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Original Paper

# Response Across the Health-Literacy Spectrum of Kidney Transplant Recipients to a Sun-Protection Education Program Delivered on Tablet Computers: Randomized Controlled Trial

June K Robinson<sup>1</sup>, MD; John J Friedewald<sup>2</sup>, MD; Amishi Desai<sup>3</sup>, DO; Elisa J Gordon<sup>4</sup>, MPH, PhD

<sup>1</sup>Department of Dermatology, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

<sup>2</sup>Comprehensive Transplant Center, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

<sup>3</sup>Division of Nephrology, Department of Medicine, University of Illinois at Chicago, Chicago, IL, United States

<sup>4</sup>Center for Healthcare Studies, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

**Corresponding Author:**

June K Robinson, MD

Department of Dermatology

Northwestern University Feinberg School of Medicine

676 N St. Clair St

Suite 1260

Chicago, IL, 60611

United States

Phone: 1 312 926 7449

Fax: 1 312 926 8106

Email: [june-robinson@northwestern.edu](mailto:june-robinson@northwestern.edu)

## Abstract

**Background:** Sun protection can reduce skin cancer development in kidney transplant recipients, who have a greater risk of developing squamous cell carcinoma than the general population.

**Objective:** A culturally sensitive sun-protection program (SunProtect) was created in English and Spanish with the option of choosing audio narration provided by the tablet computer (Samsung Galaxy Tab 2 10.1). The intervention, which showed skin cancer on patients with various skin tones, explained the following scenarios: skin cancer risk, the ability of sun protection to reduce this risk, as well as offered sun-protection choices. The length of the intervention was limited to the time usually spent waiting during a visit to the nephrologist.

**Methods:** The development of this culturally sensitive, electronic, interactive sun-protection educational program, SunProtect, was guided by the “transtheoretical model,” which focuses on decision making influenced by perceptions of personal risk or vulnerability to a health threat, importance (severity) of the disease, and benefit of sun-protection behavior. Transportation theory, which holds that narratives can have uniquely persuasive effects in overcoming preconceived beliefs and cognitive biases because people transported into a narrative world will alter their beliefs based on information, claims, or events depicted, guided the use of testimonials. Participant tablet use was self-directed. Self-reported responses to surveys were entered into the database through the tablet. Usability was tested through interviews. A randomized controlled pilot trial with 170 kidney transplant recipients was conducted, where the educational program (SunProtect) was delivered through a touch-screen tablet to 84 participants.

**Results:** The study involved 62 non-Hispanic white, 60 non-Hispanic black, and 48 Hispanic/Latino kidney transplant recipients. The demographic survey data showed no significant mean differences between the intervention and control groups in age, sex, income, or time since transplantation. The mean duration of program use varied by the ethnic/racial group, with non-Hispanic whites having the shortest use (23 minutes) and Hispanic/Latinos having the longest use (42 minutes). Knowledge, awareness of skin cancer risk, willingness to change sun protection, and use of sun protection increased from baseline to 2 weeks after the program in participants from all ethnic/racial groups in comparison with controls ( $P < .05$ ). Kidney transplant recipients with inadequate (47/170, 28%) and marginal functional health literacy (59/170, 35%) listened to either Spanish or English audio narration accompanying the text and graphics. After completion of the program, Hispanic/Latino patients with initially inadequate health literacy increased their knowledge more than non-Hispanic white and black patients with adequate health literacy ( $P < .05$ ). Sun protection implemented 2 weeks after education varied by the ethnic/racial group. Outdoor activities were reduced by

Hispanics/Latinos, non-Hispanic blacks sought shade, Hispanic/Latinos and non-Hispanic blacks wore clothing, and non-Hispanic whites wore sunscreen ( $P < .05$ ).

**Conclusion:** Educational program with a tablet computer during the kidney transplant recipients' 6- or 12-month follow-up visits to the transplant nephrologist improved sun protection in all racial/ethnic groups. Tablets may be used to provide patient education and reduce the physician's burden of educating and training patients.

**Trial Registration:** ClinicalTrials.gov NCT01646099; <https://clinicaltrials.gov/ct2/show/NCT01646099>

(*JMIR Cancer* 2015;1(2):e8) doi:[10.2196/cancer.4787](https://doi.org/10.2196/cancer.4787)

## KEYWORDS

culturally sensitive; electronic health intervention; kidney transplant recipients; post-transplant outcomes; skin cancer; squamous cell carcinoma; sun protection; tablet computer; patient education; mobile health

## Introduction

### Background

Sun protection is important for kidney transplant recipients, as they have a 20- to 100-time greater risk of developing squamous cell carcinoma (SCC) than the general population [1]. Effective sun protection has been reported to reduce the development of SCC in non-Hispanic white kidney transplant recipients when practiced over a 2-year period [2]. The impaired quality of life experienced by kidney transplant recipients from disfigurement and loss of function from many surgical procedures to remove SCC, as well as the anxiety and fear about the return or spread of SCC, may be alleviated by implementing sun protection, which would reduce the risk of developing SCC.

Although non-Hispanic white kidney transplant recipients with skin that sunburns easily and tans poorly have the greatest risk of developing SCC, SCC also occurs in many Hispanic/Latinos and non-Hispanic blacks [3]. Hispanic/Latinos and non-Hispanic blacks display considerable diversity in the sun sensitivity of their skin. Some individuals in these groups have sun-sensitive skin [4]. The term "people with skin of color," bridges descriptions of race and ethnicity, and allows self-identification by those with mixed ethnicity/race. People with skin of color commonly do not perceive sunburn/skin cancer as relevant because they and their families lack sufficient experience with sunburn/skin cancer as well as with using sun protection [5]. Because of increased skin cancer risk, effective sun-protection counseling is needed for all kidney transplant recipients, regardless of skin color. However, the need for culturally sensitive sun-protection counseling of kidney transplant recipients with skin of color may be unrecognized by patients and providers due to the assumption that their skin color provides sufficient sun protection.

The development of this culturally sensitive, electronic, interactive sun-protection educational program, SunProtect,

was guided by the transtheoretical model, which focuses on decision making influenced by perceptions of personal risk or vulnerability to a health threat, importance (severity) of the disease, and benefit of a behavior to the health outcome [6]. Because the tablet personal computer (tablet) supports presentation of videos, we created storytelling testimonials in English and Spanish with non-Hispanic white, Hispanic Latino, and non-Hispanic black kidney transplant recipients. Our decision to develop video testimonials was guided by transportation theory, which holds that narratives can have uniquely persuasive effects in overcoming preconceived beliefs and cognitive biases because people transported into a narrative world will alter their beliefs based on information, claims, or events depicted [7,8]. These videos specifically aim to improve knowledge about skin cancer and address relevance to people with skin of color by giving personal details about developing skin cancer and sun-protection use. Patients identify with the storytellers, which increases the likelihood that social influence will shift their normative beliefs.

### Objective

SunProtect was particularly developed for patients with lower health literacy and from racially/ethnically diverse backgrounds, which is especially important given that minorities comprise 42% of living kidney transplant recipients in the United States [9] (Figure 1). In addition, approximately one third of kidney transplant recipients have limited health literacy, and thus, the educational content included terms that are easily understandable through multiple interactive media, including audio, video, pictorial, and textual information written below a 6th-grade reading level [10-12]. This pilot research evaluated the impact of SunProtect on knowledge, intentions to use sun protection, and use of sun protection among non-Hispanic white, Hispanic Latino, and non-Hispanic black kidney transplant recipients before and 2 weeks after education.

**Figure 1.** Introduction to the program showed the range of ethnicities and races.



## Methods

### Setting and Recruitment

Kidney transplant recipients from 2 urban Chicago programs, Northwestern Medicine and University of Illinois at Chicago, were eligible for participation in the study if they met the following inclusion criteria: (1) had received a kidney transplantation within the past 2-24 months, (2) spoke and read English or Spanish, (3) aged between 18 and 70 years, (4) could see well enough to read a newspaper, (5) lived in the greater Chicago area, and (6) self-identified as non-Hispanic white, non-Hispanic black, or Hispanic Latino. Patients were excluded from the study if they had a previous self-reported history of skin cancer as verified in their medical record, previously participated in sun-protection educational research conducted by this research team, a history of dermatologic disease treated with ultraviolet light (eg, psoriasis, atopic dermatitis), and were under the care of a dermatologist within the last 5 years.

Research coordinators recruited potential participants by calling them (over telephone) 1 week before their scheduled appointment with the transplant nephrologist. Patients were told about the sun-protection educational study and asked if they were interested in participating during their visit to the transplant nephrologist and 2 weeks later by telephone.

### Design

#### Accrual

Accrual was purposefully stratified to obtain representation of all 3 ethnic/racial groups. Written consent was obtained by a research assistant. From mid-May to mid-July 2014, consenting participants used a tablet to complete an online self-report pretest survey in the physicians' offices. Immediately after completing the pretest, participants were randomized using a random allocation sequence for each ethnic/racial group (1:1) to receive SunProtect, an educational sun-protection program, or to be in the control group. The control group received general skin care information. The software program gave the participants their allocation, and thus, the kidney transplant recipients were not blinded to their condition. Two weeks later, participants were called by a research assistant, who did not enroll the kidney transplant recipient and was blinded to their condition, and asked to respond to the same sun-protection survey questions used in the pretest. The Institutional Review Boards of Northwestern University and the University of Illinois Hospital and Health Sciences System approved the study and participants were compensated for study participation.

#### Educational Sun-Protection Program

SunProtect was derived from an educational sun-protection workbook created and used in our prior research [13]. Sun-protection options described in SunProtect included

restricting outdoor exposure between 10 am and 4 pm, seeking shade when outdoors, wearing protective clothing (hats, long sleeved shirts, long pants, and sunglasses), and/or applying broad-spectrum sunscreen with a sun-protection factor of 30 or more.

Text screens (n=36) were evaluated with the Flesch-Kincaid test to assure that the grade level did not exceed 6th-grade reading level. SunProtect had an introductory section in which program navigation was demonstrated, and the language (English or Spanish) and audio guide were selected by touching

one of the following 4 images: non-Hispanic white woman, Hispanic Latino woman, Hispanic Latino man, or non-Hispanic black man. The topics of 8 sequential chapters were as follows: importance of sun protection, skin cancer, risk of developing skin cancer, ways people get sun exposure, choices of sun protection, frequently asked questions about sunscreen, protective clothing, and personalized sun-protection recommendations (Table 1). Videos demonstrated effective sunscreen application. Participants used headphones to listen to the program in the waiting room.

**Table 1.** SunProtect content.

Chapter	Screen (N)	Supplemental content	
		Photographs Title (N)	Video and testimonials title (playing time in seconds)
Navigation	1		
Select language + program audio guide	1	5	
Table of contents	1		
Why protect against the sun?	1	Sunburn (2), dark spots (2)	
What is skin cancer?	3	Basal cell carcinomas (2), squamous cell carcinomas (2), melanoma (2)	
What is the chance of a kidney transplant recipient getting skin cancer?	6	Kidney transplant recipient's risk (1), public's risk (1), select skin tone (1), ease of sunburn (2), time from transplant to get skin cancer (1)	Testimonial: Surprised by sunburn (10)
How do people get sun exposure?	3	Outdoor activities (2): Select outdoor activities you do	
ABC rule for sun protection	3	Avoid sun (1), block sun (1), cover up in the sun (1)	Testimonials (3), skin irritation from sun (7), using sunblock (9), wearing a hat (8)
Frequently asked questions about sunscreen	9	Broad-spectrum sun blockage (3), amount to use (1), two coats of sunscreen (1)	Lotion, gel, cream, and stick sunscreen consistency (77); application of sunscreen stick (32); sunscreen spray to arm (20); sunscreen lotion (31); difficulty of spraying sunscreen on your own back (14); incorrect sunscreen spraying (10); application of sunscreen lotion to face: correct (35 seconds)/incorrect (21 seconds)
What types of protective clothing are good to wear?	2	Protective clothing (1), correct hat (2)	
Your personal sun-protection recommendation: • Request personal sun-protection recommendation • Request tip for early recognition of skin cancer	6	Doctor gives personal recommendation for sun protection (1), tips to remember sun-protection gear (1)	

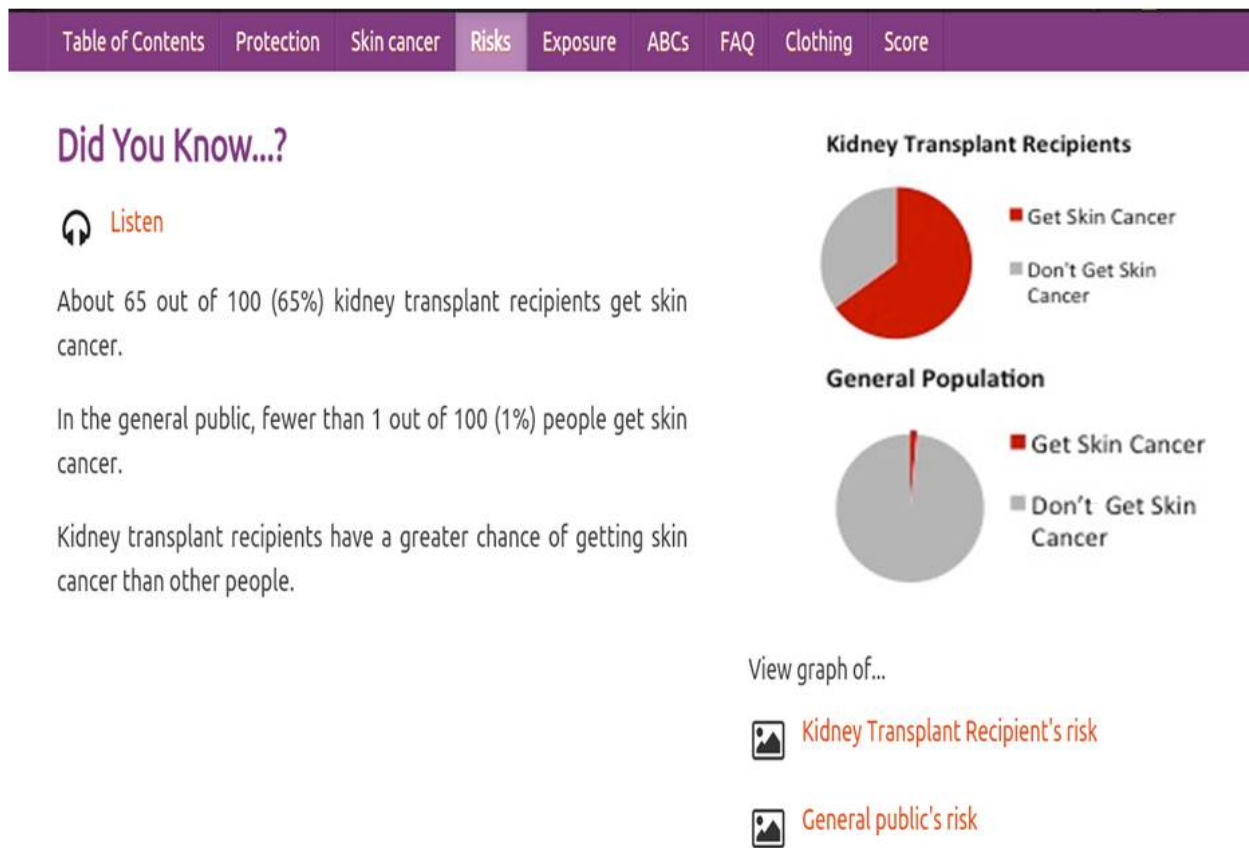
The tablet screen was divided into 3 parts with the primary content on the left half of the screen. Supplementary content, which was available on the right side of the screen, was accessed by touching the icon (Figure 2). SunProtect was displayed on a Samsung Galaxy Tab 2 10.1, a tablet personal computer (tablet) with a touch screen and was created in collaboration

with the Center for Behavioral Intervention Technologies at Northwestern University.

Upon touching the headphone icon, audio narration presenting the same content as the written text was available for all program screens. Users could elect not to listen to the audio narration, skip pages and chapters, or repeat them.



**Figure 2.** Users toggled between the 2 pie graphs presenting the risk of developing skin cancer in kidney transplant recipients and in the general population.

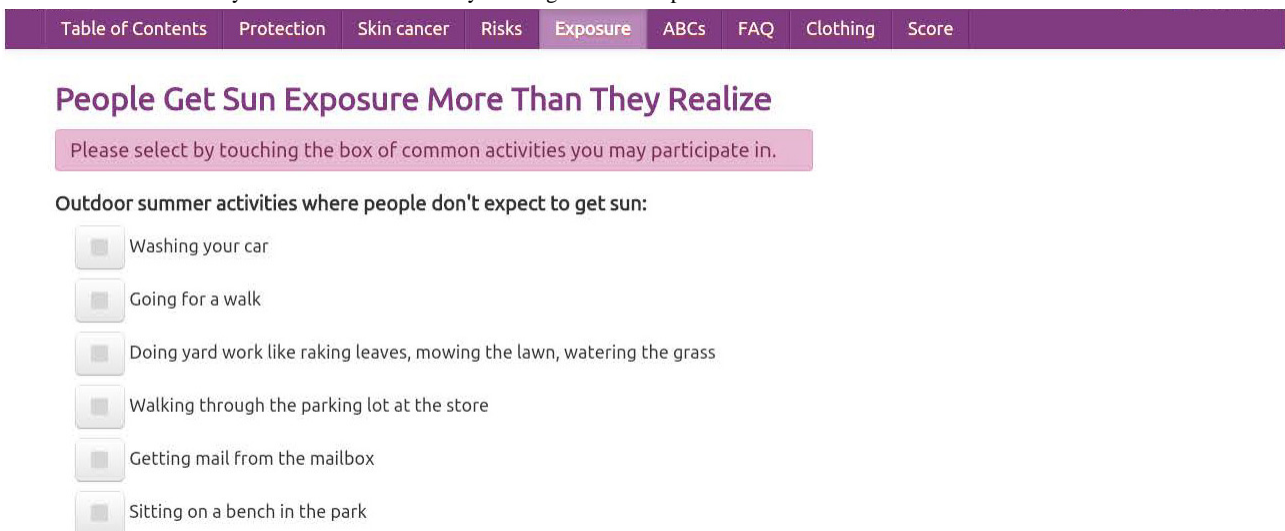


**Personalizing the Sun-Protection Recommendation**

The educational tablet program included interactive components in which the participants selected (1) the color bar that most closely matched the color of their skin in the sun-protected location of the upper inner arm, (2) the daily outdoor activities

they usually performed, and (3) their commonly used sun-protective behaviors, if any (Figure 3). These 3 self-reported items were used to develop tailored sun-protection recommendations for each user. Their personal sun-protection recommendations were delivered at the end of the SunProtect program by a physician appearing on screen (Figure 4).

**Figure 3.** Users selected daily activities with commonly unrecognized sun exposure.



**Figure 4.** Personalized sun-protection recommendation from the doctor.

## Congratulations!

I hope that you have learned that it is important to use sun protection and ways to protect yourself.

Your skin tone number is 4.

This means that when you will be outdoors gardening it is important for you to remember to apply sunscreen with an SPF of 50 or more about 20 minutes before you go out. Apply sunscreen to all skin that is not covered by clothing and use the “two coat” method you learned today. You also told me that you would try to remember to wear a hat. Some of the reminders that you thought would work for you are:

- Put your hat on a rack by the door so you can grab it on your way out
- Keep sunscreen in your purse.

Using sun protection will keep you from getting skin cancer.

Congratulations on your decision to keep your skin healthy.

June K. Robinson, MD  
Department of Dermatology  
Northwestern University Feinberg School of Medicine



### Cultural Sensitivity

At the beginning of the program, participants selected the preferred language, English or Spanish, and their choice of narrators. Two Hispanic Latino bicultural, bilingual research coordinators translated the text and audio narration of the program from English to Spanish. Several bilingual physicians and health professionals then validated the translation of the text and audio narration from Spanish to English.

Culturally appropriate language (eg, the term “skin irritation” from the sun) was used in place of “sunburn” to describe the response of people with skin of color to sun exposure. Sunburn and skin irritation from sun exposure were depicted as occurring in people with skin of color as well as in the skin of non-Hispanic white people after “getting some sun.” Language such as “tan” as a response to sun exposure was explicitly avoided because in our previous research, non-Hispanic blacks and Hispanic Latinos reported that they “got dark” rather than “tan” [5].

Because many non-Hispanic black kidney transplant recipients did not know how to swim, examples of outdoor activities commonly enjoyed by non-Hispanic white, such as swimming, were not used in the workbook. Family outdoor activities were


emphasized because Hispanic Latino kidney transplant recipients noted the importance of time spent with the extended family (eg, a picnic in the park).

Lastly, photographs of skin cancers and skin changes from sun exposure occurring in people with all skin tones were presented (Figure 5). The audio narration of images of sunburn and skin irritation addressed non-Hispanic white, non-Hispanic black, and Hispanic Latino people’s beliefs about preferences for and the ability to get darker skin color, skin irritation, and skin cancer from exposure to the sun. For example, the audio accompanying a picture of a non-Hispanic black man with a bit of pink color on his cheek stated, “People with skin of color that in the past may not have gotten pink from being out in the sun may get a bit pink after their transplant.” The picture of a Latina with dark spots on her face was accompanied by the following narration: “Many Latinas use sun protection to keep from getting dark spots from the sun.” A bald non-Hispanic black man, who was a kidney transplant recipient, related his story of getting a sun irritation on his bald head when he went to Florida to Disney World with his grandchildren on spring break and forgot to take his hat (Figure 6). The content did not change during the randomized controlled trial (Trial Registration: ClinicalTrials.gov NCT01646099).



**Figure 5.** Explanation of squamous cell carcinoma with examples in kidney transplant recipients with skin of color.

Table of Contents Protection **Skin cancer** Risks Exposure ABCs FAQ Clothing Score


## Squamous Cell Carcinoma

 Listen

Squamous cell carcinoma is the most common skin cancer in kidney transplant recipients. It may look similar to basal cell carcinoma. Squamous cell carcinoma tends to grow on the ears, lips, hands and arms. It is easily treated if found early, but can result in death if left untreated.

Some people may become uncomfortable seeing other examples. If you wish, you may view more examples of:


 [Squamous Cell Carcinomas](#)

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**Figure 6.** Testimonial from a non-Hispanic black kidney transplant recipient relating skin irritation from the sun on his bald scalp because he forgot his hat.


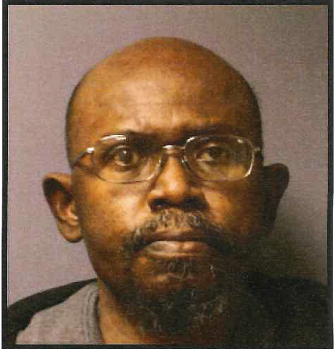
Table of Contents Protection Skin cancer Risks Exposure ABCs **FAQ** Clothing Score

## How to Protect Your Skin – the ABC's


 Listen

### C=Cover

When outdoors, cover your skin with protective clothing, sunglasses and hats.

Learn more about...

 [A recipient's hat story](#)



## Measures

### *Health Literacy*

Health literacy was ascertained by a written self-administered survey in Spanish or English of the Short Test of Functional Health Literacy in Adults (S-TOFHLA) administered as a timed 7-minute 36-item survey [14]. Health literacy was categorized into one of the following 3 groups: adequate health literacy (36-23), marginal health literacy (22-17), and inadequate health literacy (16-0).

