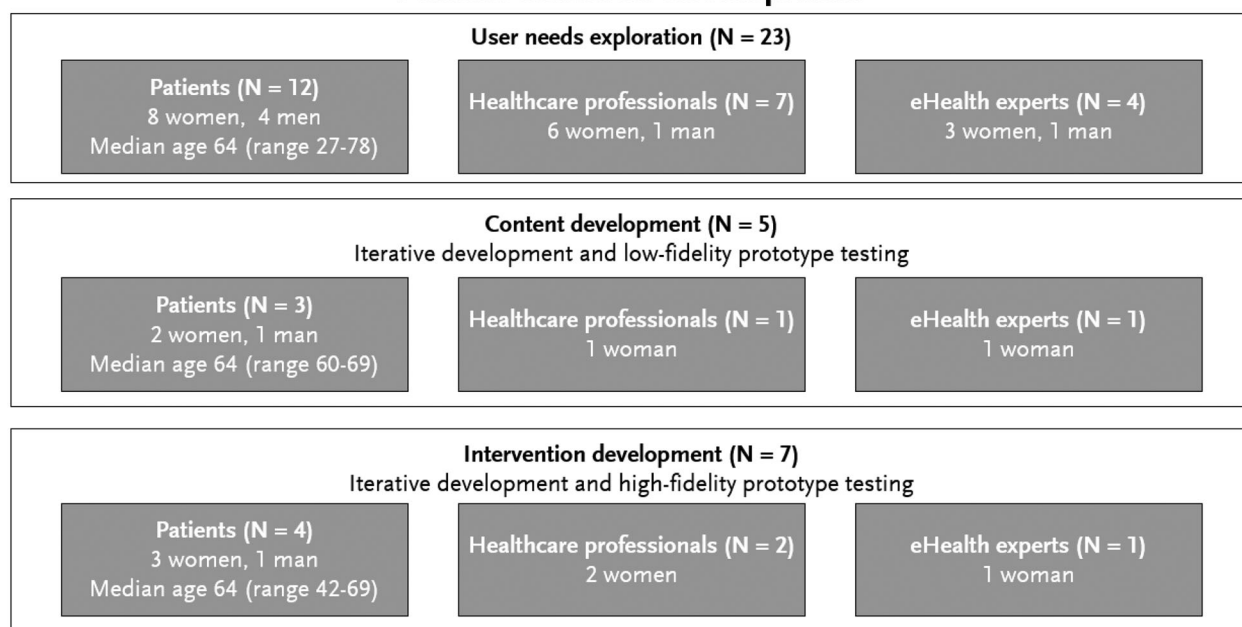


Figure 1. Patient-centered development process and interview participants.

Table 1. Main results of patient and expert interviews.

Category	Theme	Code	Condensed meaning unit	Meaning unit
Patients	Overall intervention need	Overall intervention need	Many patients were supportive of the development of an online ACT intervention for CIPN	'I've also used another app, so I'm familiar with it. I definitely see positives in it'.
			Some patients did not think it was necessary but would use it to improve their situation regarding CIPN	'I'm always up for ways to minimize my pain and to have minimal discomfort, but I think I'm already doing a lot of that myself'.
			Some patients felt no need because they did not experience any problems in dealing with CIPN	'I think I just already do that myself. ... I know very well what I want and don't want and what I consider important and what I consider less important. Things I consider less important have no priority for me at all'.
Psychosocial aspects	ACT	All patients appreciated and agreed with the elements of ACTC		'Accepting that those symptoms are there, and they won't go away but you can learn to live with them'.
		Some patients enjoyed doing mindfulness.		'Not only accepting thoughts and learning to live with, but also looking at possibilities and limitations'.
		Some patients had difficulty with (the concept of) mindfulness.		'I'm not meditative every day either, but sometimes you have one of those days when you think 'oh yes nice rest'. Yes, I like that. ... Yes. It can be very helpful to take some distance from the thoughts you have about your complaints'.
Content	Communication social environment	Many patients experienced difficulties with communicating to social environment in daily life		'I participated in a study on mindfulness. I found it very confronting'.
		Many patients perceived psychoeducation as useful		'That people really say the most terrible things to you. ... That's often quite difficult too I think. ... And also accept that people who don't have that don't understand it either. Because you can't blame them. That, I didn't understand it before either. But they can so say things to you that would almost get you into an argument'.
		Some patients had a strong need for peer support		'Well I've missed a lot of information. ... I also like a piece of information. ... What it is and what it does to you and that it is not strange. And that it is actually quite normal because I think that already helps a bit with acceptance'.
Exercises	Intensity	Some patients had no need for peer support		'I do like it. I also always really enjoy talking to fellow sufferers'.
		All patients liked doing exercises		'No. ... Then you're going to put energy into something that will only annoy you'.
		All patients wanted to have autonomy in the moment and duration of use		'By doing assignments or things like that, you also become much more aware of it and then it sticks much more in your mind than if you just read or listen to something and don't do anything with it'.
Theme Guidance	Code Guidance need	Many patients indicated that exercises should be short		'I think 2-3 times a week half an hour would work for me. And then you can arrange that yourself in that week'.
		Condensed meaning unit		'As long as it's not half an hour or three quarters of an hour, because people obviously have to have the time. But 15 or 20 min, should be quite doable'.
		Some patients had guidance needs		Meaning unit 'I want to fill out 2 things but then I want to talk to you online'.
Usability	Ease of use	Many patients preferred a user-friendly and accessible intervention		'I talk easily and if I want to talk about something I can share it with my social environment like friends or colleagues'.
		Many patients experience chemo-brain		'Yeah, user-friendly. ... Well, when you start, a bright homepage with really clear imagery. ... So, a good layout and divided into good chapters that can also be found again. So that when you start that you don't have to search through everything but that you can go straight to where you left off'.
				'Because you do have to deal with that concentration span after chemo, because I felt like I seemed demented at times'.

(continued)



Table 1. Continued.

Category	Theme	Code	Condensed meaning unit	Meaning unit
Experts	Intervention development	Multimedia	Many patients indicated that variety in multimedia is important Many patients indicated that multimedia (e.g., text) should not take too long	'It has to be something very concrete. Something catchy. That makes you think 'oh yeah'. ... Yes, it's the combination of it all.' 'If you're going to offer a text about neuropathy and it's somewhat scientific or medical, it shouldn't be too long because, then people will drop out.'
		Device	Some patients preferred using a laptop or computer	'I think anyway, you might take a little more time to actually sit down and open that website for that than if you get a notification and you're on the train and you just quickly fill it out before the stop'. 'I would do it on the tablet, because I find it easier to work with.'
	Comorbidities	Design	Some patients preferred using a tablet Some patients preferred using a smartphone Many patients preferred a calm design, especially regarding colors	'I just find it easiest on my phone'. 'Yes, personally I'm not into those very wild colors because it's distracting. ... Yes, should be a little quiet in color, yes'.
		Fatigue	Some patients acknowledged that it is crucial to include information about comorbidities	'I would do it, because the pain always gives fatigue. ... Yes, that, um, that yes, illnesses are always linked to fatigue, I think. So, I would definitely include that, yes'.
	Implementation	Fear of recurrence	Some patients acknowledged that it is crucial to recognize that patients had a life-threatening disease	'Well, I think you can explain that it's normal for people to be afraid that the cancer will recur'.
		Healthcare professionals	Some patients indicated that it was important to involve healthcare professionals and hospitals in implementation	'In principle, I would always like it if at least health care providers knew about it. ... Being able to offer it and that if you do something with it that they also know what you're talking about.'
	Overall intervention need	External parties	Some patients indicated that it was important to involve external parties in implementation	'That's why I also said of see if you can experience a combination with a foundation, whichever one that is. Then you also don't have to constantly chase an app like that yourself'.
		Overall intervention need	Some experts acknowledged the importance of patients' motivation	'Well I think people are definitely motivated. ... I think people there are willing to invest per week in that'.
	Psychosocial aspects	ACT	Many experts acknowledged the importance of acceptance of pain and limitations	'A person can only accept if he feels that there is an alternative. ... And that alternative is picking up activities that are worthwhile for you. ... I don't think you can make that switch overnight. You need a number of exercises'.
		Mindfulness	Few experts perceived mindfulness as an important aspect of ACT Few experts recognized mindfulness as an element that needs specific attention	'Yes, you will have to move toward mindfulness'.
Exercises	Intensity	Many experts mentioned the importance of giving explanation about the focus and application of mindfulness	'You have to be careful about how I bring that for example, because many people already switch off when you use the word mindfulness. They find that spiritual very quickly'.	
			'You want to get them to practice anyway, so you have to explain; hey you have trouble concentrating so what's going to happen when you do this exercise is you're going to keep thinking 'oh I can't do this, I can't do this'. But, the good news is you can't do it wrong because you're practicing'.	
Content	Psychoeducation	Few experts perceived repetition of exercises as crucial Some experts perceived autonomy in when and how long to practice as important Few experts indicated psychoeducation as important	'Behavior change, I think, is more easily achieved by spending a little time with it every day than a few very long sessions'.	
			'Maybe it's best if they can choose. I want five or 10 min every day or I want 15 min to half an hour twice a week'.	
Communication to social environment	Patient's voice	Few experts indicated communication to social environment as an important topic Some experts indicated the patient speaking as an important topic	'After that I think you have to increase knowledge of what exactly is going on. ... Patients sometimes don't know exactly what caused it. ... It helps to in being able to accept and deal with this'.	
			'How to talk about it with your partner? ... So, the social environment. How do you talk about it?' 'People really enjoy watching those videos. ... People do find it very nice to know that they are not the only ones struggling with something'.	