### *Demographic Information, Knowledge, Attitudes, and Sun-Protection Behavior*

A brief self-report survey of demographic information was administered on the tablet. Participants could select the English or Spanish versions to read and could elect to hear the audio narration. People with inadequate health literacy as determined by the score received on the S-TOFHLA were invited to have the survey administered by the research coordinator. Demographic information consisting of sex, age, marital status, race/ethnicity, education, annual household income, and months since receiving the transplant was only assessed in the first survey.

Knowledge of skin cancer and sun protection was assessed with the following 9 statements with “agree” or “disagree” responses: (1) people with a kidney transplant take medicine that may make their skin sensitive to the sun; (2) only people with a kidney transplant who have sun-sensitive skin, who freckle and sunburn easily, have to worry about getting a skin cancer; (3) applying sunscreen after being out in the sun is enough protection; (4) when the sun is high in the sky, seek shade to avoid the strong rays of the sun; (5) clothing does not protect the skin from the sun; (6) sunglasses protect the delicate skin around the eyes; (7) it takes about a teaspoon of sunscreen to cover the skin of the whole body; (8) a baseball cap is a good hat for sun protection; (9) walking outside at noon for an hour is not enough time outside to need sun-protective gear. Recognition of their personal risk of developing skin cancer was an item with a 5-point Likert scale. Hours of outdoor sun exposure were assessed by their weekday and weekend duration of outdoor activities between 10 am and 4 pm. Willingness to change sun-protection behavior (20 items with a 5-point Likert scale) and current sun-protection behavior(s) focused on the use of sun protection by wearing sunscreen, wearing protective clothing, wearing sunglasses, and seeking shade (20 items with a 5-point Likert scale). The same items were assessed with all participants by a self-report survey at 2 study time points (before and 2 weeks after the baseline visit). The psychometrically validated measures among kidney transplant recipients were previously reported [13]. The survey items, which could be “read” to the kidney transplant recipients selecting the audio version, elicited the same responses online or in writing in a sample of 20 kidney transplant recipients.

### *Educational Program Evaluation: Usability, Use, and Satisfaction*

To test the “usability” of SunProtect, research coordinators performed 1-2-hour cognitive interviews with 4 non-Hispanic white and 4 non-Hispanic black kidney transplant recipients in

English, and 5 Hispanic Latino kidney transplant recipients in Spanish, which were audio and video recorded. Each interview was transcribed and translated into English to (1) evaluate and provide feedback on the overall look of the screen, the font size, color scheme, and navigation buttons; (2) solicit suggestions for improving behavioral alternatives; and (3) evaluate the cultural sensitivity of the tablet program. Three reviewers independently reviewed the audiotapes, field notes, and coded the data. The team met to discuss the interpretations, come to consensus, and identify data-driven approaches to revise the content. Revisions to content presented on the screens of the tablet were made in an iterative process after conducting 3 interviews with at least one individual from each racial/ethnic group.

Measures of the “use” of SunProtect were the duration of program use, the time spent on an individual page/screen, repetition of any portion of a chapter, selection of audio narration, and viewing of supplementary figures, videos, and/or testimonials.

Participants rated their “satisfaction” with the program’s ease of use, usefulness of content, and visual appeal of the presentation on a 5-point scale, with 5 being the greatest ease of use, content usefulness, and appeal of presentation.

### *Written Material Requested*

At the end of the program, participants had the option to request that their personal sun-protection recommendations and/or the tip sheet for early detection of SCC with color illustrations be sent by email [15].

### *Participant Waiting Time*

Research coordinators observed and kept a log of the time kidney transplant recipients spent in the waiting room until they were seen by the transplant nephrologists.

### *Statistical Analysis and Sample Size*

The sample size required to sensitively detect a 30% difference in using sun protection between the 3 ethnic/racial groups was 180 (60 in each group completing the study), assuming an alpha less than .05 and power of 0.8 or more in a two-tailed test. Attrition was estimated at 20%, with N=60 in each group. The effect size in each group was 20 with 95% confidence interval ( $\pm 1-39$ ).

Program use and evaluation, change in knowledge, and requests for written materials were compared between groups using Chi-square tests of association and Wilcoxon rank sum tests. Summary statistics are presented as counts and percentages, or mean (standard deviation) as appropriate. All analyses were run at a nominal type I error rate of 5%, and performed in SAS version 9.2 (Cary, NC, USA).

## Results

### **Population**

Of the 522 eligible kidney transplant recipients approached, 170 were accrued to the study (170/522, 32.6% participation rate). Eight eligible recipients at the University of Illinois at Chicago could not enter the study due to failure of the Wi-Fi

service. All participants in the baseline assessments completed the 2-week follow-up, including 60 non-Hispanic black, 62 non-Hispanic white, and 48 Hispanic Latino, who were mostly men (101/170, 59.4%) with a mean age of 51 (Table 2). There were no statistically significant differences in race/ethnicity, sex, annual household income, age, time since transplantation, or history of work-related sun exposure between the intervention and control groups. Spanish narration was preferred by Hispanic

Latino kidney transplant recipients (45/48, 94%). Twenty-eight percent of the kidney transplant recipients had inadequate health literacy. Inadequate health literacy was present in Hispanic Latino kidney transplant recipients (45/48, 94%;  $P<.05$ ). Non-Hispanic black kidney transplant recipients (45/60, 75%) had marginal health literacy in comparison with non-Hispanic whites ( $P<.05$ ).

**Table 2.** Demographics of population (N=170).

Characteristics	Intervention <sup>a,b</sup>	Standard of care <sup>a,c</sup>	P value <sup>d</sup>
<b>Race/Ethnicity</b>			.183
	Non-Hispanic white	32 (38.1)	30 (34.9)
	Hispanic/Latino	23 (27.4)	25 (29.1)
	Non-Hispanic black	29 (34.5)	31(36.0)
Male	45 (53.6)	56 (65.1)	.376
Married	49 (58.3)	41 (47.7)	.060
College education or higher	37 (44.0)	30 (34.9)	.099
<b>Annual household income</b>			.648
	<10,000	16 (19.0)	14 (16.3)
	10,000-19,999	12 (14.3)	13 (15.1)
	20,000-34,999	14 (16.7)	13 (15.1)
	35,000-50,999	18 (21.4)	14 (16.3)
	51,000-100,000	13 (15.5)	22 (25.6)
	>100,000	11 (13.1)	10 (11.6)
Age in years, mean (SD)	51.0 (12.5)	49.0 (14.2)	.334
Months since transplant, mean (SD)	17.3 (15.1)	18.0 (15.3)	.733
Work-related sun exposure	35 (41.7)	38 (44.2)	.896

<sup>a</sup>Values in the “Intervention” and “Standard of care” columns are provided as n (%), unless indicated otherwise.

<sup>b</sup>N=84

<sup>c</sup>N=86

<sup>d</sup>P values from Chi-square tests of association or t tests

### Participant’s Self-Reported Knowledge, Attitudes, and Sun Protection

Overall, there were significant gains in knowledge, perception of being at risk to develop skin cancer, and willingness to change sun protection for all kidney transplant recipients using the intervention in comparison with controls (Table 3). The increase in knowledge of Hispanic Latino kidney transplant recipients was significantly greater than the increase in knowledge by non-Hispanic white and non-Hispanic black kidney transplant

recipients ( $P<.05$ ; Table 3). The greatest willingness to change sun protection was demonstrated by Hispanic Latino kidney transplant recipients ( $P<.05$ ). Sun protection varied by the ethnic/racial group (eg, Hispanic Latino kidney transplant recipients choose to wear clothing, non-Hispanic black kidney transplant recipients seeking shade and wearing clothing, and non-Hispanic whites using sunscreen). Non-Hispanic black kidney transplant recipients, who had markedly fewer daily hours of outdoor exposure than the other 2 groups, did not demonstrate a significant reduction in outdoor exposure ( $P<.05$ ).

**Table 3.** Change in knowledge, intentions to use sun protection, and sun-protection use by kidney transplant recipients.

Participant self-reported variable <sup>a</sup>	Non-Hispanic white N=62		Hispanic/Latino N=48		Non-Hispanic black N=60		Wilcoxon rank sum <i>P</i> values
	Intervention N=32	Control N=30	Intervention N=23	Control N=25	Intervention N=29	Control N=31	
	<b>Knowledge (1-10 scale)</b>						
Pretest	3 (2.5)	3 (2.1)	2 (0.2)	2 (0.7)	2 (1.8)	2 (1.1)	
Post-test	5 (3.4)	3 (2.5)	8 (1.1)	4 (1.3)	4 (2.6)	5 (2.3)	.04 <sup>b</sup>
<b>Attitudes</b>							
<b>Recognize personal skin cancer risk (1-5 scale)</b>							
Pretest	2 (1.3)	2 (0.7)	1 (0.5)	1 (0.7)	1 (0.6)	1 (0.8)	
Post-test	3 (1.6)	2 (1.1)	4 (0.7)	2 (1.1)	2 (1.7)	1 (0.4)	.02 <sup>b</sup>
<b>Willingness to change sun protection (20-100 scale)</b>							
Pretest	22 (0.7)	20 (1.0)	22 (1.0)	21 (1.3)	21 (1.0)	22 (1.5)	
Post-test (immediate)	66 (24.3)	21 (0.6)	85 (10.2)	22 (09)	43 (20.2)	23 (2.4)	.01 <sup>b</sup>
<b>Sun protection used at 2 weeks</b>							
<b>Sun protection (20-100 scale)</b>							
Pretest	47 (10.1)	48 (9.7)	28 (4.7)	29 (5.4)	31 (6.9)	30 (4.7)	
Post-test (2 weeks)	60 (11.6)	50 (10.1)	55 (3.9)	30 (1.4)	46 (10.3)	31 (6.3)	.01 <sup>b</sup>
<b>Daily hours outdoors (0.5-6 hours)</b>							
Pretest	2.4 (0.7)	2.1 (1.4)	3.7 (1.2)	4.0 (2.1)	1.1 (0.5)	1.0 (0.9)	
Post-test (2 weeks)	1.6 (0.9)	2.5 (0.7)	2.4 (1.8)	4.3 (1.9)	1.0 (0.5)	1.0 (0.8)	.01 <sup>b</sup>

<sup>a</sup>All values are reported as mean (SD)

<sup>b</sup>Statistically significant Wilcoxon rank sum test

#### *Participant Concern*

Two kidney transplant recipients became concerned about lesions and asked to have them checked by one of the authors (JKR). However, both were benign.

#### **Participant Waiting Time**

The patient waited in the waiting room for about 30 minutes (SD 12 minutes).

#### **Usability of, Use of, and Satisfaction With the Program**

*Usability* testing was performed until no further changes were suggested by the last 3 participants (1 non-Hispanic white, 1 Hispanic Latino, and 1 non-Hispanic black). The button and font sizes were changed, and the icon symbols were enlarged.

The mean duration of “use” was 27 minutes (range 23-42 minutes) with Hispanic Latino kidney transplant recipients using the program the longest (Table 4). Compared with non-Hispanic white kidney transplant recipients, Hispanic Latino and non-Hispanic black kidney transplant recipients spent significantly longer time viewing “why protect against the sun” and repeatedly viewed the images of sunburn occurring in people with all types of skin ( $P<.05$ ). Hispanic/Latino and non-Hispanic black kidney transplant recipients also spent a significantly longer time viewing the images of skin cancer and the videos about sunscreen types and application methods than did non-Hispanic white kidney transplant recipients ( $P<.05$ ).

**Table 4.** Use and evaluation of SunProtect by kidney transplant recipients.

Variable	Non-Hispanic white <sup>a</sup>	Hispanic/Latino <sup>b</sup>	Non-Hispanic black <sup>c</sup>	Wilcoxon rank sum <i>P</i> value
<b>Program use</b>				
Mean duration (minutes)	23	42	32	.046 <sup>d</sup>
<b>Screens repeated<sup>e</sup></b>				
Why protect against the sun	1 (0.2)	1 (3.4)	1 (2.7)	.02 <sup>d</sup>
What is skin cancer	3 (4.1)	7 (5.6)	5 (4.9)	.03 <sup>d</sup>
Chance of getting skin cancer	2 (4.1)	2 (4.6)	2 (4.3)	.45
Sunscreen application	1 (5.0)	4 (9.1)	3 (8.2)	.03 <sup>d</sup>
<b>Program evaluation<sup>f</sup></b>				
Ease of use	4 (0.5)	4 (0.5)	4 (0.2)	.85
Usefulness of content	5 (0.0)	5 (0.0)	4 (0.6)	.70
Appealing presentation	4 (1.0)	4 (0.7)	4 (1.0)	.73
<b>Request written material<sup>g</sup></b>				
Sun-protection recommendations	12/32 (37.5)	10/23 (43.5)	9/29 (31.0)	.64
Tips to detect skin cancer	27/32 (84.4)	19/23 (82.6)	24/29 (82.8)	.85

<sup>a</sup>N=32<sup>b</sup>N=23<sup>c</sup>N=29<sup>d</sup>Statistically significant Wilcoxon rank sum test<sup>e</sup>Values presented as number of times repeated (SD)<sup>f</sup>Values presented as mean (SD), on a scale of 1-5<sup>g</sup>Values presented as n/N (%)

There was no significant difference among the 3 racial/ethnic groups in the duration of viewing the section on risk of developing skin cancer (4.1 minutes by non-Hispanic white, 4.6 by Hispanic Latino, and 4.3 by non-Hispanic black) or the number of repetitions of screens. On average, users “toggled” between the pie charts depicting relative risk rates for developing skin cancer for kidney transplant recipients and the general population 4 times (Figure 1).

Patients without prior experience using a tablet were not able to implement the navigation directions presented on the tablet (45 Hispanic Latinos, 16 non-Hispanic blacks, 5 non-Hispanic whites, 66/170, 39%). For users without prior experience using a tablet, the research assistant demonstrated screen navigation for 39% of users and stayed in an adjacent room to be available to assist the participant with concerns. Seven participants required further assistance in accessing the videos.

Spanish “audio narration” was chosen by Hispanic Latino kidney transplant recipients with inadequate health literacy (45/48). Most non-Hispanic white kidney transplant recipients, who had adequate health literacy, did not choose the audio narration (48/60). Inadequate and marginally functional health literate kidney transplant recipients chose the audio narration in either Spanish or English with statistically significantly greater frequency than kidney transplant recipients with adequate functional health literacy ( $P<.05$ ).

Participants from all racial/ethnic groups were “satisfied” with the ease of use of the program (4/5), and with the visual appeal of the presentation of content (4/5). The content was deemed useful (5/5) by non-Hispanic white and Hispanic Latino kidney transplant recipients; however, non-Hispanic black kidney transplant recipients felt the content was less useful (4/5).

### Requests for Written Material

While the requests for personal sun-protection recommendations were limited to 20% or less of the participants, more than 80% of participants requested the tip sheet for early detection of SCC with color illustrations.

## Discussion

### Principal Findings

The results of this pilot study found that SunProtect, as delivered by tablet, was effective in increasing knowledge, perception of being at risk of developing develop skin cancer, willingness to change sun protection, and change in sun protection 2 weeks after education among kidney transplant recipients with a range of health literacy. Hispanic/Latino kidney transplant recipients had the least health literacy and gained the greatest increase in knowledge and willingness to change. Participants appeared to have benefited from the ability to listen to the audio presentation in the language of their choice, to move at their own pace, and

to repeat screens and chapters to inform their sun-protection decisions. In this research, the 3 most commonly repeated content areas were kidney transplant recipients with skin of color getting sunburn or skin irritation from the sun, how to use sunscreen, and explanations of skin cancer. The chapter about skin cancers had the longest duration of use and the most repetition of content. Knowledge gained by the kidney transplant recipients with inadequate literacy, who elected to listen to the audio descriptions of skin cancer photographs, was greater than by the kidney transplant recipients with adequate literacy, who chose to read the narrative descriptions and did not listen to the audio description. The most frequently requested written material was the tips for early detection of skin cancer. While lack of prior experience using a tablet may have contributed to longer duration of use by some participants, the interest in learning about skin cancer as demonstrated by length of viewing and number of repetitions was common to all participants.

SunProtect provided health information in a manner that was well suited and liked by patients with limited health literacy. Patients with limited health literacy may be less likely to ask questions than others [16]. By listening to the program in their choice of language and repeatedly viewing the images, kidney transplant recipients with limited health literacy were able to learn. The program informed, taught, and counseled using examples of skin cancers occurring on kidney transplant recipients with skin of color, provided testimonials and videos intended to help the kidney transplant recipient understand, reach a decision, and make a choice about sun protection. The tablet format was an effective medium of health communication because it was uniquely able to provide video content and testimonials that could not be made available in face-to-face communication with the health care provider. Written materials do not provide the same level of engagement for the user as the tablet can provide by allowing kidney transplant recipients to choose to listen to the testimonial of a patient. For example, self-directed patients used the tablet to repeatedly view and compare the pie graphs communicating their risk of developing skin cancer. Previous studies have demonstrated greater adherence with sunscreen use among participants educated with videos than those educated with pamphlets [17,18].

Health care providers have limited amounts of time to spend with each patient. The material presented by the tablet supplements customary education provided by health care providers. Furthermore, the usual waiting time for kidney transplant recipients was approximately 30 minutes, which will

allow the tablet to be used in the waiting room before the meeting their health care providers. Lastly, when provider and patient do not share a common language, attempts to bridge the language barrier may be difficult; thus, the Spanish language provided by the tablet in text on the screen with audio narration and in the videos may help communicate the sun-protection options.

### Limitations

A limitation of this study is the 2-week period of follow-up. A longer follow-up would be needed to determine whether there was decay in sun-protection behavior. The research was performed in a city with temperate weather, and thus, it may not be possible to generalize the findings to locations with longer periods of sunny weather. In the interest of decreasing participants' fatigue, confidence in their ability to perform sun protection was not determined. An additional limitation was obtaining the self-reported outcome measures in 2 different ways. The pretest survey was completed on the tablet by the participant. Two weeks after the education, the survey responses were obtained by telephone interview, which may have introduced observer effect. Furthermore, enrollment of Hispanic Latino kidney transplant recipients did not achieve the sample size of 60 completing the study that was needed for analysis of ethnic/racial differences in adoption of sun-protection behavior(s).

### Conclusions

Kidney transplant recipients from diverse racial/ethnic groups and health literacy levels who used SunProtect became aware of their risk of developing skin cancer, increased their knowledge of skin cancer and sun protection, showed willingness to change their sun protection, and changed their sun-protection behavior. Because presurvey and postsurvey items would not be used in routine practice, reinforcement of the need for and relevance of sun protection by the survey will not be done. Regular life-long sun protection can decrease kidney transplant recipients' chance of developing skin cancer. Future research is needed to examine kidney transplant recipient's long-term adherence to sun protection and feasibility of delivery in a variety of practices.

Delivery of education with a tablet equipped with headphones may be done in the waiting room before a regularly scheduled 6- or 12-month follow-up visits to the transplant nephrologist. Technology may be used to provide patient education and reduce the physician's burden of educating and training patients.

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### Conflicts of Interest

Dr Robinson owns the trademark on the software.

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## Abbreviations

**SCC:** squamous cell carcinoma

**S-TOFHLA:** Short Test of Functional Health Literacy in Adults

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Original Paper

# Needs and Preferences of Partners of Cancer Patients Regarding a Web-Based Psychological Intervention: A Qualitative Study

Nadine Köhle<sup>1</sup>, MSc; Constance HC Drossaert<sup>1</sup>, PhD; Suzan Oosterik<sup>2</sup>, MSc; Karlein MG Schreurs<sup>1,3</sup>, PhD; Mariët Hagedoorn<sup>4</sup>, PhD; Cornelia F van Uden-Kraan<sup>5</sup>, PhD; Irma M Verdonck-de Leeuw<sup>5,6</sup>, PhD; Ernst T Bohlmeijer<sup>1</sup>, PhD

<sup>1</sup>University of Twente, Department of Psychology, Health & Technology, Enschede, Netherlands

<sup>2</sup>Stichting Mindfit, Zwolle, Netherlands

<sup>3</sup>Roessingh Research & Development, Enschede, Netherlands

<sup>4</sup>University Medical Center Groningen, Department of Health Psychology, Groningen, Netherlands

<sup>5</sup>VU University, Department of Clinical, Neuro- & Developmental Psychology, section Clinical Psychology, Amsterdam, Netherlands

<sup>6</sup>VU University Medical Center, Department of Otolaryngology/Head and Neck Surgery, Amsterdam, Netherlands

**Corresponding Author:**

Nadine Köhle, MSc

University of Twente

Department of Psychology, Health & Technology

P.O. Box 217

Enschede, 7500 AE

Netherlands

Phone: 31 053 489 2092

Fax: 31 053 489 2895

Email: [n.kohle@utwente.nl](mailto:n.kohle@utwente.nl)

## Abstract

**Background:** Evidence-based, easily accessible, supportive interventions for partners of cancer patients are limited, despite the fact that they often suffer from diminished emotional, social, physical, and relational functioning. To develop a new intervention that will fit their demands, it is important to consult potential users.

**Objective:** To examine partners' interest in a Web-based psychological intervention and to identify their needs and wishes regarding such an intervention.

**Methods:** Semistructured interviews were conducted with 16 partners of cancer patients, who varied in terms of age, gender, education, employment, type, and stage of disease. Partners were asked (1) whether they would use a psychological Web-based intervention and which preconditions (maximum time, structure, participate alone or with their partner) it should meet; (2) which functionalities (information, peer support, online psychological counseling) the intervention should contain; and (3) which topics (eg, taking care of oneself) should be addressed. Data were coded by 2 coders independently.

**Results:** The need for a Web-based intervention varied. Arguments for being interested in a Web-based intervention included the need for acknowledgement; the need for someone they could talk to; and the need for information, tips, and support. Based on their experiences as a partner of a cancer patient, participants would prefer an intervention that is not too time-consuming (about 1-2 hours a week) and which is based on a "step-by-step" approach, meaning that the content of the intervention should match the stage of their partner's disease. Also, they would prefer a positive approach, which means that the intervention should be a source of hope and energy. Most participants stated that they would prefer to participate without their ill spouse, because they do not want to burden their partners with their own problems. An intervention should contain information and optional peer support. Participants' opinions about online psychological counseling in the intervention were divided. Arguments for online psychological counseling were that a professional could check on them and they were able to ask questions. Arguments against online counseling were that partners were not in need for guidance or they had enough support from usual care. Topics with the highest priority were "coping with feelings and emotions," "should I or shouldn't I spare my partner?," "communicating with each other," "asking for help and refusing help," and "moving on with life after cancer treatment." Furthermore, participants suggested additional topics of "dare to enjoy" and "acceptance of the patient's disease."

**Conclusions:** A Web-based intervention can be a valuable addition to existing support initiatives for partners of cancer patients. This study provides important information about the content and form of such an intervention. Flexibility and a positive approach seem to be the most important features.

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## KEYWORDS

cancer; oncology; partner; needs; web-based interventions; interventions

## Introduction

### Partners of Cancer Patients

Cancer not only affects the patients' lives, but also the lives of their loved ones. Partners of cancer patients may suffer from diminished emotional, social, physical, and relational functioning [1-11]. The couples' relationship often changes because of shifting roles and responsibilities [3,4], feelings of inequality [5,12], reduced social activities, less financial resources [6,7], and a decrease of sexuality and intimacy [8]. Problems often occur when patients and partners avoid talking about the disease, their feelings, and changes in their relationship [9]. Recent studies have shown that clinical levels of psychological distress are highly prevalent in partners of cancer patients (especially in female partners) and can even be higher than the levels experienced by patients themselves [1,2,13]. Cancer can directly and indirectly affect the physical well-being of partners [6], because many partners have barely time to relax and they often neglect their own health [9].