(continued)

Table 1. Continued.

Category	Theme	Code	Condensed meaning unit	Meaning unit
Comorbidities	Integration in intervention		Many experts indicated that the intervention could be applied to other complaints, but that it should mainly focus on CIPN	'It quickly becomes very diffuse and large when you also include all these other issues and people often just suffer from one thing most prominently. And you actually start with one thing and of course they end up with the other things, because that feeds into each other.'
		Guidance need	Many experts indicated that guidance was highly important, but needs would vary between patients	'I myself always found the option that there is a possibility on patient initiative so to speak. ... I think it's nice that you can get some kind of extra help with self-help. But some people also choose very explicitly for just something unguided.'
		Peer support need	Some experts suggested peer support as a relevant component	'What you always hear, but I don't know if you can facilitate that, is that they sometimes can learn a lot from each other.'
		Adherence	Many experts suggested to take adherence into account	'I don't think dropout is necessarily a problem at all. ... It can also just be an early positive.'
		Ease of use	Few experts mentioned ease of use is important.	'Why does Google work? Because it is simple.'
Intervention development	Information		Many experts acknowledged that information should be comprehensive and easy to understand.	'That you don't have too much information thrust upon you'.
		User-characteristics	Many experts mentioned the importance of considering different user-characteristics such as health literacy and digital literacy	'You have people with low health skills and people with average health skills and people with high health skills'.
		Multimedia	Many experts indicated variety in multimedia is advisable	'A mix of, because some people like to read things, some people learn more when they see a video, some people do better when they see some pictures. So, if you can get a balanced mix in there .... Then I think everyone gets the most out of that.'
			Many experts acknowledged that texts, videos and audio should not be too long and too difficult	'As a result, you have to watch the language, but length and formatting are also super important. You don't want it to be a Word document'.
		Design	Some experts indicated a calm design, especially regarding colors, would be necessary.	'We had a very simple first page that didn't have too much on it and they all appreciated that. ... So, basically it should be quiet, and it shouldn't have too many bells and whistles and not too many bold colors. ... It shouldn't have too many stimuli'.
Implementation	Healthcare professionals		Few experts indicated that it was important to involve healthcare professionals and hospitals in implementation	'So I think you just need to find some places and have health care providers refer to them'.
		External parties	Few experts indicated that it was important to involve external parties in implementation	'In that sense, you have to use and the entry points of the existing environments where patients already come. <i>Thuisarts.nl</i> could be one place. <i>Kanker.nl</i> , de <i>Verwijsgids Kanker /KWL</i> , the Dutch Federation of Cancer Patients Organizations, the patient associations. Those are places where patients come and that's where you need to offer it.'

patient group as many experience a 'chemo brain' which comes with self-perceived difficulties regarding thinking and memory due to chemotherapy [38]. Preferences regarding type of device to use for the online intervention differed. Patients agreed that recognizing that patients have had a life-threatening illness is important. Finally, patients described it was important that the intervention is eventually implemented at hospitals or external parties (e.g., patient websites), given findability and reliability.

### Interviews (experts)

Experts ( $N = 11$ ) included oncologists ( $N = 2$ ), oncology nurses ( $N = 2$ ), psychologists ( $N = 3$ ), and eHealth experts ( $N = 4$ ) (Figure 1). Interviews varied from 15 to 45 min in 36 codes and 10 themes; psychosocial aspects, overall intervention need, exercises, content, intervention development, usability, guidance, peer support, comorbidities, and implementation.

Table 1 shows the main results of the interviews, including experts' perceptions of patients' needs and experts' quotes. Experts described being pleased with the development of the intervention, stating that it can provide a helpful resource for patients. They also acknowledged the importance of acceptance of pain and limitations. Furthermore, mindfulness was indicated as important. Experts pointed to a potential stigma on mindfulness and highlighted a need for explanation about application of mindfulness. Repetitive exercises were perceived as crucial for practice and attaining knowledge. Furthermore, psychoeducation, communication to social environment, and paying attention to the patient's voice were indicated as important topics by multiple experts. Furthermore, experts acknowledged the importance of patients' autonomy. Experts indicated the importance of explaining that the intervention is also applicable for other comorbidities besides neuropathy. Guidance from a therapist

was indicated as highly important, but it was also acknowledged that needs would vary between patients. Peer support was suggested by some experts as relevant. Experts mentioned the importance of user-friendliness and accessibility as health literacy and digital literacy may vary between patients. In terms of multimedia, experts indicated that variety is important, noting that texts, videos, and audio files should be short and easy to understand. It was also acknowledged that adherence is a major pitfall in online interventions, and that meeting patients' needs is crucial to prevent non-adherence. Finally, experts emphasized the importance of implementation at hospitals or external parties (e.g., patient websites).