Despite the known multiple and serious effects of cancer on partners' lives, the availability of evidence-based, easily accessible, supportive interventions for partners of cancer patients is still limited. The interventions that do exist vary widely in their scope, aims, target groups, intensity, used methods, and theoretical frameworks [9,14,10]. Northouse et al [9] classified the interventions into 3 major types: psychoeducation, skills training, and therapeutic counseling. The majority of the interventions belong to the first type, and these primarily strive to provide information about the optimal patient care. Skills training tries to improve skills regarding coping with the situation, communication, and problem solving. Therapeutic counseling, finally, aims to address concerns regarding cancer or caregiving. The interventions also vary widely in terms of how demanding they are: most interventions are delivered as face-to-face visits, with the majority provided in a clinical setting, they take between 1.7-18 hours; they comprise between 2-16 sessions; and they last for 1.2-56 weeks from first to last session [9]. Most existing interventions are developed for couples (both partners and cancer patients) and since usually no differentiation is made between their needs, the focus is inevitably often on the patients' care and well-being. Only a few interventions have primarily addressed partners' well-being [9,14]. Furthermore, partners of cancer patients often make no or only limited use of existing interventions [14]. Many of the interventions described in the meta-analysis of Northouse et al [9] and reviews of Ussher et al [14] and Applebaum and Breitbart [10] report difficulties with inclusion or high dropout rates. Reported reasons for low participation are, for example, that partners are often not aware of their own health complaints

and that they therefore do not feel in need of support [15]. Participation is also connected to the demands of the illness, when the demands are high (eg, intensive treatment), existing interventions seem to ask too much from the partners and they will not participate [16]. Other identified barriers to make use of the offered resources are being unaware of existing sources, being reluctant to ask for help or to talk about sensitive topics, and being afraid that their own requests may affect the care of the patient [17]. Another possible explanation may be that the existing interventions do not fit to the specific needs of partners of cancer patients [14]. Ussher et al [14] recommend prior needs assessments before development.

Another recommendation was to examine the potential for using the Internet to deliver interventions to the caregivers of cancer patients [9,10]. The Internet offers new opportunities to deliver easily accessible and (cost-) effective supportive interventions. Possible advantages of Web-based interventions include a low threshold, flexibility, and possibilities to follow the intervention at any time that suits the client [18]. These features might be especially important for partners of cancer patients since they have less time for their own mental and physical health. The Internet also bears the possibility to tailor information and feedback to the individual needs of a client. This may be beneficial to partners of cancer patients because they are only confronted with information that is relevant to them [19]. Despite these benefits, the availability of Web-based interventions for partners of cancer patients is also still limited [20]. To the best of our knowledge, no studies exist that have examined the views and opinions of partners regarding a Web-based intervention.

### Aim of the Study

Accordingly, the aim of this study was to examine partners' interest in a Web-based psychological intervention and to identify their wishes, desires, and needs regarding such an intervention. This study focused on the following questions: (1) "Is there a need for a Web-based intervention and which preconditions (maximum time, structure, participate alone or with their partner) should it meet?"; (2) "Which functionalities (information, peer support, psychological guidance) should the intervention contain?"; and (3) "Which topics (eg, taking care of oneself) should be addressed?"

## Methods

### Study Design and Ethical Approval

A qualitative research design was chosen to gain insights into the wishes, desires, and needs of partners of cancer patients regarding a Web-based psychological intervention. Semistructured interviews were conducted. The Ethics

Committee of the University of Twente (Behavioural, Management, and Social Sciences) provided ethical approval for this interview study and the study was conducted according to the declaration of Helsinki.

### Participants and Procedures

Partners of cancer patients were recruited in a large hospital in the region of Twente, an area in the east of the Netherlands. A nurse practitioner informed partners of cancer patients of the ongoing study and she handed out information leaflets. In case partners were interested in participating, they had to fill out a reply card with their name and telephone number on it, and return it to the nurse practitioner. Subsequently, the nurse practitioner contacted the researchers so that they could get in touch with the partner. Additionally, partners were recruited through convenience sampling. Partners were people from the network of the researchers and they were called and asked if they wanted to participate in this study. In case they were interested, they received an information leaflet by mail or email and after reading the information they could decide if they still wanted to participate. Once the participants had given their informed consent, they were interviewed. The interviews took place at the participants' homes. There were 2 researchers (NK and SO) that conducted 16 interviews together. Both researchers are psychologists and were trained in conducting interviews. Initially, the researchers proposed to interview the partner alone, without their ill spouse. However, during 3 interviews the (patient) partner was also present, because the partner explicitly wanted the patient to be there. After the 16 interviews data saturation was reached, meaning that no more new information was found [21]. All interviews were audio-recorded—with the prior permission of the participants—and the audiotapes were transcribed verbatim.

### Interview Scheme and Mock-Ups

All interviews started by asking participants to introduce themselves and to give a short overview of their partner's disease and how this had affected them personally. After that,

partners were asked about their ideas and opinions about a Web-based psychological intervention. As many participants had difficulties conceptualizing the idea of a Web-based intervention, 2 mock-ups of a possible Web-based intervention for partners of cancer patients were shown to the respondents. These mock-ups were based on an existing Web-based intervention called "Living to the full" (Figures 1 and 2 show this) [22-24]. Participants were encouraged to elaborate on their motives for (not) wanting a Web-based intervention. With an open-ended question, we asked the participants which functionalities a Web-based intervention should contain. We continued by asking their opinion about the preselected functionalities: information, peer support, and online psychological counseling. Regarding the preconditions of the intervention, we invited participants to reflect on the following issues: maximum time, structure, and participate alone or with ill partner. Participants were encouraged to motivate their answers and to add other functionalities or preconditions. Finally, we asked partners which topics should be addressed in a Web-based intervention. First, an open question was posed. In addition, the researchers had prepared 9 cards with words of potential topics. These topics were based on literature and suggestions of 5 experts in the field who we have consulted beforehand. The topics were: (1) coping with feelings and emotions; (2) taking care of oneself; (3) sparing your partner or not?; (4) communicating with each other; (5) sexuality and intimacy; (6) asking for help and refusing help; (7) moving on with life after cancer treatment; (8) living with cancer; and (9) if the end is near. Participants were asked to pick those cards which were possibly relevant to them and which should be targeted in a Web-based intervention. Participants were asked to motivate their choice. Also, they were encouraged to add more topics with an extra "empty" card. At the end of the interview, participants completed a short questionnaire about sociodemographics (such as gender, age, education, employment). The interviews took between 40 minutes and 2 hours, with an average duration of 65 minutes.



Figure 1. Mock-up of a possible Web-based intervention.



Figure 2. Mock-up of a personal home page (after participants have logged in).



**Data Analysis**

There were 2 coders (NK and SO) that independently coded all transcripts. First, the coders read and reread all transcripts to

familiarize themselves with the content. Then, relevant fragments were selected and coded into one of the 4 main themes: (1) need for Web-based intervention; (2) preconditions;

(3) functionalities; and (4) topics. Subsequently, all fragments were further categorized into subthemes using inductive analysis. Inductive analysis means that the subthemes derive from the data, instead of from predefined categories. After every 5 transcripts, the coders met to discuss their categories. When coders disagreed about the categorization, discussion took place until consensus was reached. The final categories were defined on the basis of consensus between the 2 researchers.

## Results

### Participants

The characteristics of the 16 participants and their ill partners are listed in [Tables 1](#) and [2](#). Participants were heterogeneous regarding gender, age, education, and employment. The partners of the participants were diagnosed with a variety of cancers, they varied in prognosis, and most of them were not under treatment (2 under surveillance, 6 in recovery) when the interviews took place. There were 3 of the participants that were widow/widower and used recollection to answer our questions.

**Table 1.** Characteristics of the participants (N=16).

Characteristics	N	% <sup>a</sup>
<b>Gender</b>		
Male	10	63
Female	6	38
<b>Age</b>		
Mean (SD)	51.7 (12.8)	
Range in years	30-68	
<b>Religious</b>		
No	2	13
Yes	13	81
Unknown	1	6
<b>Children</b>		
No	2	13
Yes	14	88
<b>Education</b>		
Low	7	44
Medium	4	25
High	5	31
<b>Employment</b>		
Full- or part-time work	10	63
Retired	3	19
Disabled	0	0
Other	3	19

<sup>a</sup>Percentages may not total 100 due to rounding

**Table 2.** Characteristics of the ill partners (the patients) (N=16).

Characteristics	n	%
<b>Age</b>		
Mean (SD)	52.5 (13.5)	
Range in years	32-71	
<b>Type of cancer</b>		
Lung cancer	1	6
Acute lymphatic leukemia	1	6
Hodgkin's lymphoma	1	6
Prostate cancer	1	6
Ovarian cancer	1	6
Testicular cancer	1	6
Breast cancer	2	13
Kahler's disease	1	6
Cervical cancer	1	6
Brain tumor	2	13
Skin cancer	2	13
Non-Hodgkin's lymphoma	1	6
Oesophagus cancer	1	6
<b>Undergoing treatment</b>		
Yes	5	31
No	8	50
Deceased	3	19
<b>Prognosis (self-reported)</b>		
Good	6	38
Poor	4	25
Uncertain	3	19
Deceased	3	19

### Need for a Web-Based Psychological Intervention

There were 2 of the participants that gave no answer to the question if they were in need for some kind of a Web-based intervention. One of them had no Internet access at home and the other did not use the Internet. They also had difficulties in imagining what a Web-based intervention would look like, even after being given a short explanation of a possible intervention and after being shown the mock-ups. We decided nevertheless to continue the interview with these partners, because we thought these might still give us valuable information about, for example, which topics should be addressed in a Web-based intervention for partners of cancer patients.

Among the remaining participants (n=14), the need for a Web-based intervention varied. There were 6 of them that explained that they would like some kind of Web-based intervention, 4 had ambivalent feelings toward such an intervention, and 4 partners were not interested. Participants' arguments for being interested in a Web-based intervention could be divided into 3 categories: (1) the need for

acknowledgment; (2) the need for someone you can talk to; and (3) the need for information, tips, and support regarding their specific needs as a partner of a cancer patient, as illustrated in the following citations,

*I really missed something offered to me as a partner of a cancer patient.* [Female, 63, partner had Oesophagus cancer]

*Sometimes you need to tell your story. But my friends were all in a different situation, they just became parents or they were pregnant. A totally different life situation. Therefore, they had problems talking to me. And for my part, I didn't want to be a burden to them either.* [Female, 30, partner had skin cancer]

*I was looking for acknowledgment. Acknowledgment for all the emotions that you experience as a partner of a cancer patient. Fear, anger, helplessness[...]* [Female, 51, partner died of acute lymphatic leukemia]

Participants who had ambivalent feelings toward a Web-based intervention mentioned various arguments. One of them said that she was not sure whether she had the need for an intervention targeting the partner or not. This need actually changed from moment to moment. However, she was sure that she would prefer face-to-face contact instead of Web-based support. Also, for her it felt wrong to spend some personal time while her partner was ill and she mentioned that she was afraid of losing valuable time with him.

*Time was too valuable to participate in a Web-based intervention because we already knew that he wouldn't get better anymore. [Female, 55, partner died of lung cancer]*

Another participant said that it was difficult for him to give an answer to this question because—at the time his wife was ill—he was not aware of the fact that he actually needed support. His mere focus lied on his wife's health and her needs and he wanted to be the “hero” for her. His own (health) problems were not important to him at all. He said that the choice to make use of such an intervention would depend on the way this intervention would have been offered to him, see the following quote,

*It is difficult to give an answer to this question, because I think it depends on how such an intervention was offered to me. If it was something like a therapy or help program...? Well look, as partner of a cancer patient you don't know that you are actually in need for help or, rather, you are convinced that you are not in need for help[...]. In my opinion, I tried to be the hero. And it doesn't fit in the role of a hero to participate in a help program[...]. I think “support” is a more appropriate word to use[...]. I would have been interested in something that aims to improve my skills as caregiver. [Male, 43, partner died of ovarian cancer]*

Another participant welcomed the idea of a Web-based intervention for partners of cancer patients, because he was convinced that a lot of partners are in need of such an intervention. However, he was not sure if he also shared that need. In his opinion, he and his wife managed the situation well (they indicated that they had a down to earth approach to cope

with the disease), but they were not sure if this way of coping was the most appropriate and effective way. He guessed that he probably would take a look at what such an intervention could offer him. In particular, he would be interested in acknowledgment.

*But sometimes I am wondering, in the beginning people sometimes said to us “that you can be so down to earth in coping with it (the disease)”. Then you can ask yourself “who is the crazy one?”. Maybe our approach is not the right one at all. [Male, 30, partner had non-Hodgkin's lymphoma]*

A participant explained that she would only be interested in an intervention that targets effective ways of coping with the disease instead of talking about the situation and problems again and again.

*If you are there [at a meeting with a psychologist], I've heard that you have to talk about your problems every time[...]. You always have to tell the same old story and I think it is important to look forward. It is not necessary to look back at what has happened in the past[...]. How can you cope with it? How can you process it without constantly talking about the problem again? [Female, 68, partner had skin cancer]*

There were 4 participants that explained that they were not interested in a Web-based intervention, because they simply were not in need for support. There was a participant, for example, that explained that she is engaged in a variety of social activities (eg, choir, yoga class) and that the situation is not affecting her in a way that she would need help. Furthermore, she trusts the medical staff of her husband and accordingly she never used the Internet for looking up information about her husband's disease. Other arguments mentioned were that participants think that they were not “the type” to participate in such an intervention, or that they want to spend all their time with their spouse instead of participating in any kind of support. Yet, 2 of the 4 participants were convinced that other partners would be interested in an intervention that targets their specific situation as a partner of a cancer patient. All the arguments regarding the need for a Web-based psychological intervention are listed in [Table 3](#).

**Table 3.** Arguments regarding the need for a Web-based psychological intervention.

Variable	Arguments pro	Arguments con
Need for Web-based intervention	Need for acknowledgment	Experiencing no problems or not being aware of any problems
	Need for someone you can talk to	Having sufficient support from social network or own coping-strategy seems fine
	Need for information, tips, and support	Not wanting to lose valuable time with ill partner or feeling that it is wrong to spend personal time while partner is ill Being afraid of too much negativity through rehashing the problem; intervention seems not appealing

### Preconditions of a Web-Based Intervention

There were 4 participants that gave no answer to these questions, because they had no computer at home (n=1), they had no experiences using the Internet (n=1), or they were not able to

give an indication (n=2). The majority of the remaining participants (n=10) reported that the intervention should not be too time-consuming. It appeared that partners who are more certain about their need for a Web-based intervention would be willing to spend more time on it. There were 8 participants that

mentioned that they could spend about 1-2 hours a week in an intervention,

*I think that it is really important, so one and a half hours is not too much. This doesn't mean that you have to spend the time without a break. [Female 58, partner has brain tumor]*

There were 2 participants that indicated that they were willing to spend about 3.5 hours a week in such an intervention.

Regarding the structure of the intervention, 3 participants explicitly mentioned that they would prefer a “step-by-step” approach, which means that the content of the intervention should match the stage of their partner’s disease. For example, participants did not want to receive information about the terminal phase if their partner had just been given a diagnosis of cancer, as is illustrated by the following quote,

*Try to look at it step-by-step. This is a tip I received from my brother. Try not to think too far ahead and try to avoid the thought “what if...?” and all the bad scenarios. Be aware of the things that are really important at this moment. [Male, 43, partner died of ovarian cancer]*

Also, participants mentioned that the intervention should have a positive approach. According to them, thinking positively and accentuating what still can be done, instead of what no longer can be done, is a source of hope and energy for both the partner and the cancer patient,

*[...]as long it is a little bit positive. I'm not interested in the negative things. Because they only result in a depressed mood. [Female, 68, partner had skin cancer]*

There were 8 of the participants that preferred to participate in the intervention without their ill spouse. One of the reasons for this preference is that their ill spouse is not in need for help. Another reason is that they did not want to burden their partners with their own problems, and that they could express their feelings and emotions more freely if they participated in the intervention alone.

*I would prefer to participate in the intervention on my own. I think this is of added value. I would have the chance to tell my story and show my emotions freely without anyone knowing. [Male, 30, partner had non-Hodgkin's lymphoma]*

Furthermore, one partner argued that partners’ and patients’ needs are different and that it is therefore difficult to combine both in one intervention,

*No, for my partner it is different. He really has a different point of view, because he is the patient. And he is focused on himself, and as a partner you have to focus not only on yourself but also on your partner. And you have to manage in daily life. I think that these are two different things. [Female, 63, partner had Oesophagus cancer]*

There were 3 of the participants that felt that it would be important to participate in the intervention together with the ill spouse. They explained that the disease affects the lives of both partners and that it is essential to cope with the situation as a couple.

*I think you should do this together, because you are in this situation together. [Female, 58, partner has a brain tumor]*

There were 4 interviewees that suggested that participants should be able to choose whether they want to participate alone or together with their partner, for example,

*I think you should be free in this choice. I have the need to participate in such an intervention, but my partner doesn't. In this case it is not necessary to participate together. [Female, 30, partner had skin cancer]*

## Desired Functionalities of a Web-Based Intervention Information

The majority of the participants (n=14) were interested in information (see [Table 4](#)). Relevant medical information should come from a reliable source, should be presented in a clear and intelligible way, and it should match their partner’s stage of disease. According to 7 participants, it would be sufficient to include links to other reliable websites (eg, the website of the Dutch Cancer Society). There were 7 participants that doubted if medical information would be actually necessary, because they already received a lot of medical information in the hospital, or because they feared that the presented information would be too general. Alongside the medical information, participants also expressed a need for information and practical tips about what it means to be partner of a cancer patient (this is further described in the section “Important Topics to Be Addressed by the Intervention” and [Table 5](#)).



**Table 4.** Arguments and preferences regarding the various functionalities of a Web-based psychological intervention.

Variable	Arguments pro	Arguments con	Preferences	
<b>Functionalities</b>	Information	Being informed about all aspects of disease	Information overload	Medical and practical information is preferred
		Being informed about what it means to be a partner of a cancer patient	Information usually too general	From reliable source
		Practical tips can be helpful		Be clear and intelligible
	Peer support	Acknowledgment	No time to support others	Possibility to read experiences and tips of other partners
		Confirmation	Problems with managing own problems	Possibility to participate (anonymously) on Web-based platforms
		Support	Doubting helpfulness of peer support	
		Someone who will listen	Afraid of being confronted with negative experiences	
	Online psychological counseling	Signaling	Professionals' advices in the hospital are sufficient	Feedback tailored to personal situation
		Improving motivation	No further support is needed	Feedback from reliable person
		Possibility to ask questions	Term "psychological guidance" is too heavy No need; satisfied with regular health care	

**Table 5.** Relevant topics for a Web-based intervention, according to the partners (n=16).

Topic	n
Coping with feelings and emotions	16
Should I or shouldn't I spare my partner?	16
Communicate with each other	16
Asking for help and refusing help	16
Moving on with life after cancer treatment	16
Sexuality and intimacy	13
Taking care of oneself	10
Living with cancer	10
The end is near	10

### Peer Support

The majority of the participants (n=10) were interested in some form of peer support (see Table 4). They were looking for acknowledgment, confirmation, support, and someone who would listen to them, as expressed by these quotes,

*Look for other partners of cancer patients. They will understand you immediately and can help you. You will definitely find acknowledgment.* [Female, 51, partner died of acute lymphatic leukemia]

*The information you receive is valuable, because everyone is looking for confirmation[...] You are doing something instinctively, but you are uncertain if this is the right thing to do. You want to know how other*

*partners handle it. [Female, 63, partner had Oesophagus cancer]*

*Often it is enough that somebody is listening. People often only want to tell their story. [Female, 51, partner died of acute lymphatic leukemia]*

Opinions about the best form of peer support varied, however. Some indicated that it would be sufficient to read about experiences of partners of cancer patients. Others wanted to actively participate on Web-based platforms (whether anonymously or not), because they wanted to share their experiences with other partners of cancer patients or they appreciated the personal contact for understanding, support, and acknowledgment.

However, a group of participants were not sure about their interest in contact with peers (n=4) or they were not interested in peer support at all (n=2). Arguments against peer support were that it was enough for them to cope with their own situation and that they did not have time to support others.

*I don't know how other partners handle this issue, but I definitely had no time for it[...]I'm not sure how much capacities I had left at that moment to listen to another person's story. But I guess very little. [Male, 43, partner died of ovarian cancer]*

In addition, they doubted whether experiences of other partners of cancer patients would be helpful to them, and they were afraid to be confronted with negative experiences, as illustrated with the following quotes.

*I have to confess that I tried to avoid peer support, because there were always people with even worse stories. And if you are in a period of hope and the other person is in a period of despair, this can negatively affect your own mood and hope. [Male, 43, partner died of ovarian cancer]*

*I think that peer support about medical issues can be negative. It scares people about situations, which might not have been come up yet. [Male, 30, partner had non-Hodgkin's lymphoma]*

### **Online Psychological Counseling**

There were 2 participants that gave no answer to this question. Of the remaining participants, opinions about online psychological counseling varied (see Table 4). There were 9 participants that were positive about some kind of online psychological counseling. First, they liked the idea that a professional could check on them and would be able to signal if something went wrong (eg, if their mental health was deteriorating).

*I think this is quite important. Imagine that someone is writing something in a depressed tone. Then a psychologist would be able to intervene and check on him or her. [Male, 30, partner had non-Hodgkin's lymphoma]*

Second, they thought that a personal online counselor could improve their motivation to complete the Web-based intervention, and third they liked the idea that they would be able to ask questions, as illustrated in the following quotations.

*No obligations and flexibility are necessary, but it is also important that there constantly is someone who - how should I call it - someone who wakes you up if necessary. [Male, 43, partner died of ovarian cancer]*

*Yeah, I think that people need this and that they would like the idea to rely on it (the psychological guidance)[...]The website shouldn't just say: "Deal with it". It is necessary, well look, if they pick a topic and have a lot of questions about it, then these questions need to be answered. [Female, 58, partner has a brain tumor]*

However, 3 of the participants also mentioned that they would prefer feedback that is focused on their personal situation. General feedback would not be enough to satisfy their needs. Furthermore, 1 participant mentioned that he would prefer guidance from a person he knows, definitively someone who is capable, and knows how things work. There were 3 interviewees who also mentioned that online psychological counseling should not be mandatory, but offered as a possibility.

There were 5 participants (3 of these were generally not in need of a Web-based intervention) that were not interested in online psychological counseling, because they had no need for it or they were already satisfied with the help given by doctors and nurses in the hospital and they felt they did not need any further support.

We encouraged participants to bring up any other functionalities. However, they didn't come up with anything else.

### **Important Topics to Be Addressed by the Intervention**

As described earlier, participants were asked to choose topics that were relevant to them and should be addressed in a Web-based intervention. Participants reported that all the proposed topics were valuable to partners of cancer patients. However, they emphasized the importance of the topics "coping with feelings and emotions," "should I or shouldn't I spare my partner?," "communicating with each other," "asking for help and refusing help," "moving on with life after cancer treatment," and "sexuality and intimacy" (see Table 5). Furthermore, 4 participants suggested an additional topic "dare to enjoy". The topic refers to enjoying those things that they still can do, instead of regretting what they cannot do anymore. This is an important source of hope and energy for the cancer patient as well as for the partner. There was 1 participant that added the topic "acceptance of the patient's disease". She had difficulties accepting their partner's disease and she wished to get some help with that process.

## **Discussion**

### **Need for a Web-Based Intervention**

In this study, we examined partners' interest in a Web-based psychological intervention, and their needs and wishes regarding such an intervention. We found that the need for a Web-based intervention varied. Arguments for being interested in a Web-based intervention were: (1) the need for acknowledgment; (2) the need for someone who would listen; and (3) the need for information, tips, and support. Arguments against such an intervention were: (1) not experiencing any problems or not

being aware of any problems; (2) having sufficient support from the social network or their own coping-strategy seems fine; (3) not wanting to lose valuable time with their partner or feeling that it's wrong to spend some personal time while the partner is ill; and (4) being afraid of too much negativity through rehashing the problem or an intervention seems not appealing. These results correspond with findings of previous research among cancer caregivers. For example, Harding and Higginson [25], Ussher et al [14], and Northouse et al [9] have found that many informal cancer caregivers are not asking for help, because they are often not aware of their own needs and problems, and they are mainly focused on the well-being of the patient. We think that it is of the utmost importance that we create more awareness for the challenging situation partners (or other caregivers) of cancer patients are confronted with every day. Both partners and the general public should be alerted (eg, through awareness campaigns) about the effects and consequences that often come along with a diagnosis of cancer. Also, partners should be informed about the different possibilities to receive help (eg, social workers, psychologists, nurse practitioners, Web-based interventions), as some partners in our study explicitly stated that they were not aware of any initiatives. By offering (information about) different kinds of support, we can ensure that everyone receives that kind of support that he or she needs and prefers. For some cancer caregivers, it is probably enough to be acknowledged that cancer may also affect their lives. Others may wish to consult a psychologist or they have a good relationship with their general practitioner, medical staff, or they receive sufficient support from their network. We think that a Web-based intervention can help caregivers who have little time to seek help; who experience a high threshold to consult a psychologist; who want to stay anonymous; or who want to check if they are in need for support before actually seeking help from a health care professional.

In our sample, we have seen that most of the partners had no or only little experience with e-Health interventions and also there were misconceptions about psychological interventions in general (eg, the idea that psychologists only want to rehash the problem). To inform partners about the possibilities of a Web-based intervention and to overcome misconceptions, we would recommend the use of both written and visual (eg, demonstration video) information about the content and nature of such an intervention.

We can conclude that partners of cancer patients differ in their opinions about the need for a Web-based (or any other) psychological intervention. Our data suggest that more awareness for the situation of cancer patients is needed, and information about existing options for support is lacking. In addition, our data show that there is a considerable group of partners who would be interested in a Web-based psychological intervention.

### Preconditions

Overall, participants reported that an intervention should not be too time-consuming. They were afraid of losing valuable time with their partners and they also emphasized that they were already challenged with managing caregiving responsibilities

and everyday tasks. According to the participants, they were able to spend about 1 to 2 hours a week on a Web-based intervention. For the successful implementation of such an intervention, it is important to meet the specific needs of the partners. The advantages of Web-based interventions (low threshold, high accessibility, flexibility) will be useful to fulfill these needs.

As far as the content of the intervention is concerned, the participants in our study would prefer a step-by-step approach. This means that the content should match the patient's stage of disease. The participants would also prefer a positive approach. They explained that they are confronted with enough misery (almost) every day and that it would be important that a Web-based intervention would also focus on positive things in life and in their specific situation. They indicated that such an intervention should be a source of hope and energy. This preference fits in with the developments in the field of psychology. Psychology traditionally focused on dysfunction. Positive psychology, in contrast, aims to focus on the positive features that make life worth living such as hope, optimism, happiness, and well-being [26]. Accordingly, we think that it could be of great value if an intervention for partners of cancer patients is based on concepts stemming from positive psychology, such as acceptance, values, resilience, mindfulness, and self-compassion.

As described earlier, most available supportive interventions aim at the couple (patient and partner) and usually no differentiation is made between their needs [9,14]. However, we have found that most of our participants would prefer to participate alone. They doubted that patients' and partners' needs could be combined in a single intervention. A small group of participants would prefer to participate together with their ill spouse because the disease affects both their lives. These participants explained that it is essential to cope with the situation together. According to these different preferences, we would recommend a flexible approach (participating alone versus participating together) for a future Web-based intervention for partners of cancer patients.

### Desired Functionalities

Participants in our study indicated that a Web-based psychological intervention should contain information as well as peer support. We found that participants were mainly interested in information and practical tips about all aspects of the disease and the consequences of being a partner of a cancer patient, coming from a reliable source. Previous research among partners of cancer patients has shown similar findings [27,28]. However, some partners in our study doubted if medical information is necessary for a Web-based intervention. They indicated that they have already received a lot of information in the hospital, or they feared that the information would be too general. Other researchers reported a similarly wide range of information needs of partners of cancer patients [7,29,30]. The different preferences regarding information needs should be considered in a Web-based intervention for partners.

Most participants were interested in peer support because they were looking for acknowledgment, confirmation, support, and someone who would listen. However, their wishes regarding

the type of peer support varied. Whereas some participants would prefer the possibility to merely read experiences and tips of other peers and to stay anonymous, other participants preferred to actively participate in Web-based platforms. Rozmovits and Ziebland [30] also showed the general need for peer support in a study on the information needs of cancer patients. In this study, participants reported that having access to the experiences of peers was generally positively valued because it results in reduced feelings of fear and isolation during their illness, and it was both informative and reassuring. Furthermore, van Uden-Kraan et al [31] found that active participation in a Web-based support group by sending postings and nonactive participation by mere reading of postings from others are equally effective.

Despite the positive effects of peer support, some partners of our study indicated they had no interest in contact with other peers. They explained that they struggle with their own situation and that they did not have time to support others. Besides, they doubted whether the experiences of other partners would be helpful to them. These results are in line with various previous studies [32,33]. It seems that partners have ambivalent feelings toward peer contact: they do feel the need, yet they are afraid of being confronted with negative stories of other peers. Therefore, we would advocate that a future Web-based intervention for partners of cancer patients should offer the possibility to get in touch with peers. However, we would recommend a flexible approach in participation where partners will be able to engage in the type of contact with peers that actually matches their wishes (participation vs nonparticipation; active vs passive peer support) and type of peer support (eg, Web-based platform vs private messages).

The need for online psychological counseling during participation in a Web-based intervention varied. Most of our participants liked the idea that a professional would guide them through the intervention, but others rate the presence of a professional as unnecessary. We can conclude that there are different preferences regarding psychological guidance. Recent studies have revealed that personal guidance is essential for the effectiveness of, and adherence to, eHealth interventions [34-37]. Yet, there is no consensus about the amount or form of support. For example, a study on the self-help intervention "Living to the full" with email support has indicated that short support messages were as effective as more extensive counseling [38], and a study of Kelders [39] has shown that automated support (consisting of a weekly feedback message) was as effective as a weekly feedback message given by a personal online counselor. However, more research in this field is needed to, for example, examine whether personal guidance is more effective for certain groups of partners. For a Web-based intervention for partners of cancer patients, it would definitely be useful if the different preferences regarding online psychological counseling could be considered.

### Topics

Our participants agreed about the relevance of all the mentioned topics. They were especially interested in topics like "coping with feelings and emotions," "should I or shouldn't I spare my partner?," "communicating with each other," "asking for help

and refusing help," and "moving on with life after cancer treatment". Furthermore, participants suggested extra topics of "dare to enjoy" and "acceptance of the disease".

In line with the fact that partners are (often) unaware of their own health complaints and therefore do not ask for help [9,14,40], participants in this study rated the topic "taking care of oneself" as less important than the other topics. Based on these outcomes, we think it is essential that an intervention targeting this group should be framed as informal and easily accessible support, from a positive perspective.

### Limitations

There are some limitations to this study. First of all, this qualitative study was performed with a rather small number of respondents. We aimed to explore the needs and wishes of a group as heterogeneous as possible. We feel that we have succeeded in this effort as a wide range of people (in terms of gender, age, type, stage of disease, treatment) participated. However, the selective group of participants may not be representative for all partners of cancer patients. Therefore, it may be worthwhile to develop a quantitative questionnaire based upon the outcomes of this study, to corroborate the results in a larger sample of partners of cancer patients. In a quantitative study, it would also be possible to identify variables (eg, gender, age, type, stage of disease, treatment) that are related to the intention to make use of a Web-based intervention.

Second, during recruitment, partners were told (in the information leaflet) that the interview was about a Web-based intervention. This could have led to selection bias. It might have been that partners of cancer patients who were not (regularly) using the Internet would have been less likely to participate.

Third, it should be noted that during 3 interviews the patient was also present. We agreed to this when the partner wanted their spouse to be present. However, it could have been possible that the presence of the patient had influenced the partner's answers. Perhaps they were more cautious talking about their personal needs and wishes in order to protect their partner's feelings.

Fourth, we have to note that 3 of our participants were widow/widower and that they used recollection to answer our questions, whereas the other participants used their current state. We asked the 3 partners to report on what would have been helpful to them in case their partner was still alive. We do not know for sure if these answers would have been the same when their partners were still alive, but it appears from our study results that the opinions of these 3 participants are in line with those of the other participants.

At last, it might have been difficult for partners to decide upon their interest in an intervention that does not exist yet. Also, the majority of the participants had no experience with e-Health interventions. We have tried to overcome these problems by using mock-ups. The participants responded well to these mock-ups and they said that these were helpful during the interview. We would therefore recommend the use of mock-ups, prototypes, or demonstrations to other researchers that are willing to develop a Web-based intervention.



## Conclusions

We conclude that a Web-based intervention can be a valuable addition to existing support initiatives for partners of cancer patients. Furthermore, it is important that there is more awareness for the challenging situation partners of cancer

patients are facing. This study yields important information about the content and form of a Web-based intervention for partners of cancer patients. In particular, flexibility and a positive approach seem to be the most important features. Also, information should be provided about the content and nature of an intervention in order to overcome misconceptions.

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## Conflicts of Interest

None declared.

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Original Paper

# Lifestyle Modification Experiences of African American Breast Cancer Survivors: A Needs Assessment

Selina A Smith<sup>1\*</sup>, PhD, MDiv; Mechelle D Claridy<sup>2\*</sup>, MPH; Mary Smith Whitehead<sup>3\*</sup>, MPH, CHES; Joyce Q Sheats<sup>4\*</sup>, RN, MPH; Wonsuk Yoo<sup>5\*</sup>, PhD; Ernest A Alema-Mensah<sup>6\*</sup>, DMin, PhD; Benjamin E-O Ansa<sup>4\*</sup>, MD, MSCR; Steven S Coughlin<sup>7\*</sup>, PhD

<sup>1</sup>Institute of Public & Preventive Health Georgia Regents University, Department of Family Medicine, Medical College of Georgia, Augusta, GA, United States

<sup>2</sup>Department of Community Health and Preventive Medicine, Graduate Education in Public Health, Morehouse School of Medicine, Atlanta, GA, United States

<sup>3</sup>SISTAACH Talk, Breast Cancer Support Group, for Women of Color, Miami, FL, United States

<sup>4</sup>Institute of Public & Preventive Health, Georgia Regents University, Augusta, GA, United States

<sup>5</sup>Institute of Public & Preventive Health, College of Dental Medicine, Georgia Regents University, Augusta, GA, United States

<sup>6</sup>Department of Community Health and Preventive Medicine, Morehouse School of Medicine, Atlanta, GA, United States

<sup>7</sup>Division of Public Health, Department of Health Science and Sustainability, University of Massachusetts, Lowell, MA, United States

\* all authors contributed equally

**Corresponding Author:**

Selina A Smith, PhD, MDiv

Institute of Public & Preventive Health Georgia Regents University

Department of Family Medicine, Medical College of Georgia

1120 15th Street, CJ2300

Augusta, GA, 30912

United States

Phone: 1 706 721 1104

Fax: 1 706 721 6829

Email: [SESMITH@gru.edu](mailto:SESMITH@gru.edu)

## Abstract

**Background:** Little is known about the rates of obesity among African American (AA) breast cancer survivors (BCSs), the availability and use of lifestyle modification methods suitable for this population, and the impact of changes in dietary intake and physical activity on health-related quality of life (HR-QoL).

**Objective:** The objectives of the study were to describe obesity rates, dietary intake, and physical activity as lifestyle modification strategies; examine predictors of engagement in these strategies post diagnosis; and learn more about salient features of lifestyle interventions from AA BCSs participating in a breast cancer support group.

**Methods:** The needs assessment included four components: (1) a literature review to determine existing lifestyle modification strategies of AA BCSs; (2) secondary data analysis of the 2010 National Health Interview Survey, Cancer Control Supplement to examine HR-QoL; (3) administration, to 200 AA BCSs, of an assessment tool relating to weight and breast cancer history, dietary intake, and physical activity through a variety of approaches (eg, Internet, mail, in-person, and telephone); and (4) focus group discussions to frame lifestyle interventions.

**Results:** Preliminary findings indicate that AA BCSs are underrepresented in lifestyle intervention research, have disparities in HR-QoL outcomes, do not meet current cancer prevention guidelines, and have recommendations for effective strategies for lifestyle modification.

**Conclusions:** As analyses of the needs assessment are completed, the research team is partnering with community coalitions and breast cancer support groups in Miami, Chicago, Houston, Los Angeles, and Philadelphia to develop community-engaged intervention approaches for promoting adherence to cancer prevention guidelines.

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**KEYWORDS**

African Americans; breast cancer; cancer survivors; nutrition; physical activity

## Introduction

### Background

Based on Surveillance Epidemiology End Result data, an estimated 226,870 women were diagnosed with breast cancer (BrCa) in 2012, and 39,510 women died of the disease [1]. Nationwide, for most age groups, BrCa incidence rates are higher in Caucasian (white) women than in African-American (AA) women. Despite having a lower overall incidence, AA women have a higher incidence before 40 years of age and, at any age, are more likely to die from BrCa than other ethnic groups [2]. In addition to biological differences, this poorer outcome is attributed to late-stage diagnosis, unequal access to medical care, and lack of health insurance. Once BrCa is diagnosed, body composition also has a negative impact on clinical outcome; women who are obese at diagnosis have a 1.5- to 2.5-fold increased risk of recurrence and death compared to their normal weight counterparts [3-5]. Weight gain is common among BrCa patients after diagnosis and for those who become post menopausal after chemotherapy [6-11]. Effective long-term lifestyle modification is a target in reducing recurrence and enhancing prognosis among BrCa survivors (BCSs). Although a lifestyle change can halve the risk of recurrence and reduce the risk of BrCa-associated mortality by one third, many patients do not engage in lifestyle modification strategies (eg, changing dietary intake and enhancing physical activity). This is of particular concern among AA BCSs, as AA women have higher obesity rates than white women. Limiting use of these strategies among BCSs are psychosocial factors that may include anxiety and cancer-related fears [12,13], negative body image [14,15], depression [16-18], relationship changes [19], and/or financial stress [20].

Little is known about the rates of obesity among AA BCSs, the appropriate intervention methods available to them, and the utilization and impact of lifestyle modifications on health-related quality of life (HR-QoL). The goal of this assessment was to learn more about the lifestyle modification needs of AA BCSs.

### Objectives

The objectives of this study were to consider obesity rates, dietary intake, and physical activity as targets for lifestyle modification strategies; to examine predictors of engagement in these strategies post diagnosis; and to learn more about salient features of lifestyle interventions from AA BCSs. Since there are gaps in care for AA BCSs [21], a fragmented transition from active treatment to survivorship [22], and long-term implications of inadequate dietary intake on recurrence [23], Survivors Involving Supporters to Take Action in Advancing Health (SISTA AH) Talk, a BrCa support group, was selected as the study population because it is an untapped, indigenous resource for learning about and promoting lifestyle changes. The objective of SISTA AH Talk is to provide a forum for AA women to communicate about and make sense of their BrCa experience in order to achieve improved physical and mental health outcomes. We anticipate that inclusion of the target

population in determining their lifestyle modification needs and experiences will result in development of testable interventions.

### Rationale for the Needs Assessment

Although incidence rates are 4% lower for AA women relative to white women, AA women are more often diagnosed with BrCa at younger ages and with more aggressive and advanced tumors [24,25]. Modifiable lifestyle risk factors related to energy balance [26] may contribute to racial/ethnic disparities in BrCa incidence and mortality.

Racial-ethnic disparities in modifiable BrCa risk factors are large and persistent, particularly between white and AA women [27]. Data from the Behavioral Risk Factor Surveillance System (BRFSS) relating to lifestyle factors revealed three disparity risk categories for AA women: (1) obesity (35.7% vs 23.7% for whites); (2) inadequate fruit and vegetable consumption (12.6% vs 17.4% for whites); and (3) physical inactivity (63.8% vs 50.3% for whites) [28]. Prevalence of overweight or obesity among AA women is 82% relative to 61% for white women [29]. Obesity and weight gain after BrCa diagnosis are associated with poorer outcomes, including decreased QoL, increased recurrence, BrCa deaths, and all-cause mortality [30]. For overweight and obese women, a sustained loss of 10% of initial weight reduces the risk of recurrence of a new primary BrCa [31]. According to the American Institute on Cancer Research (AICR), eating a healthy diet, maintaining a healthy weight, and being physically active can prevent about one-third of the most common cancers in the United States [32]. To reduce risk of recurrence, the AICR also recommends that cancer survivors adhere to cancer prevention guidelines.

## Methods

### Human Subjects

The Institutional Review Board at Morehouse School of Medicine approved the study protocol; participants received information on the study and consented participation.

### Literature Review

The first step in the needs assessment was completing a systematic review of the literature for English language articles in MEDLINE, MEDLINE In-Process, PubMed, and the Cochrane Library (Central Register of Controlled Trials). No date restrictions were applied, and free-text and Medical Subject Headings terms were used to identify studies including (but not limited to), lifestyle practices, dietary intake, physical activity, psychosocial factors, and QoL. Next, to search for areas of interest, terms were combined, for example, weight loss AND African American AND women AND interventions. The search did not include abstracts from conferences. Relevant, full-text publications that were potentially relevant were screened for inclusion based on the following criteria: (1) study design (prospective or retrospective observational studies, randomized clinical trials, or meta-analyses); (2) population (AA women); (3) lifestyle modification (diet, physical activity, weight control/loss); and (4) psychosocial factors (QoL, anxiety and



cancer-related fears, negative body image, depression, relationship changes, financial stress).

### Secondary Data Analyses

Next, data from the national surveys were used to describe lifestyle and cancer risk behaviors of AA women. Baseline dietary intake, physical activity, and cancer risk behaviors of this population were established through an examination of the following secondary datasets.

The BRFSS is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury [33]. The BRFSS measure of physical activity was used to capture typical weekly physical activity and scored in metabolic equivalent minutes/day (metabolic equivalent of task min<sup>-1</sup> x day<sup>-1</sup>), including duration and intensity.

The National Health and Nutrition Examination Survey (NHANES) is a program of studies designed to assess the health and nutritional status of adults and children in the United States [34]. Our methods for measuring weight loss were adapted from the NHANES weight history questionnaire. By combining questions on self-directed diet changes (eg, “ate less food”, “ate less fat”, and “switched to foods with lower calories”) into a single item (“dieted on your own without joining a program or following a special diet book”) and separating commercial programs and self-help programs, modifications were made to the questions.

The National Health Interview Survey (NHIS) is the principal source of information on the health of the civilian, noninstitutionalized population of the United States [35]. The NHIS Cancer Control Supplement (CCS), administered every five years, focuses on issues pertaining to knowledge, attitudes, and practices in cancer-related health behaviors, screening, and risk assessment. The National Cancer Institute and the Centers for Disease Control and Prevention cosponsor the NHIS CCS. The cancer survivorship portion of the survey was included in our assessment tool and used to examine HR-QoL.

The final step was to condense lifestyle modification data. Results from the literature search and secondary data analysis were summarized to describe evidence-based, lifestyle modification efforts among AA women.

### Lifestyle Needs Assessment Tool Development

Validated scales (related to dietary intake/physical activity, weight loss history, and cancer risk) were selected from the datasets described above for inclusion in the needs assessment. Criteria for selection were based on the capacity of the measures to answer three questions: (1) Are AA BCSs aware of the relationship between lifestyle modification in preventing BrCa recurrence and enhancing QoL during and after treatment?; (2) If offered, will AA BCSs engage in lifestyle modification activities?; and (3) Which lifestyle modification strategies are most appealing to the targeted population?

The final tool assessed: (1) demographics (race/ethnicity, age, gender, education, income, religious affiliation, marital status, insurance, employment); (2) knowledge, attitudes, and beliefs (KABs) (BrCa survival/prognosis, diet/physical activity

interventions); (3) BrCa history (BrCa diagnosis and treatment history, menopausal status, treatment side effects); (4) lifestyle modification needs and experiences (physical activity levels, dietary intake, self-reported current height and weight, self-reported weight at time of diagnosis, current weight loss attempt, number of weight loss attempts since BrCa diagnosis, weight loss methods tried); and (5) HR-QoL related to adjustment to BrCa, for example, cancer-specific HR-QoL (eg, emotional, physical, and social well-being), depression, fear of recurrence, diminished physical strength, change in relationships, change in body image, and financial stress.

Good readability, layout, and design were factors in developing the assessment tool. The Flesch reading ease (FRE) score was used to assess readability. The reading ease scores on the FRE scale are 0-100. If the score of a written text is less than 60, the document is considered difficult to read by the general public. To determine the time required to complete the assessment tool, 10 AA BCSs were interviewed. The time to completion was on average 45 minutes and unclear items were revised for clarity. The assessment tool was retested prior to finalization. The final needs assessment had a readability score of less than 80.

### Lifestyle Needs Assessment Tool Administration

A form letter to participants was developed. It stressed the usefulness of the information garnered from the tool to develop lifestyle interventions for AA BCSs and encouraged the subjects to complete the assessment tool.

Because the tool is an initial step in developing lifestyle interventions specific to the targeted population, engagement during the needs assessment phase is imperative to long-term success (eg, developing lifestyle interventions).

The final step was providing modes for administration of the assessment tool. Based on past research experiences with AA BCSs, we were aware of the need for multiple modes for administering the measure. In an assessment of BrCa gene-environmental interactions among multigenerational AA women with SISTAAH Talk members, we visited homes, met at infusion centers, communicated by telephone, and employed similar approaches to reach the targeted population. Assessment tools were self-administered electronically on the Internet, by email, or by mail to home addresses. They were also administered by an interviewer in-person or by telephone.

### Focus Group Discussions

There were four focus groups that were conducted with 8-12 BCSs engaged in 90-minute sessions to address intervention content. A moderator initiated each discussion with a structured set of questions. Sample size was determined based on the principle of saturation, which suggests that, with as few as four discussions, no additional information will be obtained. This qualitative sampling technique was used to ensure that perspectives across age groups were obtained. An interview guide was developed for this purpose. Responses were digitally recorded, transcribed verbatim, manually coded, and summarized. Qualitative content analysis was used to analyze the data [36]. Coding steps included developing preliminary themes, creating additional codes based on themes that arise, developing nonsubstantive codes, and producing detailed codes



for analysis of specific topics. NVIVO 10, a computer-assisted qualitative data analysis software, was used to facilitate the coding process (ie, to determine the degree of agreement/disagreement across themes and to calculate interrater reliability scores) [37]. A process of double coding was used to overcome coder differences in reliability scores [38]. Recurring themes were identified, the research team came to consensus on coded themes, and themes were summarized for analysis.