### Personas

Based on the patient interviews, three personas were developed. These personas represent different target groups within users. They included Caucasian patients from different user groups: gender (1 male, 2 female), age (one i.e., adolescent and young adult [AYA]), one middle-aged, and one elderly), social status (1 student, 1 parttime employee, 1 pensioner), and daily limitations (1 study-related, 1 work-related, 1 daily task related). One example of a persona is shown in Figure 2.

### Intervention content development and low-fidelity prototype testing

The online intervention was called *Embrace Pain* (in Dutch: *Omarm Pijn*) and includes an 8-week asynchronous intervention with six sessions. Sessions contain sub-session with experiential information, exercises, metaphors, mindfulness audio files, and quotes. A complete overview of all exercises can be found in Van de Graaf et al. [39]. Quotes and personas to supplement the session information and exercises

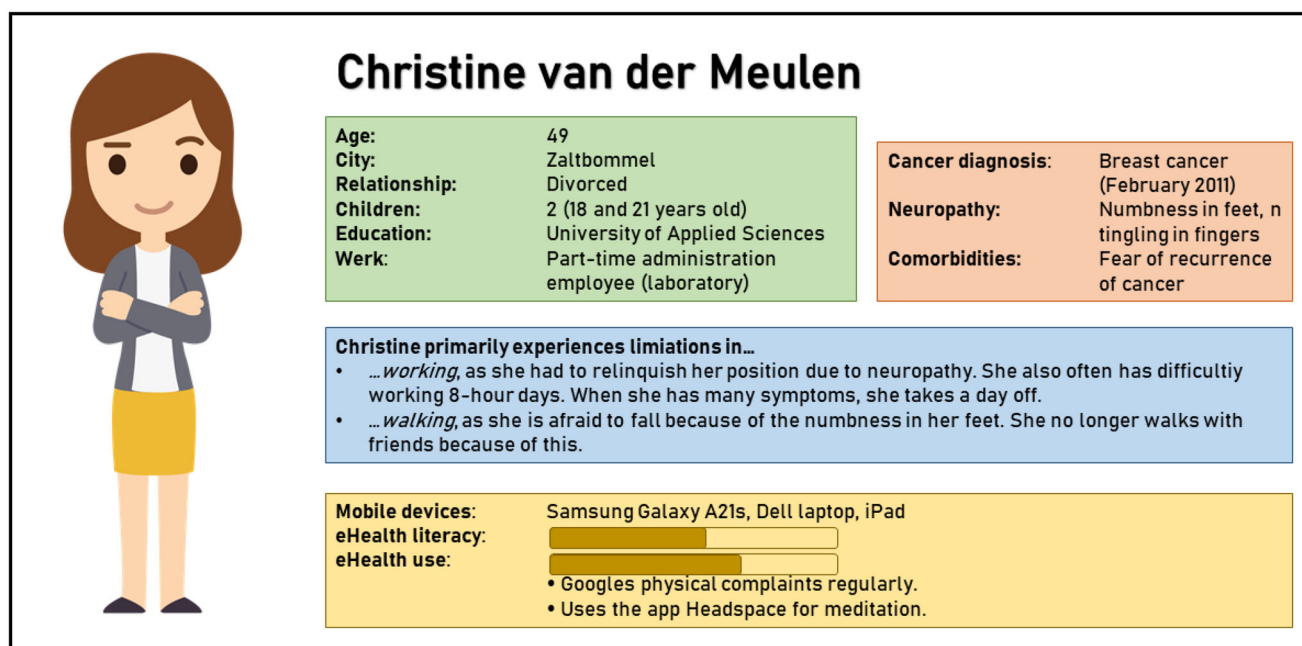


Figure 2. Example of persona.



**Welcome.** Explanation of the online environment, contact options, additional help, other long-term consequences than CIPN, and tips.

**Module 1: Chronic neuropathic pain.** Patients learn about neuropathy after chemotherapy and (chronic) pain. It helps to understand what this training focusses on and why the training can help.

**Module 2: On the way to values.** Patients learn what values are and which activities can bring them to their values. Patients work on what their values are.

**Module 3: Away from my values.** Patients learn about pain and additional thoughts and feelings that can keep them away from their values. Patients look at how they manage pain and what it costs them.

**Module 4: On the road with skills.** Patients learn about commitment and defusion. Patients look at dealing with pain and additional thoughts and feelings differently.