### Statistical Analysis

Descriptive statistics were performed by determining means and SDs for continuous variables and frequencies and percentages for categorical variables from demographics, KABs, BrCa history, lifestyle modification experiences, and needs as well as psychosocial factors captured by the assessment tool. The t-score units, calculated by means and SDs for scores, were used to estimate the HR-QoL for four items and for physical and mental status. Multivariable linear regression analyses were performed to assess the influence of the multidimensional aspects of HR-QoL after adjusting for confounding demographic variables (age, marital status, and education) as covariates. The t-scores, odds ratios (OR), and related 95% confidence intervals (CI) were derived from multivariable analyses. The significance level was set at 0.05, and all tests were two-sided. All statistical analyses were accomplished with SAS version 9.2 (SAS Institute, Cary, NC).

## Results

### Findings From African-American Breast Cancer Survivor Studies

The literature review revealed that, although lifestyle changes can halve the risk of recurrence and reduce the risk of BrCa-associated mortality by one third, many patients do not engage in such strategies. Limited research on AAs exists because they have been underrepresented in studies examining health behaviors that improve BrCa survival [39]. The Women's Healthy Eating and Living (WHEL) Study, one of the few studies with AA women, showed that, at baseline, AA survivors were more likely to be obese (45% vs 25% for whites), to consume more calories from fat (+3.2%), to have fewer servings of fruits (-0.7/day), and to be less successful at making and maintaining dietary changes than whites [40,41]. Greenlee et al [42] conducted a randomized controlled trial with the commercially available *Curves* program, following 42 Hispanic and AA BCSs for 6 months. The trial resulted in weight loss that was not maintained at 6 months after the intervention. A community-based pilot study of 24 AA BCSs who engaged in walking as physical activity [43], resulted in increases in steps walked per day and decreases in body mass index (BMI), body weight, and waist/hip circumferences, with most changes maintained at 3 months. A pre post design, that included one of two weekly sessions dedicated to exercise, was used to test a 6-month intervention with 23 AA BCSs [44]; participants experienced changes in weight, BMI, and social support. In a 16-week, home-based motivational exercise program for 13 AA BCSs, there was a post intervention increase in total minutes of physical activity and improved physical functioning [45,46].

### Secondary Data Analysis

In our secondary analysis of the NHIS 2010 data, female AA BCSs age 35 and older (n=62) were compared to AA female survivors of other cancers (SOCs) (n=74), and to AA women with no history of cancer (NHCs) (n=1566) of the same age. Differences in HR-QoL were assessed, including four items each and summary physical and mental health estimated in t-score units with one degree of freedom. All analyses were weighted and adjusted for age, marital status, and education. There were no statistically significant differences for BCSs and NHCs, but the SOCs reported poorer physical health relative to NHCs [ $t_1=5.8$ , 95% CI 2.8-8.8]. Further, there were no statistically significant differences between BCSs and NHCs, but SOCs reported poorer mental health relative to NHCs [ $t_1=3.3$ , 95% CI 0.6-5.9]. A comparison of differences between SOCs and NHCs showed three items in which SOCs were more likely to report poorer physical health relative to NHCs (ability to carry out physical activities, OR 3.4 95% CI 1.7-6.7, level of fatigue, OR 2.0 95% CI 1.1-3.7, and level of pain, OR 3.3 95% CI 1.3-3.9).

### Lifestyle Needs Assessment

AA BCSs were recruited from SISTAAH Talk, a BC support group in Miami, Florida (n=240; mean age 56.90 years; SD 11.80; range 25-92 years old), and they consented to complete a self-administered lifestyle assessment survey. More than half reported poor physical functioning; were overweight/obese (68%); did not limit portion sizes to control weight (89%); consumed <5 vegetables and fruits/day (75%), and >5 servings red (75%) and processed meats/week (94%).

### Focus Group Discussions

There were four focus group discussions (n=42; mean age 45.73 years; SD 7.91; range 35-75 years old) that identified barriers to and intervention approaches for enhancing dietary intake, and themes emerging from content analysis converged into the following categories: "talk" as central; peer-facilitated sessions; support group approach; no "pamphlet only" control group; "hands on" or interactive nutrition education; supporters (co-survivors); and community-based (not "placed") research.

## Discussion

### Future Direction

With the successful implementation of this protocol for health needs assessment and the availability of preliminary findings from qualitative analyses, our study team is now planning health promotion trials in partnership with community coalitions and BrCa support groups in Miami, Chicago, Houston, Los Angeles, and Philadelphia to develop community-engaged intervention approaches for promoting adherence to cancer prevention guidelines. The focus of these proposed studies, which are at the protocol development and planning stage, is on increasing physical activity and improving diet among AA BCSs, with the goal of reducing risk of BrCa recurrence, improving survival, and increasing HR-QoL in this at-risk population. We anticipate that both feasibility trials and cluster-randomized controlled trials will be undertaken once the study protocols have undergone peer review and extramural funding is secured.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AA:** African-American  
**AICR:** American Institute on Cancer Research  
**BCSs:** breast cancer survivors  
**BMI:** body mass index  
**BrCa:** breast cancer  
**BRFSS:** Behavioral Risk Factor Surveillance System  
**CCS:** Cancer Control Supplement  
**CI:** confidence intervals  
**FRE:** Flesch reading ease  
**HR-QoL:** health-related quality of life  
**KABS:** knowledge, attitudes, and beliefs  
**NHANES:** National Health and Nutrition Examination Survey  
**NHCs:** no history of cancer  
**NHIS:** National Health Interview Survey  
**OR:** odds ratio  
**SISTA AH:** Survivors Involving Supporters to Take Action in Advancing Health  
**SOCs:** survivors of other cancers

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Original Paper

# Feasibility and Preliminary Efficacy of an Online Intervention to Increase Physical Activity in Nova Scotian Cancer Survivors: A Randomized Controlled Trial

Cynthia C Forbes<sup>1</sup>, PhD; Chris M Blanchard<sup>2</sup>, PhD; W Kerry Mummery<sup>1</sup>, PhD; Kerry S Courneya<sup>1</sup>, PhD

<sup>1</sup>University of Alberta, Edmonton, AB, Canada

<sup>2</sup>Dalhousie University, Halifax, NS, Canada

**Corresponding Author:**

Kerry S Courneya, PhD

University of Alberta

Van Vliet Complex, University Hall

Edmonton, AB,

Canada

Phone: 1 780 492 2829

Fax: 1 780 492 6548

Email: [kerry.courneya@ualberta.ca](mailto:kerry.courneya@ualberta.ca)

## Abstract

**Background:** Physical activity (PA) behavior change interventions among cancer survivors have used face-to-face, telephone, email, and print-based methods. However, computer-tailored, Internet-delivered programs may be a more viable option to achieve PA behavior change.

**Objective:** The objective of this study is to test the feasibility and preliminary efficacy of a Web-based PA behavior change program among cancer survivors.

**Methods:** Nova Scotian cancer survivors (N=415) who previously expressed interest in a research study were approached. Interested participants were asked to complete an online assessment of PA and quality of life (QOL) before being randomized to either a theory-based PA behavior change program using the PA tracking website UWALK (UCAN; n=48) or usual care (UC; n=47). After the intervention (9 weeks), participants completed another online assessment of PA and QOL as well as measures to evaluate the program and website. Descriptive analyses from surveys and Web analytic software were used to assess feasibility and mean change scores were used to test efficacy.

**Results:** Of all contacted survivors, 95 (22.3%, 95/415) completed baseline measures and were randomized with 84 (88%, 84/95) completing the 9-week assessment. The behavior change program and website were rated highly on the satisfaction items. Average logins were 10.3 (1.1 per week) and 26.0% (111/432) of the weekly modules were completed. Most participants (71%, 29/41) indicated they were more aware of their daily PA levels and 68% (28/41) found the site easily navigable. Adjusted group differences in total exercise minutes favored the UCAN group by an increase of 42 minutes (95% CI -65 to 150;  $P=.44$ ,  $d=0.17$ ). Results were more pronounced, though still nonsignificant, among those not meeting guidelines at baseline where UCAN increased PA by 52 minutes compared to a decrease of 15 minutes in UC (adjusted between group difference=75, 95% CI -95 to 244;  $P=.38$ ,  $d=0.27$ ).

**Conclusions:** We found that Internet-delivery may be a feasible alternative to more costly methods to promote PA among Nova Scotian cancer survivors. Moreover, there was a trend toward increased PA among those in the UCAN group, especially among those who were not meeting PA guidelines at baseline. Future research should focus on recruiting inactive cancer survivors and engaging them in the website to determine the optimal potential of Web-based interventions for promoting PA in cancer survivors.

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**KEYWORDS**

Web-based; survivorship; home-based; exercise; efficacy; feasibility



## Introduction

Physical activity (PA) improves quality of life (QOL), symptom control, and possibly even survival in cancer survivors [1-8]. Despite these benefits, many cancer survivors do not accumulate the recommended 150 minutes of at least moderate-intensity PA per week [2,9,10]. A recent survey among breast, prostate, and colorectal cancer survivors living in Nova Scotia showed less than half of survivors were meeting PA guidelines [11]. Therefore, interventions focusing on behavior change are necessary to help increase PA levels among these cancer survivors.

An essential step in promoting behavior change is the use of targeted messages to increase motivation for the specific behavior. Investigating the PA correlates and preferences of cancer survivors is important when developing these targeted messages. To date, theory-based behavior change interventions designed to increase PA levels among cancer survivors have employed face-to-face, telephone, email, and print-based methods [9,12-17]. Encouraging results suggest a positive influence of these interventions on PA among cancer survivors.

Recent meta-analyses and reviews [18-25] have summarized the effectiveness of technology when delivering interventions among the general population as well as various chronic disease populations. Overall, the research has found various forms of technology to be effective in facilitating PA behavior. Davies et al [19] reviewed computer-tailored or Web-delivered behavior change interventions across various groups and found effect sizes for change in PA were small but significant in the healthy population ( $d=0.11$ ) in those with chronic disease ( $d=0.19$ ) and in those who were overweight ( $d=0.28$ ). The benefits of using an Internet-delivered program is the efficiency and reach that it can provide.

Face-to-face counseling is time consuming, resource intensive, and requires participants to live near a physical location [18,21,23,24]. This is particularly important in regions with a large rural population such as Nova Scotia, which is approximately 43% rural [26]. The Internet provides people who may not be able to access standard education sessions with an alternative. Having components of the educational content given in oncologist consultations delivered via the Internet could relieve some of the burden on oncologists to deliver the message and help patients to retain information. Previous research into the PA counseling and programming preferences of cancer survivors in Nova Scotia [27] revealed that 76% of the sample had access to the Internet. Approximately 50% of the sample indicated that they would be willing to receive PA information online and would be able to complete the questionnaires online as well.

Currently, there is only one study that examined PA behavior change among cancer survivors using an online delivery [28]. Lee and colleagues [28] randomized 59 women in Seoul, South Korea who completed breast cancer treatment, into either a Web-based self-management PA and diet intervention group developed using the transtheoretical model (TTM) [29] or a control group, which received an educational booklet on PA and diet. They found that the Web-based intervention group

increased the proportion of people meeting moderate-intensity activity guidelines of  $\geq 150$  minutes more so than the control group (from 33% to 66% versus 35% to 36%, respectively). However, the small sample of nonrepresentative (younger, more educated) breast cancer survivors makes generalizing these results difficult. In addition and similar to many studies using the TTM as a template, this study did not fully operationalize the multidimensional model which is a limitation when determining effectiveness [30].

The primary purpose of this study is to test the feasibility of an Internet-delivered PA behavior change intervention among breast, prostate, and colorectal cancer survivors living in Nova Scotia. A secondary purpose is to examine the preliminary efficacy of the intervention for improving PA and QOL. We hypothesized that it would be feasible to use an Internet-delivered program to deliver a behavior change program to breast, prostate, and colorectal cancer survivors living in Nova Scotia. In addition, we hypothesized that the website program would result in an increase in self-reported PA and QOL, although we did not anticipate a statistically significant difference given the feasibility nature of the study.

## Methods

### Study Procedures and Population

Participants were recruited from a sample ( $N=415$ ) of breast, prostate, and colorectal cancer survivors living in Nova Scotia who had previously taken part in a survey study and had indicated an interest in future studies [11]. The sample was contacted via email, mail, or telephone with an invitation to participate that included an information sheet from the investigators explaining the purpose of the study and instructions on how to proceed if interested, a consent form, and a copy of the primary publication from the previous survey. Eligibility criteria were (1) being able to speak and read English, (2) having access to the Internet, and (3) being able and interested in an Internet-delivered program designed to increase weekly PA levels.

### Design

This study was a pilot 2-group randomized controlled trial to compare a usual care group (no intervention) with an Internet-delivered behavior change group. The focus of the behavior change program specifically was to increase PA in the form of steps or minutes. Eligible participants provided informed consent and completed a baseline questionnaire to gather demographic, behavioral, and PA information prior to randomization.

### Randomization

A rolling blocked randomization was completed after baseline measures were collected to ensure participants did not have an overly long wait to start the intervention. Participants were randomly allocated to one of two groups using a computer generated random numbers list. The 2 groups were the control group—also called usual care (UC)—and the intervention group (UCAN), which consisted of membership in a private online community called *Active Nova Scotia* housed on the PA tracking website UWALK [31] and modified for cancer survivors. Group

assignments were generated by a research assistant and assigned after blocks of baseline measures were received to eliminate bias in group allocation. Participants were then notified of their group assignment via email.

### **Intervention**

Those randomized into the UCAN group were given access to a 9-module behavior change program which was developed using previous print materials as a template [13,32]. The modules were published sequentially on the site as the intervention progressed to increase retention. Information module topics were developed from survey results of the same group [11,27] and were as follows: (1) welcome, general information about the site, types of exercise, and how to gauge intensity; (2) exercise myths, dispelling common exercise myths; (3) exercise safety, tips on how to exercise smart and safe; (4) goals and planning, how to plan and make SMART goals; (5) exercise benefits, specific benefits of exercise for cancer survivors; (6) make it fun, tips on how to keep exercise fun; (7) exercise barriers, tips on how to overcome the most common barriers identified; (8) support network, how others can help you exercise; and (9) relapse, strategies on how to avoid and deal with relapse. Each module remained available to review after the week was concluded. In addition, each module included a video relevant to the current topic featuring the first author to foster a connection and simulate face-to-face interactions.

Aside from the behavior change program, the UCAN group was able to use the UWALK website to track their PA in steps, moderate or vigorous minutes, and flights of stairs. Participants were able to see the progress of other group members as well as their own progress over time. Participants in the UCAN group also received weekly email updates informing them of new information posts as well as a brief summary of their previous weeks PA levels. Emails were developed to offer encouragement to those who were not meeting the guidelines and congratulate those who were sufficiently active. Upon being informed of their group assignment, the UC group was asked to keep their regular exercise routine over the intervention period and they would receive access to the website and the behavior change program once the follow-up questionnaire was completed.

### **Feasibility and Efficacy Measures**

#### ***Demographic and Medical Information***

All questionnaires were completed online using FluidSurveys (Ottawa, Ontario) software. Information on demographic and medical data was collected through self-report measures and included age, sex, marital status, education level, income, employment status, ethnicity, and height and weight to compute body mass index (BMI). Medical variables included date of diagnosis, cancer site, disease stage, previous treatments, current treatment status, cancer recurrence, and current disease status. Measures for the primary and secondary end points were examined at baseline (preintervention) and at 10 weeks (postintervention).

#### ***Website Engagement and Usage***

Mixpanel analytics were used to track Web-usage statistics to address our primary objective. This tracking program provides

information on number of logins, page views, and activity logged. Mixpanel analytics is a measurement tool that shows the effectiveness of a Web page in achieving a goal. It is an easy way to see how visitors use the site and identify which pages are performing well and which are performing poorly. The program tracks “actions” on pages to allow you to identify how a page is being used. They offer a variety of measurement tools to help you learn about your participants including (1) engagement (measures the actions that people take in the website); (2) retention (finds out if people come back); (3) funnel analysis (pinpoints where and why participants are lost); (4) notifications (gets participants to come back with email or push notifications); and (5) people analytics (explores who your participants are and what they do).

#### ***Program Evaluation and Adherence***

To assess program satisfaction, a primary objective, participants randomized to the UCAN group were asked to complete a section examining overall website satisfaction and usefulness of the different program features. The questions were adapted from a recent Web-based PA intervention for people with type 2 diabetes [22], which was in turn developed from the Health-eSteps [33] and Diabetes NetPLAY programs [34]. The items used a 4-point Likert-type scale ranging from “strongly disagree” to “strongly agree” for the following statements: “I enjoyed the Active Nova Scotia program,” “If I had any concerns I knew who to contact,” “I would continue to participate in the Active Nova Scotia program,” “I increased my PA because I was in this study,” “This study made me more aware of the amount of PA I get each day,” “The topics for each information post were useful and relevant,” “I liked the videos for the information posts,” “The videos in the information posts were not burdensome on my computer,” “I was able to easily find my way around the website,” “I was able to easily record my PA on the website,” “I would recommend this website to other people,” and “I will continue to use the website now that the Active Nova Scotia program has finished.” These 12 items were supplemented by 4 open-ended questions to indicate likes, dislikes, and recommendations for future development.

#### ***Physical Activity Behavior***

To address our secondary objective, PA was measured using a modified version of the validated Leisure Score Index (LSI) from Godin’s Leisure Time Exercise Questionnaire (LTEQ) [35]. Participants were asked to recall the average frequency and duration of any vigorous (heart beats rapidly, sweating), moderate (not exhausting, light perspiration), and light (minimal effort, no perspiration) intensity aerobic PA, as well as resistance exercise (lifting weights, sit-ups, pushups, therabands) in a typical week over the past month. PA sessions had to be at least 10 minutes long and performed during their free time and not occupational. The percentage of participants meeting PA guidelines was calculated using the 2008 PA Guidelines for Americans [36], which have been recommended for cancer survivors by the American College of Sports Medicine [37] and the American Cancer Society [3]. The guidelines indicate that cancer survivors should perform either 75 minutes of vigorous activity a week, 150 minutes of moderate activity a week, or a combination that double weights the vigorous minutes. PA

minutes were calculated as moderate minutes plus two times vigorous minutes and then transformed into 2 categories (1) not meeting guidelines ( $\leq 149$  minutes) or (2) meeting guidelines ( $\geq 150$  PA minutes). The percentage of participants meeting strength guidelines was defined as those engaging in two or more sessions of strength exercise per week. Strength minutes were calculated by multiplying the average minutes per session by strength frequency. Total exercise minutes were calculated by adding PA minutes and strength minutes.

### Quality of Life

As part of the secondary objective, QOL was assessed by the validated Functional Assessment of Cancer Therapy-Fatigue (FACT-F) scale which includes the 27 items from the FACT-General (FACT-G) scale plus the 13-item fatigue subscale [38,39]. The FACT-G consists of physical well-being, functional well-being, emotional well-being, and social well-being. On all scales, higher scores indicate better QOL. QOL was also assessed using the Medical Outcomes Study 36-Item Short Form (SF-36) [40], which contains 36 items that produce 8 health domains with multi-item scales. *Physical functioning* evaluates limitations in physical activities, such as walking and climbing stairs. *Role limitations* as a result of *physical* or *emotional* health conditions measure problems with work or other daily activities. *Bodily pain* assesses limitations caused by pain, and *vitality* measures levels of energy and tiredness. *Social functioning* examines the effect of physical or emotional health on normal social activities, and *mental health* evaluates happiness, nervousness, and depression. The *general health perceptions* questions examine personal health and the expectation of changes in health. A single item assesses *change in perceived health* during the last year. All items used a Likert-type scale of varying points.

### Statistical Analysis

All analyses were performed using PASW Statistics 22 (PASW Inc., Chicago, IL, USA). Feasibility was assessed using recruitment rate, website satisfaction, and usage statistics gathered from UWALK and Mixpanel. Chi-square and analyses of variance (ANOVAs) were performed to determine the differences between the intervention groups for PA behavior and QOL. Analyses of covariance (ANCOVAs) were also conducted to adjust for baseline value when comparing

intervention groups. Results were interpreted for statistical trends as well as for potential clinical significance. Using a two-tailed alpha of  $P \leq .05$ , the study had 80% power to detect medium standardized effects ( $d = 0.50$ ) after adjustment for covariates with 45 participants per condition. Trends were defined as  $P < .10$  and potential clinical significance as a standardized effect size of  $d \geq 0.33$  [41]. Intention-to-treat protocol was adhered to for all analyses. Responders and nonresponders were compared to determine any differences. Based on the higher than expected number of participants meeting PA guidelines at baseline, subgroup analyses were conducted for those with less than 150 minutes versus 150 minutes or more of total exercise.

## Results

The detailed flow of participants from invitation to randomization can be found in [Figure 1](#). Of the 415 cancer survivors contacted, 197 (47.5%, 197/415) did not respond and 98 (23.6%, 98/415) were excluded for various reasons. Of the 120 (28.9%, 120/415) survivors who expressed interest, 25 were excluded for not meeting inclusion criteria where 9 (36%, 9/25) did not have Internet access or a computer, 4 (16% (4/25) did not reply after initial interest, and 12 (48%, 12/25) contacted us after recruitment had closed. Of the 95 cancer survivors, 48 (50%, 48/95) were randomized into the UCAN group and 47 (50%, 47/95) into the UC group, resulting in a 22.9% (95/415) recruitment rate. During the study 1 person withdrew due to personal issues. At the postintervention evaluation, 84 (88%, 84/95) completed 100% of the poststudy survey. Among those who did not fully complete the survey, 5 (45%, 5/11) were nonresponders, 5 (45%, 5/11) had incomplete data, and 1 (9%, 1/11) had non-cancer-related health issues. At baseline, the majority of the sample was female (56%, 53/95), married (86%, 82/95), more educated (77%, 73/95), had higher income (50%, 47/95), breast cancer (51%, 48/95), over 5 years since diagnosis (85%, 81/95), currently disease free (96%, 91/95), and indicated a perceived general health of good or better (95%, 90/95). Mean age and BMI were 65.1 years and 27.6 kg/m<sup>2</sup>, respectively. The majority of participants were not meeting minimum PA guidelines (54%, 51/95). Detailed demographic and medical information can be found in [Table 1](#).

**Table 1.** Demographic, medical, and behavioral characteristics of cancer survivors in Nova Scotia, Canada, from September to October 2014.