**Module 5: Taking a new road.** Patients learn how to convert values to behaviors. Patients look at which areas of life they want to change. Then they come up with actions that fit their values, which also need to be carried out.

**Module 6: On the road to values: from day to day.** Patients learn to perform actions in their daily lives that they feel are important, *with* pain. The training ends with things patients want to change in the long run.

**Figure 3.** Overview of *Embrace Pain* sessions and content.

were incorporated in an attempt to humanize the intervention [40,41]. An overview of all session is shown in [Figure 3](#).

In total, three patients and two experts evaluated session 2 in the content development phase ([Figure 1](#)), which resulted in adjustments to the content of all sessions. These adjustments included: (1) shortening texts to improve readability, leaving only essential information and no jargon; (2) rewriting some texts to better explain ACT processes; (3) removing several text sections that may have elicited negative emotions in patients; (4) removing references to other sessions to avoid confusing patients; and (5) rendering some exercises optional.

### **Software development and high-fidelity prototype testing**

The online intervention was built within an existing eHealth platform, named Karify. Privacy and security issues are covered by this organization. Karify is ISO 27001 and NEN 7510 certified. For programming the online environment, a standard format was used in which adjustments were made based on the needs of patients conducted from the exploratory interviews. The platform is available on smartphones, tablets, and computers. Participants receive an invitation to access the platform *via* an e-mail link to create an account.

Evaluations by three patients and three experts were performed within the online environment. Changes mostly involved textual corrections. In addition, some nuances were made to prevent misinterpretation (e.g., ‘dangerous’ and ‘alarming’ were removed). Furthermore, some exercises were removed or merged to decrease the number of exercises, leading to some adjustment of the order of sub-sessions. Additional quotes were added after positive evaluations.

Exploratory interviews showed that mindfulness should receive particular attention, as it comes with social stigmas,

which has also been shown in earlier research [42]. To lower the barrier and promote practice, nuances have been made in the delivery of mindfulness. Mindfulness exercises are called ‘focus exercises’ which might prevent scaring off people, with an explanatory text that the exercise concerns mindfulness. How mindfulness should be practiced (e.g., it is about practicing and not about the result) and how it relates to chronic pain was also clarified.

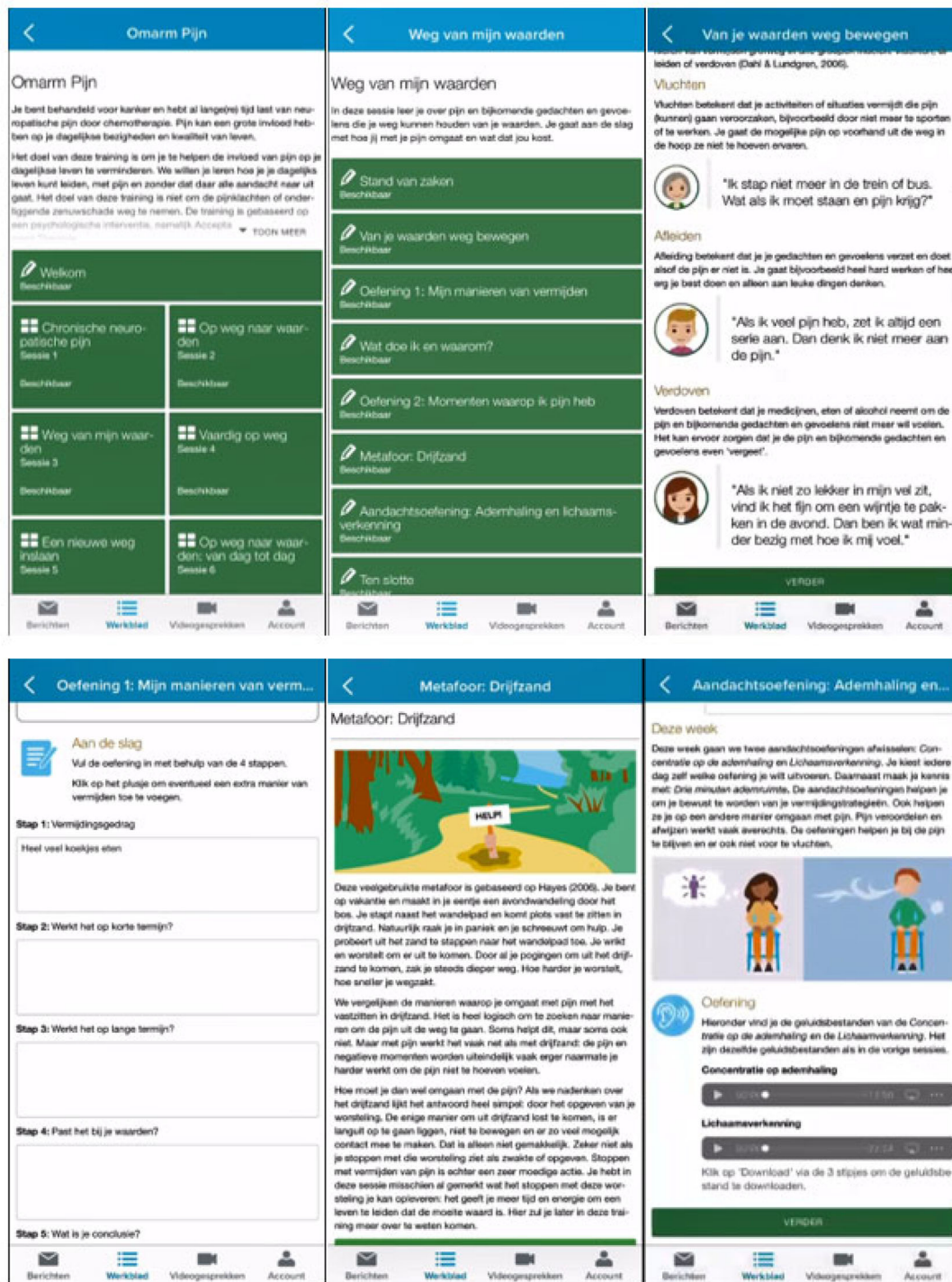
Finally, all sessions were reviewed by two researchers for final textual corrections. [Figure 4](#) shows an overview of the final version of the online intervention in Dutch. Translations of the screenshots are provided in [Appendix B](#). All parts of the intervention are mandatory, with a new session opening when the previous session has been completed. Patients are expected to spend 2 h per week to complete the intervention.

To ensure that patients did not experience any problems using the intervention, clear instructions regarding usage were presented in the ‘Welcome’ session. Furthermore, a support page was available. Additionally, the online intervention enabled asynchronous guidance through a chat feature for content-related questions and motivation.

## **Discussion**

### **Principal findings**

This study described the development of an online ACT intervention for cancer survivors with painful chronic CIPN using a patient-centered design process following the CeHRes roadmap [32]. This roadmap was considered to be an appropriate method to properly reflect the reasoning of TAM [29,30] and TTF [31] in the development. Interviews with both patients and experts were conducted to determine intervention needs. Overall, patients mainly indicated a need for a user-friendly and accessible intervention with a high

Figure 4. *Embrace Pain* application screenshots (*Omarm Pijn*; Dutch text)Figure 4. *Embrace Pain* application screenshots (*Omarm Pijn*; Dutch text).

level of autonomy. Furthermore, they valued and agreed with the elements of ACT. The interviews also showed the importance of realizing that patients have had a life-threatening illness and that is directly relates to the symptoms patients experience. These results also emerged in the expert interviews. Content was created based on patient needs and ACT-theory. During the development, adaptations have been made based on both low-fidelity and high-fidelity prototype testing. Feedback and findings resulted in an 8-week online

intervention named *Embrace Pain*, which includes six sessions consisting of texts, illustrations, quotes, and audio clips. Besides all processes of ACT, psychoeducation was included.

Regarding patients' needs regarding the online intervention, the interviews showed some interesting results. Needs regarding guidance for the online intervention varied widely. For example, some patients reported having no need for guidance, while others indicated to want extensive contact via video calling. In the final online intervention, only

guidance *via* chat was implemented. Knoerl et al. [25] suggested further improvements of their online CBT intervention for patients with CIPN, including interaction with a health care professional, which could contribute to usage. Earlier studies have indeed shown that guided online interventions show better outcomes regarding satisfaction, usage and adherence compared to non-guided versions [43–45]. As guidance involves high costs and is less appropriate for reaching large groups of people [44], it seemed appropriate to only implement low-threshold email guidance in this online intervention.

Furthermore, some interview findings were not directly incorporated into the development. First, this relates to peer support, which could be perceived as pleasant as indicated by some patients. Peer support includes helping fellows who are suffering from the same condition [46] and a systematic review has shown effectiveness in improving QoL and distress [47]. However, this only applied to interventions including peer training. Avoiding or cautious use of online peer support without peer group training has been recommended due to risk of misinformation [47,48]. Implementation of peer support was beyond the scope of this online intervention and future research should assess integration of supervised peer support. Second, no decisions were made regarding future implementation. Patients and experts indicated that implementation should be performed with healthcare professionals and external partners. Previous studies studying online interventions emphasized that is indeed important to consider external parties such as healthcare professionals and organizations [49,50]. However, implementation was not within the scope of this study, and should be considered by future research in accordance with findings from a randomized controlled trial (RCT) [39]. However, an already existing online platform (i.e., Karify) that is widely used by healthcare institutions was chosen, which facilitates implementation.