Demographic/behavior variables		Overall (N=95) n (%)	UC (N=47) n (%)	UCAN (N=48) n (%)
<b>Gender</b>				
	Female	53 (56)	26 (55)	27 (56)
Age, mean (SD)		65.1 (8.5)	65.7 (8.6)	64.5 (8.4)
<b>Ethnic origin</b>				
	White	94 (99)	46 (98)	48 (100)
<b>Marital status</b>				
	Married	82 (86)	41 (87)	41 (85)
<b>Education</b>				
	Postsecondary	73 (77)	41 (87)	32 (67)
<b>Family income</b>				
	< 60,000	32 (34)	18 (38)	14 (30)
	≥ 60,000	47 (50)	22 (47)	25 (52)
	Prefer not to answer	16 (17)	7 (15)	9 (19)
<b>Employment</b>				
	Not employed	66 (69)	34 (72)	32 (67)
<b>Smoking status</b>				
	Never	43 (45)	23 (49)	20 (42)
	Ex-smoker	47 (50)	19 (40)	28 (58)
	Current smoker	5 (5)	5 (11)	0 (0)
<b>Alcohol consumption</b>				
	Never drink	21 (22)	8 (17)	13 (27)
	Social	60 (63)	30 (64)	30 (63)
	Regular	14 (15)	9 (19)	5 (10)
<b>Meeting PA guidelines</b>				
	No	51 (54)	25 (53)	26 (54)
<b>Dog owner</b>				
	Yes	21 (22)	11 (23)	10 (21)
<b>Cancer type</b>				
	Breast	48 (51)	23 (49)	25 (52)
	Prostate	27 (28)	14 (30)	13 (27)
	Colorectal	20 (21)	10 (21)	10 (21)
<b>Disease stage</b>				
	Localized	83 (88)	42 (90)	41 (86)
	Metastasized	6 (6)	2 (4)	4 (8)
	Don't know	6 (6)	3 (6)	3 (6)
<b>Surgery</b>				
	Yes	90 (95)	46 (98)	44 (92)
<b>Radiation therapy</b>				
	Yes	43 (45)	22 (47)	21 (44)
<b>Chemotherapy</b>				
	Yes	41 (43)	16 (34)	25 (52)

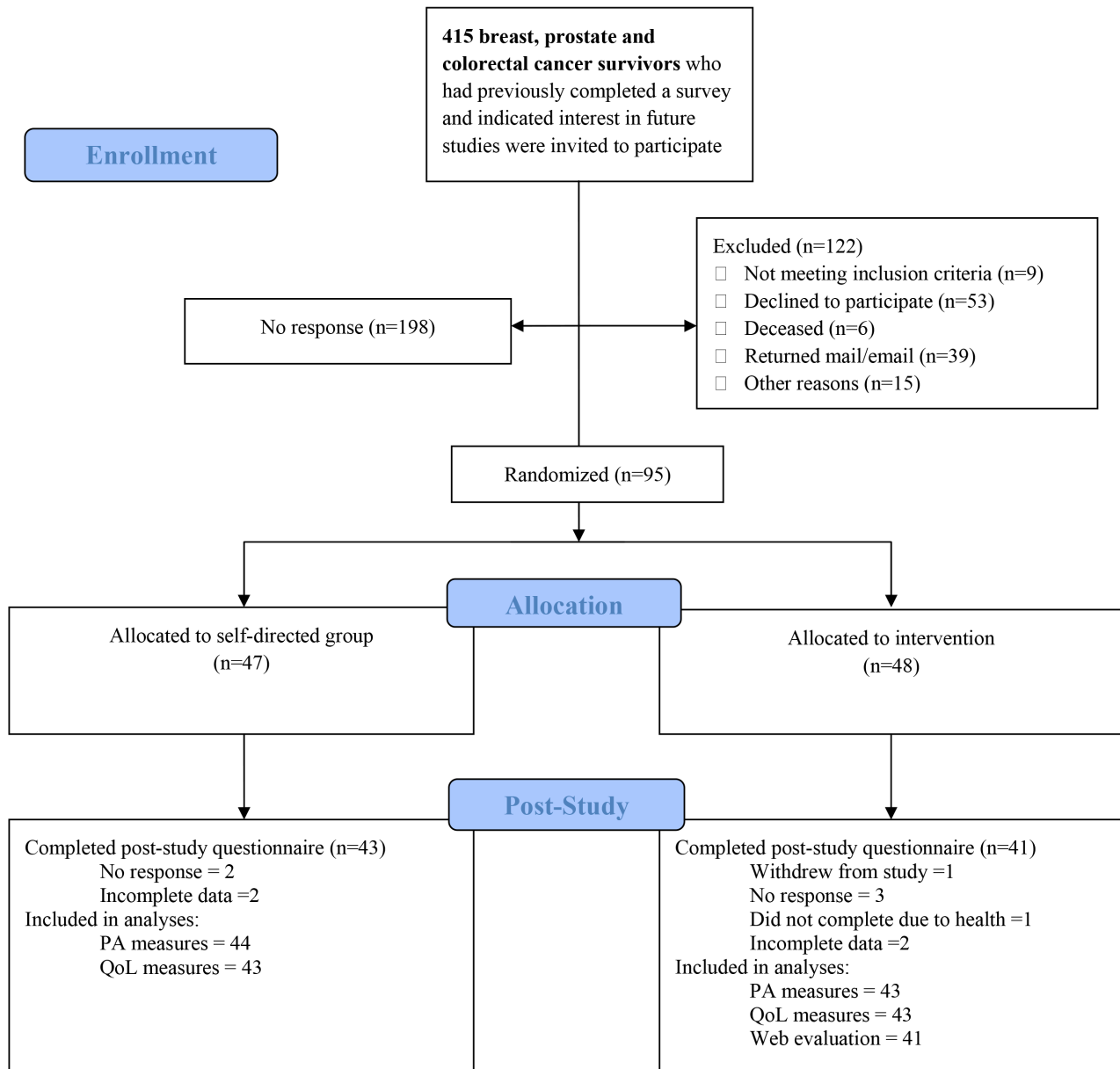
Demographic/behavior variables	Overall (N=95) n (%)	UC (N=47) n (%)	UCAN (N=48) n (%)
<b>Hormone therapy</b>			
Yes	25 (26)	10 (21)	15 (31)
<b>Current treatment status</b>			
No treatment	75 (79)	40 (85)	35 (73)
<b>Recurrence</b>			
Yes	6 (6)	0 (0)	6 (12)
<b>Current disease status</b>			
Disease free	91 (96)	47 (100)	44 (92)
Time (years) since diagnosis, mean (SD)	6.6 (2.6)	6.4 (2.9)	6.8 (2.4)
<b>General health</b>			
Very good/excellent	48 (51)	28 (60)	42 (42)
Good	42 (44)	18 (38)	24 (50)
Poor/Fair	5 (5)	1 (2)	4 (8)
<b>Comorbidity status</b>			
No comorbidities	15 (16)	5 (11)	10 (21)
1-2 comorbidities	52 (55)	25 (53)	27 (56)
≥3 comorbidities	28 (29)	17 (36)	11 (23)
<b>BMI (kg/m<sup>2</sup>), mean (SD)</b>			
Healthy weight	27.6 (4.4)	27.1 (3.9)	28.1 (4.9)
Overweight	32 (34)	16 (34)	16 (33)
Obese	33 (35)	20 (43)	13 (27)
	30 (31)	11 (23)	19 (40)

Based on data from our original survey, we were able to compare study participants (n=95) to the nonparticipants (n=320). We found that study participants were more likely to be meeting PA guidelines ( $P=.005$ ), have breast cancer ( $P=.002$ ), previous hormone therapy ( $P=.013$ ), be married ( $P=.024$ ), more educated ( $P=.014$ ), have higher income ( $P<.001$ ), be employed ( $P=.044$ ), have a stronger preference for receiving PA information via the Internet ( $P=.002$ ) or email ( $P<.001$ ), and a weaker preference for receiving information face-to-face ( $P=.019$ ).

### Website Usage

Detailed weekly Web statistics are shown in [Figures 2-5](#). The overall average number of logins was 10.3 for the 9-week duration of the intervention. There were 2293 individual PA events logged over 1085 days (average 23 days per participant) and 4319 page views recorded. The most frequently visited page was the log page where participants entered their PA data. The modules were visited 213 times over the length of the study with an overall read rate of 26%. Moreover, 94% (45/48) of participants logged in at least once, 85% (41/48) recorded PA at least once, and 67% (32/48) viewed the modules at least once.



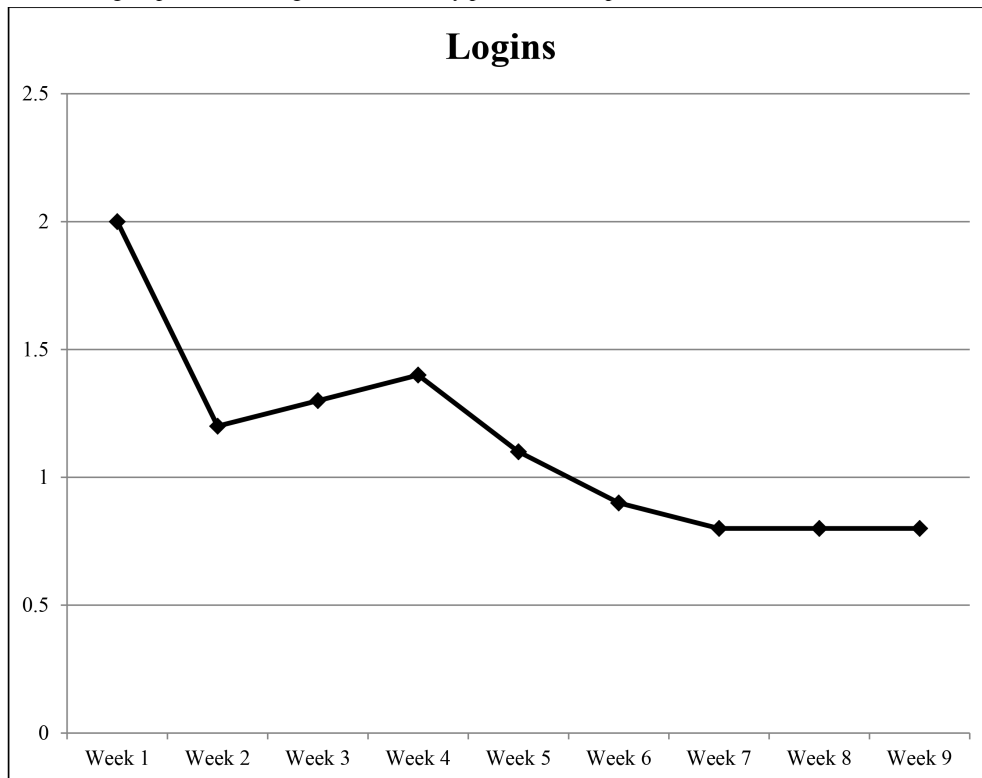
**Figure 1.** Detailed flow of study participants from invitation through postintervention.

### Intervention Satisfaction

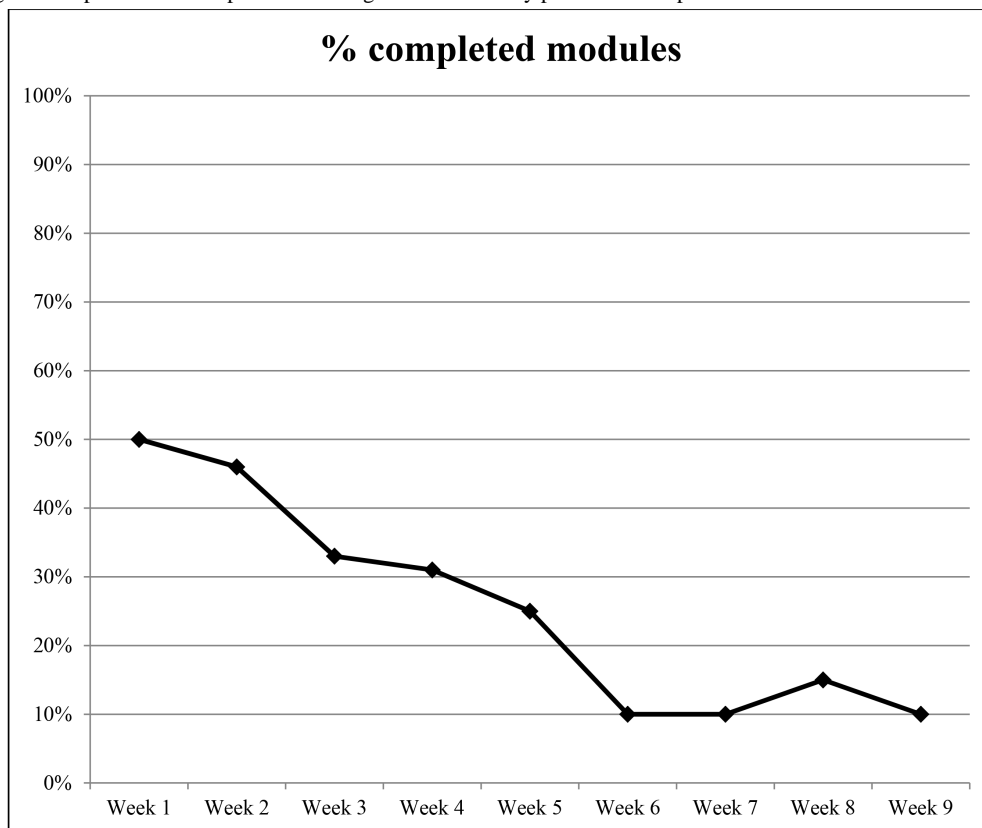
With regard to the intervention program, 73% (30/41) said they enjoyed the Active Nova Scotia program, 63% (26/41) would be willing to continue participating, 46% (19/41) indicated they increased their PA because of this program, 71% (29/41) said they were more aware of the amount of PA they get each day, and 73% (30/41) thought the information in the weekly modules

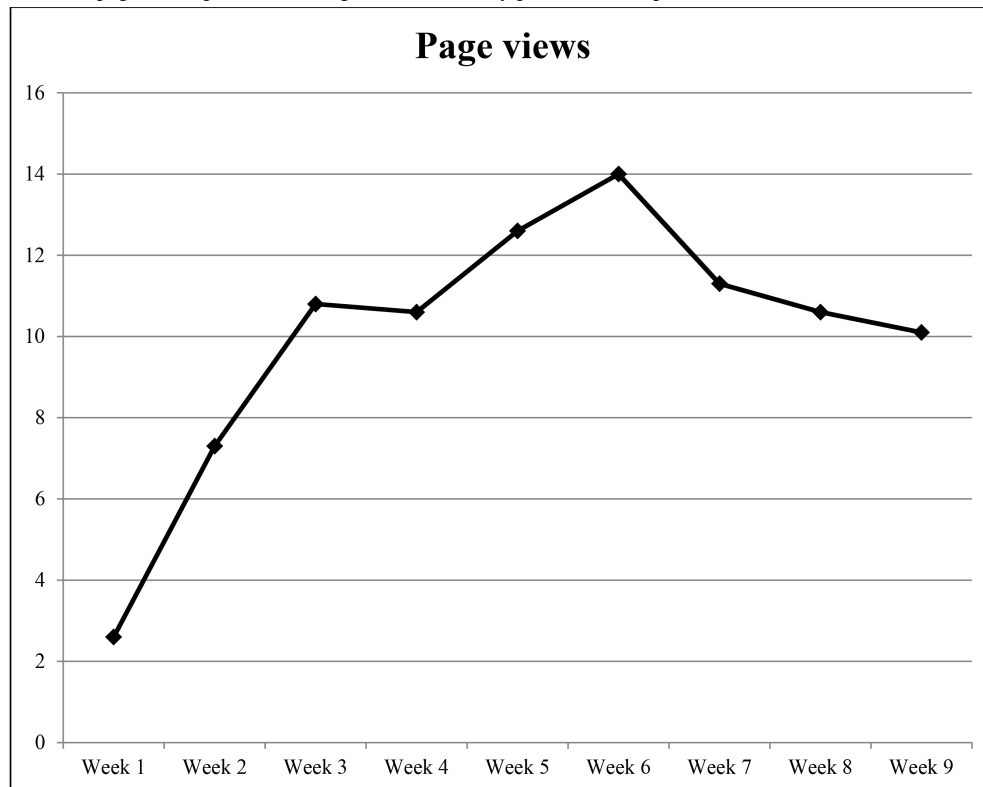
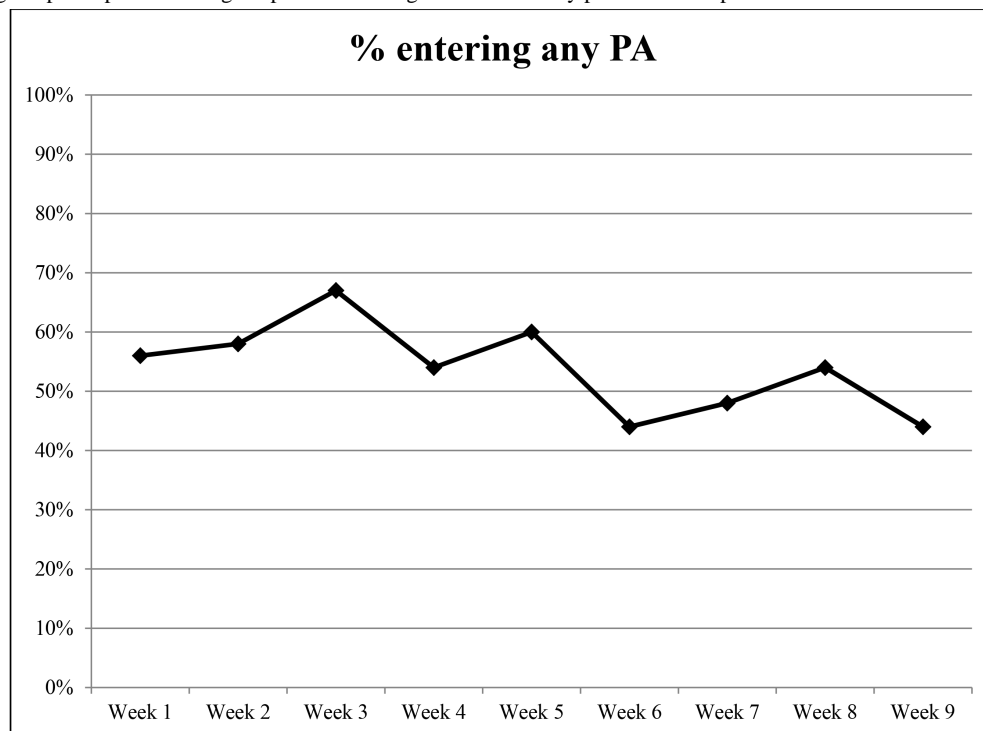
was useful and relevant. About half of the participants (51%, 21/41) liked the video posts and felt they were not too burdensome on their computer. When evaluating the website, 68% (28/41) were able to easily navigate and enter PA information on the site. When asked if they would recommend the site to others, 64% (26/41) indicated yes and 39% (16/41) said they would continue using the site after the study had finished.

**Figure 2.** Average number of logins per week during the 9-week study period from September to December 2014.



**Figure 3.** Percentage of completed modules per week during the 9-week study period from September to December 2014.



**Figure 4.** Average number of page views per week during the 9-week study period from September to December 2014.**Figure 5.** Percentage of participants entering PA per week during the 9-week study period from September to December 2014.

### Effect on Physical Activity Behavior

The differences in PA behavior between the UC and UCAN groups at baseline and postintervention are described in [Table 2](#). Overall, the adjusted between-group mean change scores favored the UCAN group; however, there were no significant differences between the groups in any PA measure. The adjusted between-group difference for total exercise minutes was 42

(95% CI -65 to 150;  $P=.44$ ,  $d=0.17$ ) in favor of UCAN. The adjusted between-group difference for strength training frequency achieved a meaningful difference of 0.5 (95% CI -0.2 to 1.1;  $P=.14$ ,  $d=0.34$ ). The subgroup analysis of the changes in total exercise minutes by baseline PA levels is illustrated in [Figure 6](#). Among those not meeting guidelines at baseline (54%, 51/95), the UCAN group (54%, 26/48) increased their PA levels by 52 minutes (95% CI -74 to 178) while the UC group (53%,

25/47) decreased by 15 minutes (95% CI -140 to 109); whereas among those meeting guidelines, the UCAN (46%, 22/48) and UC group (47%, 22/47) increased PA by 88 (95% CI -55 to 230) and 65 minutes (95% CI -57 to 186), respectively.

**Table 2.** Effects of Internet-delivered behavior change PA program on PA in Nova Scotian cancer survivors from September to December 2014 (N=87).

Outcome (N=87)	Baseline, mean (SD)	Poststudy, mean (SD)	Mean change, mean (95% CI)	Adjusted between group difference in mean change <sup>a</sup> , mean (95% CI); <i>P</i> , <i>d</i>
<b>Total exercise minutes<sup>b</sup></b>				
UC	212 (216)	241 (197)	30 (-18 to 77)	42 (-65 to 150); .44, 0.17
UCAN	231 (269)	294 (354)	64 (-45 to 172)	
<b>Total aerobic minutes<sup>c</sup></b>				
UC	194 (207)	222 (183)	29 (-19 to 76)	29 (-65 to 123); .55, 0.04
UCAN	208 (253)	258 (302)	50 (-47 to 147)	
<b>Moderate aerobic minutes<sup>d</sup></b>				
UC	117 (140)	128 (110)	11 (-32 to 53)	14 (-36 to 63); .58, 0.12
UCAN	112 (132)	140 (132)	27 (-22 to 77)	
<b>Vigorous aerobic minutes<sup>d</sup></b>				
UC	39 (66)	47 (71)	9 (-7 to 25)	6 (-27 to 38); .73, -0.03
UCAN	48 (91)	59 (109)	11 (-20 to 42)	
<b>Meeting aerobic guidelines</b>				
UC	50% (51%)	68% (47%)	19% (3-34)	-9% (-27 to 10%); .36, -0.23
UCAN	47% (51%)	58% (49%)	12% (-5 to 28)	
<b>Strength frequency</b>				
UC	0.7 (1.2)	0.8 (1.3)	0.1 (-0.2 to 0.4)	0.5 (-0.2 to 1.1); .14, 0.34
UCAN	0.9 (1.5)	1.4 (2.2)	0.5 (-0.02 to 1.0)	
<b>Strength minutes</b>				
UC	18 (35)	19 (36)	2 (-6 to 9)	12 (-10 to 35); .28, 0.04
UCAN	23 (45)	36 (84)	14 (-8 to 36)	
<b>Meeting strength guidelines<sup>e</sup></b>				
UC	25% (44%)	27% (45%)	2% (-12 to 17)	6% (-11 to 23%); .48, 0.18
UCAN	28% (45%)	35% (48%)	7% (-5 to 19)	

<sup>a</sup>Difference in mean change adjusted for baseline value.

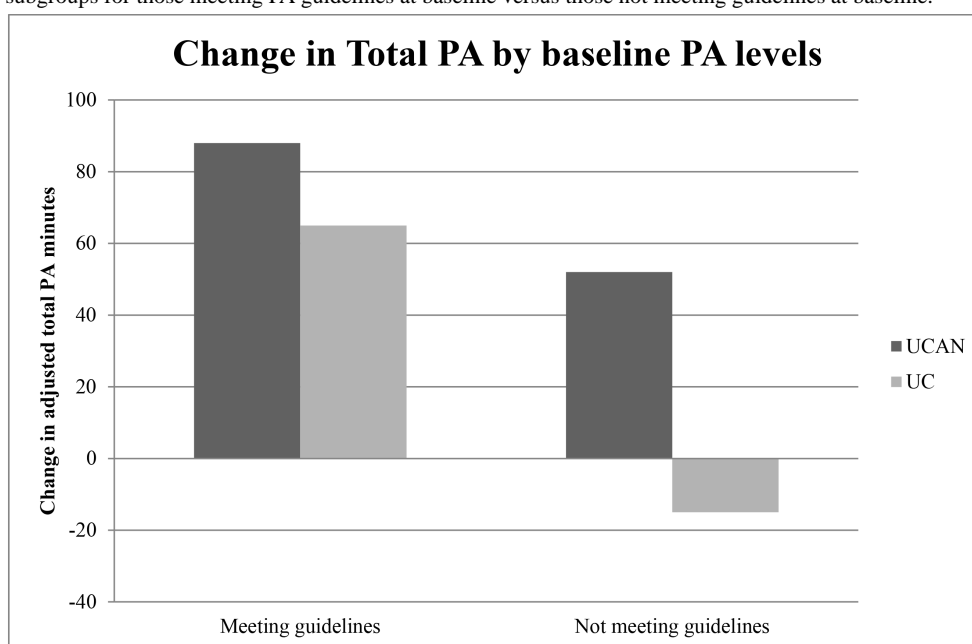
<sup>b</sup>Total exercise minutes was computed by adding total aerobic minutes to total strength minutes.