Although this study included participants with varying backgrounds (e.g., age, educational, tumor type), patients with low health literacy (i.e., patients who have difficulties obtaining, processing, understanding, and communicating about health-related information [51]) were not specifically involved. Nowadays, eHealth literacy, which relates to the ability to search, find, and appropriately use online health environments [52] is relevant as well. Based on prototype testing, texts were shortened in the current development, without compromising the content. Nevertheless, as text rather than audiovisual content is the basis of the intervention, this is less suitable for patients with low health literacy [53]. Mackert et al. suggest developing an intervention in which audio and video are the basis, with more in-depth texts for users with high health literacy. This could be considered when optimizing the intervention for possible implementation after effectiveness has been studied.

### **Strengths and limitations**

This article has several strengths. First, patients have been involved in all development phases, in accordance with the CeHReS roadmap [32]. This may eventually positively influence adaptation and future implementation [32]. Second, multiple

experts with various backgrounds (i.e., healthcare professionals and eHealth experts) have also been able to contribute to the development throughout the development process. Third, this study was designed and conducted by a multidisciplinary team, including psychologists working in clinical and scientific settings, as well as a communication and information scientist. This multidisciplinary approach helped to develop a user-friendly evidence-based intervention.

There are also several limitations. The first limitation related to the low-fidelity and high-fidelity prototype testing. We aimed to use the think-aloud method that includes a usability evaluation method in which participants perform tasks in the prototype, while being encouraged to express their thoughts and feelings for optimizing technology [54–56]. As prototype testing had to take place *via* video calls due to COVID-19, properly using the think-aloud protocol was difficult. Therefore, online interviews using the WUSQ were conducted. This may have resulted in less concrete feedback compared to an observational method such as the think-aloud method [57] and may specifically apply to the current patient group who often experience memory-problems due to older age and so-called ‘chemo brain’. It may have limited optimization of the intervention. Future research could evaluate the upcoming RCT results and conduct think-aloud usability tests to create an optimized version of *Embrace Pain*. Second, not all individual sessions have been evaluated by patients and experts. However, all sessions have been written by the same authors. Thereby, all sessions consist of the same structure and are based on the same concept (i.e., psychological flexibility). Furthermore, all sessions will be evaluated in an RCT [39]. Third, recruitment *via* digital flyers only may have resulted in a limited representation of patients who may have been less technology-competent.

### **Conclusion**

This study showed how a patient-centered development process could be applied in the development of an online self-management intervention based on ACT for patients with chronic painful CIPN. The development resulted in an 8-week online intervention called *Embrace Pain*, which was based on user needs and ACT. Next, we will perform an RCT to study the effectiveness of the online intervention [39]. Usage and adaptation also need to be assessed, as this may optimize the online intervention to enhance effectiveness.

### **Ethics approval**

ClinicalTrials.gov NCT05 371158. Registered on May 12, 2022.

### **Disclosure statement**

No potential conflict of interest was reported by the author(s).

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## Data availability statement

The data that support the findings of this study are available from the corresponding author (DG) upon reasonable request.

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## Appendix A.

**Table A1.** Participant characteristics.

Participant	Gender	Age <sup>a</sup>	Educational level <sup>b</sup>	Marital status	Tumor	Daily Internet use	Self-perceived Internet expertise	eHealth literacy (1–10)
P1	Male	25–30	Middle	Single	Hodgkin lymphoma	3–5 h	Expert	5.86
P2	Female	50–55	High	Married/living together	Breast cancer	2–3 h	Average	
P3	Female	60–65	High	Divorced	Breast cancer	>5 h	Average	6.57
P4	Female	60–65	High	Divorced	Breast cancer		Average	7.71
P5	Female	60–65	High	Divorced	Breast cancer	1–2 h	Average	
P6	Female	60–65	High	Divorced	Lung cancer	2–3 h	Average	
P7	Male	60–65	High	Married/living together	Hodgkin lymphoma	3–5 h	Expert	6.43
P8	Female	60–65	Middle	Married/living together	Colorectal and colon cancer	3–5 h		7.43
P9	Male	65–70	Middle	Married/living together	Leukemia and acute lymphoblastic leukemia	1–2 h	Expert	5.71
P10	Male	65–70	High	Married/living together	Multiple myeloma	2–3 h	Average	9.86
P11	Female	75–80	High	Single	Lung and breast cancer	2–3 h	Average	7.86
P12	Female	75–80	High	Divorced	Colorectal, colon, rectal and skin cancer	<1 h	Average	9.57

<sup>a</sup>Age ranges are shown to ensure anonymity.

<sup>b</sup>Low: primary or secondary pre-vocational; middle: secondary education or vocational education; high: Bachelor's degree or higher.