<sup>c</sup>Total aerobic minutes was computed using moderate minutes plus 2 times the vigorous minutes.

<sup>d</sup>Capped at 420 minutes per week.

<sup>e</sup>Strength guidelines is engaging in strength exercise  $\geq 2$  times per week.

**Figure 6.** Change in adjusted total PA by meeting guidelines at baseline. This figure shows the trend in PA minutes between the UCAN and UC group when analyzing the subgroups for those meeting PA guidelines at baseline versus those not meeting guidelines at baseline.



### Quality of Life

The general and cancer-specific QOL measures at baseline and postintervention are summarized in Tables 3 and 4. Change in the SF-36 measure of mental health favored the UC group with a mean change score of -2.9 (95% CI -5.1 to -0.6;  $P=.014$ ,  $d=0.37$ ). All other measures were nonsignificant. No measures met the point difference that indicates clinical significance (SF-36=3 point difference; FACT subscales=2-3 point difference).

## Discussion

### Principal Findings

Our study is one of the first to use an online platform to deliver a theory-based PA behavior change program to cancer survivors, and the first to target Nova Scotian cancer survivors. Based on recruitment, retention, and participant evaluation of the program we believe that the program is feasible. In addition, there were trends suggesting the potential effectiveness of the program for promoting PA, especially in cancer survivors who were inactive at baseline. Engagement in the program and influencing QOL, however, remain a challenge for distance-based program delivery.

Our expression of interest rate (29%, 120/415) and recruitment rate (23%, 95/415) was similar to other studies [22,28]. The previous study among cancer survivors resulted in a 17% recruitment rate but used community- and clinical-based recruitment methods that were unable to track the initial reach of the invitation [28]. Our postintervention retention (88%, 84/95) was higher than the majority of previous studies using

the Internet as a delivery method [19,28,42]. Large attrition is common among Internet-based interventions [18,20-22,42] and like previous research we had slightly higher attrition in the intervention group (15% vs 9%) despite the high satisfaction ratings [22]. It is difficult to pinpoint the reason for such high dropout rates in Web-based studies but previous research indicates it is easier for participants to disengage from Web-based interventions [43]. Using strategies to increase the contact between user-to-user and user-to-researcher may help increase the connection and make the intervention meaningful to the participant [23].

Engagement in our study was fairly low compared to other Internet-based studies [22,28]. The modules had a completion rate of 26% (111/432 potential completions). As with logins, the number of completed modules dropped after the first few weeks. Our average number of logins was 10.3 per person. This equals about once per week per person which may be insufficient to induce PA behavior change. This is similar to other studies using Internet delivery [24,42]. A meta-analysis by Davies et al [19] found the average number of logins per-person-per-week was 3.08 across 11 studies. One potential reason for our lower login average is that the website was able to automatically pull data from devices such as the FitBit without the participants having to login. One recent suggestion for increasing user engagement is to allow user-generated content (eg, creating a post to add to the newsfeed) [44] which may increase user "buy-in." This method, however, requires close monitoring as information would need to be vetted to ensure accuracy and relevance. Retaining and engaging participants remain an issue among Internet-delivered behavior change programs.



**Table 3.** Effects of Internet-delivered PA program on generic QOL in Nova Scotian cancer survivors from September to December 2014 (N=86).

Outcome		Baseline, mean (SD)	Poststudy, mean (SD)	Mean change, mean (95% CI)	Adjusted between group difference in mean change <sup>a</sup> , mean (95% CI); <i>P</i> , <i>d</i>
<b>Physical functioning</b>					
	UC	49.1 (9.7)	50.1 (7.0)	1.0 (-1.5 to 3.5)	-0.6 (-3.3 to 2.2); .68, 0.18
	UCAN	47.8 (7.9)	49.0 (8.0)	1.1 (-1.3 to 3.5)	
<b>Role physical</b>					
	UC	50.4 (7.5)	49.4 (8.3)	-0.9 (-3.4 to 1.6)	-1.0 (-4.3 to 2.2); .53, -0.06
	UCAN	48.5 (8.6)	47.0 (11.0)	-1.5 (-3.8 to 0.7)	
<b>Bodily pain</b>					
	UC	51.0 (8.4)	51.5 (9.1)	0.5 (-1.9 to 2.9)	-1.6 (-4.8 to 1.5); .30, -0.23
	UCAN	49.0 (7.6)	48.6 (9.0)	-0.5 (-2.8 to 1.9)	
<b>General health</b>					
	UC	46.0 (5.9)	47.4 (6.2)	1.4 (-0.4 to 3.2)	-1.8 (-4.2 to 0.5); .12, -0.27
	UCAN	46.7 (6.4)	46.1 (7.6)	-0.6 (-2.3 to 1.1)	
<b>Vitality</b>					
	UC	44.9 (7.9)	45.2 (8.3)	0.3 (-1.2 to 1.8)	-1.4 (-3.9 to 1.0); .25, -0.09
	UCAN	45.7 (7.2)	44.5 (9.3)	-1.2 (-3.2 to 0.7)	
<b>Social functioning</b>					
	UC	51.6 (8.7)	51.0 (8.8)	-0.6 (-2.9 to 1.7)	-1.7 (-4.9 to 1.5); .30, -0.00
	UCAN	50.3 (8.4)	48.4 (10.3)	-1.9 (-4.4 to 0.6)	
<b>Role emotional</b>					
	UC	51.8 (7.1)	51.1 (8.3)	-0.7 (-3.8 to 2.4)	1.5 (-5.3 to 2.4); .44, 0.00
	UCAN	50.6 (8.0)	49.1 (10.5)	-1.5 (-4.5 to 1.5)	
<b>Mental health</b>					
	UC	44.7 (4.8)	44.9 (5.8)	0.3 (-0.9 to 1.4)	-2.9 (-5.1 to -0.6); .014, -0.37
	UCAN	45.0 (5.6)	42.3 (8.5)	-2.6 (-4.6 to -0.6)	
<b>Physical health component</b>					
	UC	49.7 (7.8)	50.4 (7.5)	0.7 (-1.3 to 2.8)	-0.8 (-3.3 to 1.8); .55, -0.09
	UCAN	48.3 (8.0)	48.8 (7.9)	0.5 (-1.4 to 2.4)	
<b>Mental health component</b>					
	UC	47.6 (6.0)	47.1 (7.3)	-0.5 (-2.4 to 1.3)	-2.2 (-5.2 to 0.8); .14, -0.10
	UCAN	47.7 (7.6)	45.0 (10.2)	-2.7 (-5.3 to -0.2)	

<sup>a</sup>Difference in mean change adjusted for baseline value.

**Table 4.** Effects of Internet-delivered PA program on cancer-specific QOL in Nova Scotian cancer survivors from September to December 2014 (N=86).

Outcome		Baseline, mean (SD)	Poststudy, mean (SD)	Mean change, mean (95% CI)	Adjusted between group difference in mean change <sup>a</sup> , mean (95% CI); <i>P</i> , <i>d</i>
<b>Physical well-being</b>					
	UC	24.4 (4.0)	24.4 (3.7)	-0.1 (-0.9 to 0.8)	-0.6 (-1.8 to 0.5); .28, -0.06
	UCAN	25.1 (2.5)	24.2 (3.7)	-0.8 (-1.7 to 0.04)	
<b>Social well-being</b>					
	UC	19.8 (5.9)	19.3 (5.9)	-0.6 (-1.8 to 0.7)	0.5 (-1.2 to 2.1); .57, 0.20
	UCAN	21.2 (5.5)	20.8 (5.6)	-0.4 (-1.7 to 0.8)	
<b>Emotional well-being</b>					
	UC	20.6 (3.6)	20.3 (4.5)	-0.3 (-1.8 to 1.1)	0.3 (-2.0 to 1.3); .69, 0.22
	UCAN	20.2 (3.6)	19.8 (3.7)	-0.4 (-1.7 to 0.9)	
<b>Functional well-being</b>					
	UC	23.3 (4.0)	22.8 (5.5)	-0.5 (-2.0 to 1.0)	-0.4 (-2.3 to 1.4); .64, -0.11
	UCAN	23.1 (4.3)	22.2 (5.1)	-0.9 (-2.0 to 0.2)	
<b>Fatigue symptoms</b>					
	UC	41.1 (11.9)	38.2 (8.2)	-2.9 (-5.1 to -0.7)	0.2 (-2.2 to 1.8); .85, 0.06
	UCAN	41.7 (8.5)	38.4 (6.4)	-3.4 (-5.2 to -1.6)	
<b>FACT-G</b>					
	UC	88.2 (14.1)	86.8 (14.3)	-1.5 (-4.8 to 1.8)	0.9 (-5.2 to 3.5); .69, 0.06
	UCAN	89.6 (11.7)	87.0 (15.0)	-2.6 (-5.6 to 0.5)	
<b>FACT-F</b>					
	UC	129.4 (23.7)	125.0 (19.8)	-4.4 (-9.0 to 0.2)	-1.1 (-6.5 to 4.4); .70, 0.04
	UCAN	131.3 (17.6)	125.4 (20.0)	-5.9 (-9.8 to -2.1)	
<b>TOI-F</b>					
	UC	88.9 (18.7)	85.5 (15.0)	-3.5 (-7.1 to 0.1)	-1.3 (-5.3 to 2.7); .51, -0.08
	UCAN	89.9 (13.2)	84.8 (13.5)	-5.1 (-8.0 to -2.2)	

<sup>a</sup>Difference in mean change adjusted for baseline value.

Overall, the program was very well received among participants in the UCAN group despite the low usage numbers. This is similar to other Internet-based PA programs [22,28,42,45]. Most participants felt that the information provided was useful and relevant and they indicated that they were more aware of their level of daily activity. They also indicated they liked the weekly posts and videos and would be interested in continuing with the ANS program. Participants evaluated the website favorably and said they would recommend it to a friend but the majority indicated they would not continue using the site with the program finished. Very few participants contacted the study coordinator with issues related to using the website.

Engagement seems to be the biggest hurdle in testing and implementing Internet-delivered interventions. Vandelanotte et al [23] evaluated freely accessible websites that promote PA and found that many did not use tools such as self-monitoring, goal setting, and targeted feedback despite the supporting evidence [21,24,25,46]. An aspect found to be useful that our study lacked is a method of users generating their own content. Despite having a “news feed,” our users were not able to directly

message other participants which has been shown to increase effectiveness of Web-based interventions [25]. Standardizing the components of behavior change websites and thoroughly testing them will allow researchers to determine which are most effective among various populations.

As expected based on the small sample size of this pilot study, there were no significant between-group differences in any PA measure, one component we used to determine efficacy. Nevertheless, after adjusting for baseline measures, the UCAN group increased total exercise by 42 minutes more than UC (29 aerobic minutes plus 12 strength minutes) which translated into a small standardized effect size of  $d=0.17$ . This is slightly higher than the overall effect size of  $d=0.12$  found by Davies and colleagues [19]. Moreover, the largest effect of the intervention was for strength training frequency where the UCAN group added a half day per week compared to the UC group ( $d=0.34$ ). Despite the majority of PA measures showing nonsignificant increases favoring the UCAN group, the percentage of participants meeting guidelines, based on the standard cutpoint of 150 minutes, showed a nonsignificant potentially meaningful

change favoring the UC group. This finding is somewhat arbitrary because it is dependent on the baseline level of PA (ie, where participants start). There were more UC participants in the “insufficiently active” category than UCAN at baseline; consequently, the smaller increase in minutes per week may have been enough to result in a larger proportion meeting guidelines.

The previous research among cancer survivors [28] and the meta-analysis by Davies and colleagues [19] found that computer-tailored PA programs had positive effects on PA. Previous reviews also indicate that Internet-delivered interventions have positive effects on PA levels [47-49]. One possible explanation for the modest effect of our intervention is the relatively high percentage of participants meeting PA guidelines at baseline (46%, 44/95). Our invitation was to any cancer survivor who wanted to increase his/her PA with the assumption that only less active people would volunteer for such a study. Moreover, we included those meeting the guidelines because research has shown that even more health benefits can be gained by increasing activity levels to 300 or more minutes per week [36,37].

After performing an exploratory subgroup analysis we found a suggestion that the program may be more effective for those who were not meeting guidelines at baseline. Among those not meeting guidelines at baseline, the UCAN group increased their PA levels by 52 minutes while the UC group decreased by 15 minutes (Figure 3). Among those meeting guidelines, the UCAN and UC groups increased PA by 88 and 65 minutes, respectively. The suggestion that PA behavior change programs are most beneficial to those least active is similar to previous research [19]. Targeting specific populations that have lower than average PA levels (ie, cancer survivors, inactive population) may have an even larger effect on clinical and public health outcomes [19].

Not surprisingly, our study did not find any beneficial changes in QOL measures, the second component used to determine efficacy. In fact, the only significant finding was a negative effect on mental health ( $P=.014$ ,  $d=0.37$ ). It is common to find no significant benefits to QOL among distance-based PA interventions for cancer survivors even when PA increases are noted [15,50]. Similar to the PA measures, some studies have found significant improvements in aspects of QOL at postintervention that were not sustained when assessed at follow-up [32,51-57]. Over the course of the study intervention, 14 (29%, 14/48) intervention participants contacted the study coordinator indicating they were having physical or personal issues, which may be a possible explanation for the negative trend in QOL evident in this study. Based on qualitative comments left by participants at the postintervention survey, many felt that the QOL measures used did not apply to them as it had been so long since diagnosis. Approximately 85% (81/95)

of the study sample was over 5 years since diagnosis. It may be that the measures used to assess QOL are more applicable to patients on treatments. Despite our inclusion of the generic SF-36, it may be beneficial to include long-term cancer-specific QOL measures for studies among long-term cancer survivors to see if they would be more applicable.

This is the first study to deliver a computer-tailored, Web-delivered PA behavior change intervention to Nova Scotian cancer survivors, and one of the first in any cancer survivor group. This study showed that some cancer survivors are interested and willing to receive PA information through the Internet; however, modifications to the website are necessary to optimize the effectiveness. Limitations of this study are the use of self-report data, selection bias toward those more motivated and Internet savvy, the low usage rate overall, and the decline in usage over the intervention period. Despite the user-friendly website we used to pilot this program, there were comments about confusion on how to use the site and find our information. In the future, we would recommend ensuring a separate site that would be able to house the information in a more prominent position.

Our original study [11] invited people to participate in a PA survey, leading to a selection bias for those motivated to engage in PA. It is common in nonblinded studies to have self-selection bias among participants. Despite this, we were still surprised at the number of participants in the intervention meeting guidelines (46%, 44/95). It may be that the most motivated and active of the previous highly motivated and active survey sample were the ones to come forward for this intervention. In addition, our participants were more likely to prefer receiving information via the Internet which may also bias results. When being asked to participate in an online study, those who prefer this method are more likely to come forward. However, if we were to exclude those already active, our sample size would have been reduced by almost half. Previous preference research found that those who preferred Web-based interventions were more likely to have higher Internet use and higher PA participation [58]. More research into preferences for Internet delivery PA interventions should be explored.

## Conclusions

In conclusion, using a Web-based platform to deliver a PA behavior change intervention to cancer survivors may be a feasible alternative to other methods of information delivery. There was a trend toward increased activity in the UCAN group when compared to the UC group, especially among inactive cancer survivors, although no significant differences were found. User engagement remains a challenge and future research should incorporate as many of the tools previously found to be effective among Web-based interventions to increase engagement and maintain PA behavior.

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## Authors' Contributions

All authors made substantial contributions to the conception and design of the study. CF was involved in the development and administration of the intervention. CF and KC drafted the manuscript and KM and CB revised it critically for important intellectual content. CF and KC performed the statistical analyses and were responsible for the interpretation of the data. All authors read and approved the final manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

- BMI:** body mass index
- FACT-F:** Functional Assessment of Cancer Therapy-Fatigue
- FACT-G:** Functional Assessment of Cancer Therapy-General
- PA:** physical activity
- QOL:** quality of life
- SF-36:** Medical Outcomes Study 36-Item Short Form

**TOI-F:** Trial Outcome Index-Fatigue

**TTM:** transtheoretical model

**UC:** usual care

**UCAN:** UWALK Cancer Group

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Original Paper

# The Impact of Advice Seekers' Need Salience and Doctors' Communication Style on Attitude and Decision Making: A Web-Based Mammography Consultation Role Play

Tim Fissler<sup>1</sup>, BSc; Martina Bientzle<sup>1</sup>, Dipl-Psych; Ulrike Cress<sup>1,2</sup>, Dr rer soc; Joachim Kimmerle<sup>1,2</sup>, Dr rer nat

<sup>1</sup>Leibniz-Institut fuer Wissensmedien, Knowledge Media Research Center, Knowledge Construction Lab, Tuebingen, Germany

<sup>2</sup>Department of Psychology, University of Tuebingen, Tuebingen, Germany

**Corresponding Author:**

Joachim Kimmerle, Dr rer nat

Leibniz-Institut fuer Wissensmedien, Knowledge Media Research Center

Knowledge Construction Lab

Schleichstrasse 6

Tuebingen,

Germany

Phone: 49 7071 979 363

Fax: 49 7071 979 100

Email: [j.kimmerle@iwm-tuebingen.de](mailto:j.kimmerle@iwm-tuebingen.de)

## Abstract

**Background:** Patients and advice seekers come to a medical consultation with typical needs, and physicians require adequate communication skills in order to address those needs effectively. It is largely unclear, however, to what extent advice seekers' attitudes toward a medical procedure or their resulting decisions are influenced by a physician's communication that ignores or explicitly takes these needs into account.

**Objective:** This experimental study tested how advice seekers' salient needs and doctor's communication styles influenced advice seekers' attitudes toward mammography screening and their decision whether or not to participate in this procedure.

**Methods:** One hundred women (age range 20-47 years, mean 25.22, SD 4.71) participated in an interactive role play of an online consultation. During the consultation, a fictitious, program-controlled physician provided information about advantages and disadvantages of mammography screening. The physician either merely communicated factual medical information or made additional comments using a communication style oriented toward advice seekers' typical needs for clarity and well-being. Orthogonal to this experimental treatment, participants' personal needs for clarity and for well-being were either made salient before or after the consultation with a needs questionnaire. We also measured all participants' attitudes toward mammography screening and their hypothetical decisions whether or not to participate before and after the experiment.

**Results:** As assumed, the participants expressed strong needs for clarity (mean 4.57, SD 0.42) and for well-being (mean 4.21, SD 0.54) on 5-point Likert scales. Making these needs salient or not revealed significant interaction effects with the physician's communication style regarding participants' attitude change ( $F_{1,92}=7.23$ ,  $P=.009$ ,  $\eta^2=.073$ ) and decision making ( $F_{1,92}=4.43$ ,  $P=.038$ ,  $\eta^2=.046$ ). Those participants whose needs were made salient before the consultation responded to the physician's communication style, while participants without salient needs did not. When the physician used a need-oriented communication style, those participants with salient needs had a more positive attitude toward mammography after the consultation than before (mean 0.13, SD 0.54), while they changed their attitude in a negative direction when confronted with a purely fact-oriented communication style (mean -0.35, SD 0.80). The same applied to decision modification (need-oriented: mean 0.10, SD 0.99; fact-oriented: mean -0.30, SD 0.88).

**Conclusions:** The findings underline the importance of communicating in a need-oriented style with patients and advice seekers who are aware of their personal needs. Ignoring the needs of those people appears to be particularly problematic. So physicians' sensitivity for advice seekers' currently relevant needs is essential.

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**KEYWORDS**

communication style; needs; need salience; attitude; decision-making; mammography screening; online consultation

## Introduction

### Doctor-Patient Communication on the Internet

People increasingly seek medical consultation and advice on the Internet [1-5]. Many patients and advice seekers are interested in comprehensive online communication with health care professionals [6,7]. The online situation may influence how patients and physicians perceive their roles in the communication process, and this in turn may affect the further development of the doctor-patient relationship [8,9]. The application of purely text-based communication is associated with particular challenges: users cannot easily express themselves in writing and the communication setting provides only reduced social context cues [10]. These characteristics can result in feelings of anonymity [11] and may undermine information exchange [12] and decision making [13], all of which may hinder establishment of interpersonal relationships [14].

With regard to their goals, however, face-to-face and online communication methods have much in common. In both cases, doctor-patient communication serves various purposes: Physicians and advice seekers want to develop a positive interpersonal relationship, exchange information, and come to a point where they can make reasonable medical decisions [15]. This may be facilitated if people feel their needs as advice seekers are recognized and accepted. Positive dialogue should support them in evaluating medical information and making decisions, and a pleasant atmosphere has been shown to have a positive impact on the success of therapy by motivating patients [16-18]. Good doctor-patient communication can improve information exchange, which then leads to informed decisions [17].

Patients and advice seekers come to a medical consultation with various personal needs. It is unclear, however, how their needs and the salience of these needs influence their perception of a doctor's communication style. Patients' characteristics, opinions, and needs play an important role in their information processing [19,20]; it is plausible that the interplay of their needs and a physician's communication style has an impact on their attitudes toward a medical procedure and their related decision making. The aim of the present study was to examine how the salience of advice seekers' needs in an online consultation and doctors' communication skills in addressing these needs influence advice seekers' attitudes toward a medical procedure (mammography screening) and their decisions whether or not to undergo that procedure.

In the following sections, we take the literature on needs of patients and advice seekers into consideration, discuss relevant factors of need-oriented communication, and derive research hypotheses from these considerations. Then we describe the methods of our experimental study and present its results. Concluding, we discuss our findings with respect to their practical implications and provide suggestions for future research.

### Advice Seekers' Needs

In motivational psychology, needs are relatively stable characteristics that describe the tendency of individuals to pursue particular goals [21]. Patients' and advice seekers' needs in consultations can be measured by asking them for their personal hopes and expectations regarding a physician visit or a medical treatment [22]. Surveys have shown that most people have the need to receive clear, balanced, and complete information in a consultation [23-26]. When this need for clarity is addressed during a consultation, patients are more satisfied with the treatment [15].

In addition, people usually try to achieve pleasure and avoid pain [27,28]. Accordingly, in health care situations, patients expect that they will retain or restore their health and well-being through medical treatments [29]. With regard to medical prevention, one key reason why people participate in prevention activities is that they want to stay healthy and feel good [30,31]. Avoiding psychological strain is one important aspect in a woman's decision about participating in cancer screening [32]. That is, an advice seeker's need for well-being plays an important role in prevention procedures, such as mammography screening.

Meeting patients' and advice seekers' needs is a central challenge for health care [33,34]. It is well known that need fulfillment has many positive consequences. For example, need satisfaction is related to a greater adherence to medical recommendations [35] and to subjective well-being [36].