## Appendix B. Translations of Dutch screenshots

### Screenshot 1

Header: Embrace Pain

Title: Embrace Pain

You have been treated for cancer and have been experiencing neuropathic pain caused by chemotherapy for long(er) period. Pain can greatly influence daily activities and quality of life.

The goal of this training is to help you reduce the impact of pain on your daily life. We want to teach you how to live your daily life, with pain and without focusing all your attention on it. The goal of this training is not to eliminate the pain symptoms or underlying nerve damage. The training is based on a psychological intervention, namely acceptance and commitment therapy.

[Welcome

Available]

[Chronic neuropathic pain

Module 1 (Available)]

[On the way to values

Module 2 (Available)]

[Away from my values

Module 3 (Available)]

[On the road with skills

Module 4 (Available)]

[Taking a new road

Module 5 (Available)]

[On the road to values: from day to day

Module 6 (Available)]

### Screenshot 2

Header: Away from my values

Title: Away from my values

In this session, you will learn about pain and additional thoughts and feelings that can keep you away from your values. You will work on how you deal with your pain and what it costs you.

[Current situation (Available)]

[Moving away from your values (Available)]

[Exercise 1: My ways of avoiding (Available)]

[What do I do and why? (Available)]

[Exercise 2: Moments when I am in pain (Available)]

[Metaphor: Quicksand (Available)]

[Attention exercise: Breathing and body exploration (Available)]

[Finally (Available)]

### Screenshot 3

Header: Moving away from your values

These different ways of getting rid of pain and additional thoughts and feelings are called avoidance. You can roughly categorize ways of avoidance into three groups: escape, distraction or numbing (Dahl and Lundgren, 2006).

Escaping

Escaping means that you avoid activities or situations that will (or may) cause pain, for example, by not exercising or working out. You avoid the potential pain in advance in hopes of not having to experience it.

'I no longer get on the train or bus. What if I have to stand and get pain?'

Distraction

Distraction means that you resist your thoughts and feelings and pretend that the pain is not there. For example, you start working really hard or trying really hard and thinking only about nice things.

'When I have a lot of pain, I always watch TV-series. Then I don't think about the pain anymore.'

Numbing

Numbing means taking medicine, food or alcohol to stop feeling the pain and additional thoughts and feelings. It can make you 'forget' the pain and additional thoughts and feelings for a while.

'When I'm not feeling so good, I like to grab a glass of wine in the evening. Then I'm a little less concerned with how I'm feeling'.

[Further]

### Screenshot 4

Header: Exercise 1: My ways of avoiding

Title: Getting Started

Complete the exercise using the four steps.

Click on the plus sign to add an additional way of avoiding if necessary.

Step 1: Avoidance behaviors

[Eating a lot of cookies]

Step 2: Does it work in the short term?

Step 3: Does it work in the long term?

Step 4: Does it fit your values?

Step 5: What is your conclusion?

### Screenshot 5

Header: Metaphor: Quicksand

Title: Metaphor: Quicksand

This commonly used metaphor is based on Hayes (2006). You are on vacation and take an evening walk through the woods by yourself. You step off the hiking trail and suddenly find yourself stuck in quicksand. Naturally, you panic and scream for help. You try to step out of the sand toward the hiking trail. You wriggle and struggle to get out. Through all your attempts to get out of the quicksand, you sink deeper and deeper. The harder you struggle, the faster you sink.

We compare the ways you deal with pain to being stuck in quicksand. It makes perfect sense to look for ways to get out of pain. Sometimes this helps, but sometimes it doesn't. But with pain, it often works just like quicksand: the pain and negative moments often end up getting worse the harder you work to avoid feeling the pain.

So how should you deal with the pain? When we think about quicksand, the answer seems very simple: by giving up your struggle. The only way to get unstuck from quicksand is to lie stretched out on it, not move and make as much contact with it as possible. That's just not easy. Especially if you see quitting that struggle as weakness or giving up. Stopping avoiding pain, however, is a very courageous action. You may have noticed in this session what quitting this struggle can give you: it gives you more time and energy to live a life worth living. You will learn more about this later in this training.

### Screenshot 6

Header: Attention exercise: Breathing and body exploration

Title: This week

This week we will alternate between two attention exercises: Concentration on breathing and Body exploration. Each day you will choose which exercise to perform. In addition, you will be introduced to: Three minutes of breathing. The attention exercises help you become aware of your avoidance strategies. They also help you deal with pain in a different way. Condemning and rejecting pain is often counterproductive. The exercises help you to stay with the pain and not flee from it.

Title: Exercise

Below are the sound files of the Concentration on breathing and Body exploration. They are the same sound files as in the previous sessions.

Title: Concentration on breathing

Title: Body exploration

Click on 'Download' via the 3 dots to download the sound file.