In a consultation, patients perceive the physician's communication as need-oriented attention when their needs have been addressed. Even though we may assume that virtually all medical advice seekers possess a need for clarity as well as a need for well-being, we also assume that there are situations where people are more conscious of these needs, that is, where these needs are more or less salient in terms of cognitive accessibility [37]. For example, people who are invited to prepare for a medical consultation [38] or who are explicitly asked about their needs [39] are more conscious of their individual expectations and needs than people who are more indifferent in the medical consultation. The active reflection on one's needs makes those individual needs more salient. Accordingly, there are situations in health care where (1) advice seekers' needs are salient and their physicians meet those needs, (2) advice seekers' needs are salient but their physicians do not meet those needs, and (3) advice seekers' needs are not salient, making it presumably less relevant whether or not their physicians meet those needs in the communication.

### Physicians' Need-Oriented Communication

Health communication should be adapted to individual demands and preferences [40,41]. From research on this kind of tailoring and targeting of health information, it is known that if communicated health information meets individual needs, the patients consider the information to be more important [42,43]. In addition, tailored information influences people's attitudes

toward medical procedures such as mammography interventions [44,45] and increases participation in prevention programs [45-47]. The fit between the way health information is communicated and the patient's or advice seeker's individual preferences is a critical factor in health communication. Most of the research that investigated tailored health communication focused on personal characteristics such as education and age [48-52] or on clinical features [51]. But patients' individual needs are also known to influence how information is processed [42,43]. Therefore, it is suggested that the communication style be adapted to the individual needs of a patient or advice seeker [40,41].

When people seek medical advice, they are more or less conscious of their needs, meaning that their needs for clarity and for well-being can be more or less salient. When these needs are salient and people have the impression that their physician takes their needs into account by responding to specific concerns, it may make them more sympathetic to the content of the consultation. So when the fit between their needs and the physician's communication style affects their information processing correspondingly, these advice seekers would value a medical procedure more highly than when needs and communication style do not fit—if they evaluate the health information positively. This applies to the case of mammography screening, since women have a positive impression of the procedure and even tend to overestimate its benefits [20,53,54]. People also engage more actively in processing information if they perceive the information as personally relevant [55]. This is the case when information is tailored to individual aspects [44,46,47]. In the following study, we investigated whether the salience of advice seekers' needs and the need-oriented communication style of a physician influence attitudes and decisions about a medical procedure.

## Hypotheses

Hypothesis 1: The salience of an advice seeker's needs and a physician's communication style will interact to affect attitude change: People with highly salient needs will have a more positive attitude toward a medical procedure if they encounter a physician who applies a need-oriented communication style instead of a purely fact-oriented communication style. This will not apply to people without salient needs.

Hypothesis 2: The salience of an advice seeker's needs and a physician's communication style will interact to affect decision modification: People with highly salient needs will be more willing to undergo a medical procedure if they encounter a physician who applies a need-oriented communication style instead of a purely fact-oriented communication style. This will not apply to people without salient needs.

## Methods

### Study Design and Setting

This study represented a  $2 \times 2$  factorial design with need salience and communication style as between-group factors. The experiment was conducted as an online study where participants took part in a role play of a consultation about mammography screening. Mammography screening is a nationwide,

quality-assured breast cancer examination program. In Germany, like in many Western countries, all healthy women aged 50 to 69 years are invited to participate in mammography screening every two years. Younger women are invited if they belong to a high-risk group.

During the consultation, a fictitious, program-controlled physician provided information about advantages and disadvantages of mammography screening. The physician either merely communicated factual medical information or transmitted the same information but made additional comments in a need-oriented communication style by addressing both the need for clarity and the need for well-being. Independently of this encounter, participants' needs were either measured (and thus made salient) before or after the consultation with a needs questionnaire. This procedure resulted in four experimental conditions: (1) need-oriented communication style/salient needs, (2) fact-oriented communication style/salient needs, (3) need-oriented communication style/no salient needs, (4) fact-oriented communication style/no salient needs.

### Participants

One hundred women aged 20 to 47 years (mean 25.22, SD 4.71) participated in this online role play of a consultation on mammography screening. Women were recruited from volunteers registered in the institutional participant database and invited via email. The database is designed for recruiting study participants. Registration in the database is open to everyone. Four participants were excluded from further analysis because they had already undergone a mammography procedure and thus apparently already made conclusive decisions about mammography screening. This exclusion criterion implied that only women without a breast cancer diagnosis participated in the study. We included only women with German as their native language.

The remaining 96 participants were randomly assigned to one of the four experimental conditions, with 24 participants in the need-oriented communication/salient needs condition, 23 in the fact-oriented communication/salient needs condition, 24 in the need-oriented communication/no salient needs condition, and 25 in the fact-oriented communication/no salient needs condition. The participants in the four experimental conditions did not differ with regard to age ( $F_{3,92}=0.82$ ,  $P=.49$ ).

### Procedure and Material

For all participants the experiment started with the same pretest. Included in this pretest were demographic questions as well as measurements of participants' attitudes toward mammography screening and their hypothetical decision whether or not to participate in a screening (see next section for details on these instruments). Then all participants were introduced to the general experimental situation. Here, they were told to imagine that they had an appointment with their gynecologist in order to gather information about mammography screening. During this appointment they would be able to ask questions that would be answered by the doctor. Participants were told that the physician who answered their questions would not be a real person. They were assured that all answers had been approved as to their medical correctness. They were asked to imagine they were



participating in a real doctor-patient dialogue. After that general introduction, participants in the two salient needs conditions filled in a needs questionnaire that made salient their needs for clarity and well-being (see next section for details on this instrument). Then all participants engaged in the interactive online role play that took place as a text chat between the participants and a fictitious, program-controlled physician. In this role play the physician provided information about advantages and disadvantages of mammography screening. The physician either merely communicated factual information about mammography screening (in the two fact-oriented communication style conditions) or made additional comments using a need-oriented communication style (in the two need-oriented communication style conditions) where he explicitly addressed the needs for clarity and well-being.

In the online role play the fictitious physician provided participants in all four conditions with the same two advantages and two disadvantages of mammography screening. The sequence in which the participants encountered these information items in the text chat differed, however, depending on their replies to the posts of the physician character. The potential sequences of interactions in the online role play are presented in [Multimedia Appendix 1](#). For each step of communication, the participants could choose their question or answer from a predetermined selection of text modules. The role play started with a participant's opening question to which the physician either replied in a need-oriented or a purely fact-oriented manner. In the need-oriented communication style conditions, the physician emphasized, for example, that he understood that this conversation was about obtaining clarity on what exactly mammography screening is about or that well-being was important for this participant. These statements demonstrated to the participants that the doctor had recognized their needs and was willing to consider them explicitly. In the fact-oriented communication style conditions, the physician refrained from emphasizing those needs for clarity and for well-being.

The role play was technically implemented as an online questionnaire using the Enterprise Feedback Suite (Questback) as an online survey system [56]. During the role play participants were able to interact with the virtual physician by choosing one of several possible statements in each trial. With respect to their chosen answer, they were then dynamically forwarded to the next site of the role play that presented the next piece of information provided by the physician. To ensure that all four conditions of the role play presented the same information to the participants, the conversation parts that presented information about the mammography screening were identical in their wording in the different conditions. The need-oriented comments were separate and over and above these factual statements.

Following the role play, all participants filled in the same posttest questionnaire that again measured their attitude toward mammography screening and their hypothetical decision whether or not to participate. These measurements were identical to those in the pretest. In addition, the posttest asked participants to assess the arguments about mammography screening given to them during the role play to ensure that they valued the advantages of mammography screening as presented by the physician. Moreover, they replied to the item *I was easily able to put myself in the consultation situation* (immersion item) on a 5-point scale (1=*I do not agree* to 5=*I totally agree*). Finally, participants in the two no salient needs conditions filled in the needs questionnaire.

## Instruments

As pointed out above, we measured all participants' attitudes toward mammography screening and their hypothetical decisions whether or not to participate before and after the experiment. The attitude test consisted of four pairs of adjectives which participants had to rate on 7-point semantic differential scales (see [Table 1](#)). This text was based on the attitude measurement by Marteau, Dormandy, and Michie [57].

The decision measurement consisted of two items that participants had to rate on 5-point Likert scales ranging from 1=*does not apply at all* to 5=*applies completely* (see [Table 2](#)).

**Table 1.** Attitude scale.

I think that for me participation in mammography screening at the age of 50 is...	
1	advantageous <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> disadvantageous <sup>f</sup>
2	important <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> unimportant <sup>f</sup>
3	a bad thing <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> a good thing
4	convenient <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> inconvenient <sup>f</sup>

<sup>f</sup>Indicates reversely coded items.

**Table 2.** Decision scale.

1	I consider participation in mammography screening to be very reasonable.
2	I would participate in breast cancer screening using mammography.

Participants' needs for clarity and for well-being were measured with a needs questionnaire. These scales were developed on the basis of the literature mentioned above [22-32] and designed

to capture the broadness of the constructs. Hence, the items of the need for clarity scale captured how important it is for advice seekers to receive instructive and useful information in a

consultation about mammography screening. The items of the need for well-being scale inquired about how important it is for advice seekers to stay healthy and maintain their status of well-being. Each scale consisted of seven items that participants had to rate on 5-point Likert scales ranging from 1=*does not apply at all* to 5=*applies completely*. The need for clarity scale

is presented in Table 3, the need for well-being scale in Table 4.

Participants assessed the arguments (advantages and disadvantages) on mammography screening that were given to them during the role play on 7-point Likert scales ranging from 1=*very unimportant* to 7=*very important* (see Table 5).

**Table 3.** Need for clarity scale.

1	For me it is important to receive very structured counseling on mammography screening.
2	For me it is important to understand what happens to me during a mammography examination.
3	For me it is important to understand the meaning of the findings of mammography screening.
4	For me it is important to be told comprehensively about the advantages and risks of mammography screening.
5	For me it is important to comprehend what benefits I get from mammography screening.
6	For me it is important to comprehend what the screening cannot achieve.
7	For me it is important to be informed why mammography screening could be more or less reasonable for me.

**Table 4.** Need for well-being scale.

1	For me it is important to be sure that I am really healthy.
2	I would do anything to stay healthy.
3	For me it is important not to expose myself to health risks.
4	For me it is important to be psychologically and physically well.
5	For me it is important to do anything to reduce the risk of dying of breast cancer.
6	I do not want to expose myself to psychological strain.
7	I do not want to worry for no reason.

**Table 5.** Assessment of arguments about mammography screening.

1	Through early detection of a malignant tumor, it can be treated more mildly, the breast can be preserved, for example, and one can refrain from chemotherapy. <sup>a</sup>
2	A diagnostic finding may turn out to be without cause, causing tissue to be removed that later proves to be benign. <sup>b</sup>
3	A malignant tumor that would have been lethal without examination can be detected in a curable stage. <sup>a</sup>
4	A malignant tumor might be detected and treated that is not curable anymore, which would not prolong life but may prolong suffering. <sup>d</sup>

<sup>a</sup>Indicates an argument about advantages.

<sup>b</sup>Indicates an argument about disadvantages.

## Statistical Analysis

We compared the empirical values of the immersion item against the scale midpoint using a one-sample *t* test. In order to assess their internal consistencies, we calculated Cronbach alpha values of all of the scales. A basic precondition for validly testing the two hypotheses was that the needs for clarity and for well-being were actually relevant needs for our participants. In order to test the fulfilment of this precondition, we compared the empirical values against the scale midpoints using one-sample *t* tests. We compared participants' needs among the four conditions with analyses of variance (ANOVAs). To examine participants' assessment of advantages and disadvantages, we calculated paired samples *t* tests. For both attitude and decision we tested whether there were changes from the pretest to the posttest in the overall sample, applying paired samples *t* tests.

In order to test Hypothesis 1, which predicted an interaction effect of need salience and communication style on attitude change, we calculated the difference between participants' attitudes in the pretest and the posttest. Accordingly, a negatively signed value indicates a more negative attitude after the online role play than before the consultation, and a positively signed value indicates a more positive attitude than before the consultation. In order to test Hypothesis 2, which predicted an interaction effect of need salience and communication style on decision modification, we calculated the difference between participants' decisions in the pretest and the posttest. Hence, a negatively signed value indicates a stronger tendency not to participate in mammography screening after the online role play than before, and a positively signed value indicates a stronger tendency to participate after the consultation. To test Hypotheses 1 and 2 we used ANOVAs. In order to compare individual

conditions we applied least-significant-difference tests as post hoc tests.

### Ethical Considerations

This study had full ethical approval of the Leibniz-Institut fuer Wissensmedien ethics committee (approval number: LEK 2013/043). Participants were informed about privacy protection and their right to terminate participation at any time without any disadvantage. They participated voluntarily and anonymously. They were debriefed at the end of the experiment.

## Results

### Immersion

As a first step we analyzed whether the participants stated that they were able to put themselves in the fictitious consultation situation. Their rating (mean 3.74, SD 1.17) was significantly higher than the midpoint (3) of the 5-point scale:  $t_{94}=6.14$ ,  $P<.001$ ,  $d=0.63$ . This indicates that the participants were able to immerse mentally into the situation.

### Needs

The need for clarity scale had an internal consistency of  $\alpha=.74$ . The need for well-being scale had an internal consistency of  $\alpha=.76$ . The participants expressed strong needs for clarity (mean 4.57, SD 0.42) and for well-being (mean 4.21, SD 0.54) with both means being significantly higher than the midpoint (3) of the 5-point Likert scale (need for clarity:  $t_{95}=36.68$ ,  $P<.001$ ,  $d=3.74$ ; need for well-being:  $t_{95}=21.97$ ,  $P<.001$ ,  $d=2.24$ ). This finding strongly indicates that both needs of which we intended to make participants aware were real needs for them. The needs did not differ among the participants in the four experimental conditions, neither regarding the need for clarity ( $F_{3,92}=0.75$ ,  $P=.53$ ) nor regarding the need for well-being ( $F_{3,92}=0.76$ ,  $P=.52$ ).

### Assessment of Arguments

The items on advantages and disadvantages were summarized in two subscales. The advantages subscale had a good internal

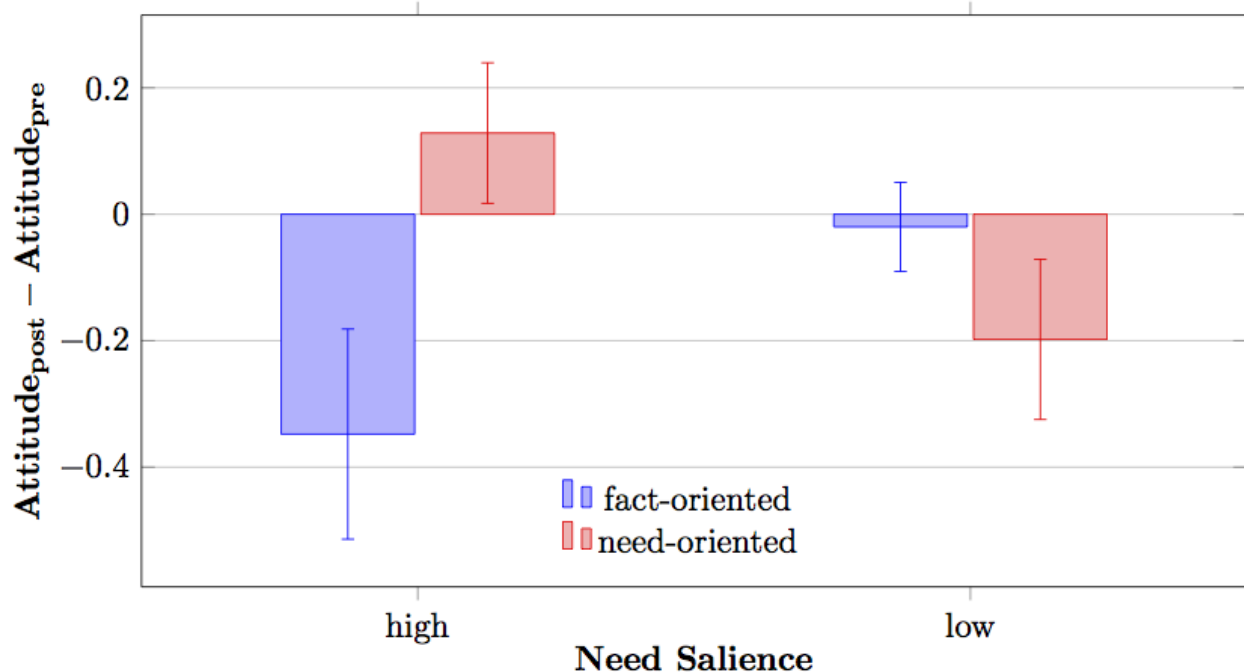
consistency of  $\alpha=.70$ . The disadvantages subscale, however, had an unacceptable internal consistency of  $\alpha=.21$ . Apparently, the two disadvantages represented quite different types of reasons for the participants. Thus, we considered the disadvantages items separately but the advantages as a scale: The participants assessed the advantages (mean 6.63, SD 0.70) to be much more important than the first disadvantage item (*tissue removal without cause*; mean 4.03, SD 1.62;  $t_{94}=15.55$ ,  $P<.001$ ,  $d_z=1.59$ ) and more important than the second disadvantage item (*prolonged suffering*; mean 4.35, SD 1.67;  $t_{95}=12.28$ ,  $P<.001$ ,  $d_z=1.26$ ).

### Attitude Change

The attitude scale had an internal consistency of  $\alpha=.75$  in the pretest and  $\alpha=.74$  in the posttest. Across all four conditions, the participants' attitudes did not differ between the pretest (mean 5.60, SD 0.86) and the posttest (mean 5.50, SD 0.96) ( $t_{95}=1.69$ ,  $P=.094$ ). However, both mean values differed significantly from the midpoint (4) of the 7-point scale (with higher values representing a more positive attitude): pretest ( $t_{95}=18.17$ ,  $P<.001$ ,  $d=1.86$ ) and posttest ( $t_{95}=15.35$ ,  $P<.001$ ,  $d=1.56$ ), indicating an overall positive attitude toward mammography screening.

As assumed in Hypothesis 1, we found a significant interaction effect of need salience and communication style on attitude change ( $F_{1,92}=7.23$ ,  $P=.009$ ,  $\eta^2=.073$ ). Those participants whose needs were salient responded to the physician's communication style, while participants without salient needs did not (see [Figure 1](#)). In the case of need-oriented communication by the physician character, those participants with salient needs showed an attitude change in a positive direction (mean 0.13, SD 0.54), while they changed their attitude in a negative direction when confronted with a purely fact-oriented communication style (mean  $-0.35$ , SD 0.80). With salient needs, communication style had a differential effect on attitude change ( $P=.007$ ), which did not occur for people without salient needs ( $P=.299$ ).

**Figure 1.** Interaction effect between communication style and need salience regarding attitude change. Standard errors are represented by error bars attached to each column.

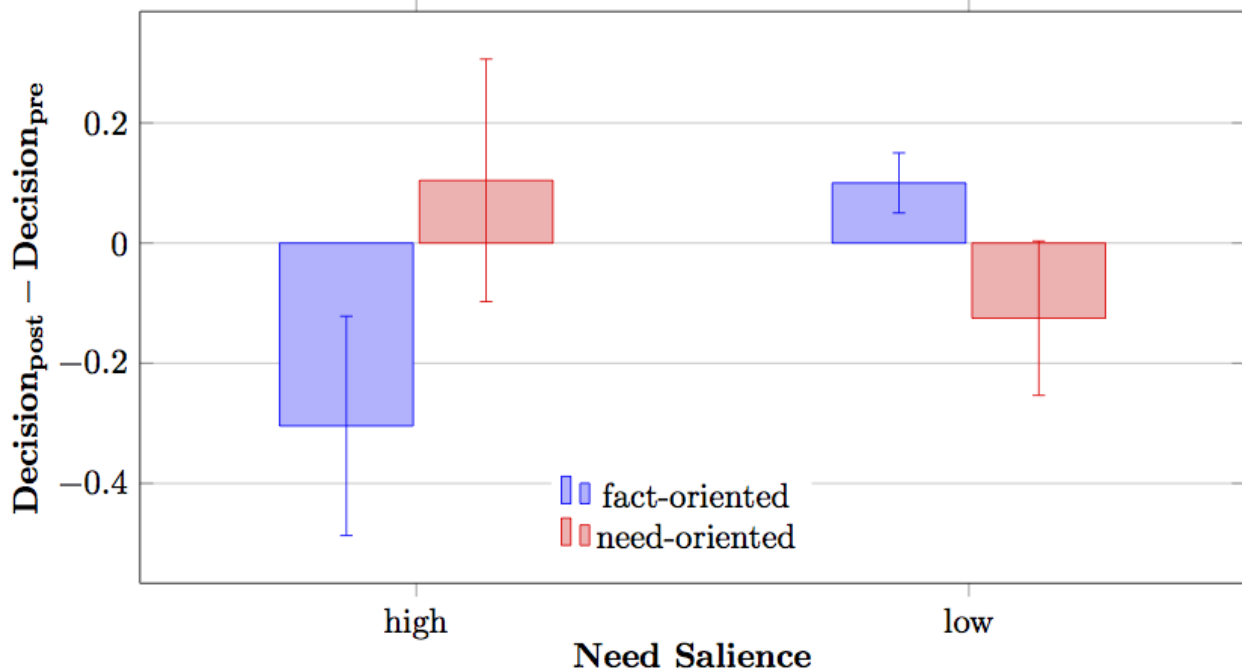


### Decision Modification

The decision scale had an internal consistency of  $\alpha=.96$  in the pretest and  $\alpha=.94$  in the posttest. Across all four conditions, the participants' decision did not differ between the pretest (mean 4.42, SD 0.94) and the posttest (mean 4.37, SD 0.92) ( $t_{95}=0.69$ ,  $P=.495$ ). However, both mean values differed significantly from the midpoint (3) of the 5-point scale (with higher values representing a stronger tendency to participate in mammography screening): pretest ( $t_{95}=14.85$ ,  $P<.001$ ,  $d=1.51$ ) and posttest ( $t_{95}=14.66$ ,  $P<.001$ ,  $d=1.49$ ), indicating an overall strong tendency to participate in mammography screening.

As assumed in Hypothesis 2, we found a significant interaction effect of need salience and communication style on decision modification ( $F_{1,92}=4.43$ ,  $P=.038$ ,  $\eta^2=.046$ ). Participants with salient needs responded to the physician's communication style in the consultation, whereas participants without salient needs did not (see Figure 2). When the physician character applied a need-oriented communication style, those participants with salient needs were more willing to participate in mammography screening after the consultation than before (mean 0.10, SD 0.99), while they were less willing to participate given a fact-oriented communication style (mean  $-0.30$ , SD 0.88). With salient needs, communication style tended to have a differential effect on decision modification ( $P=.06$ ), which we did not find for people without salient needs ( $P=.29$ ).

**Figure 2.** Interaction effect between communication style and need salience regarding decision modification. Standard errors are represented by error bars attached to each column.



## Discussion

### Principal Findings

As expected, our participants expressed strong needs for clarity and for well-being. Participants had an overall positive attitude toward mammography screening and a strong tendency to be willing to participate in that procedure. We provided them with balanced information regarding advantages and disadvantages of mammography screening during the role play, but we found that they assessed advantages of mammography screening to be more important than disadvantages. These findings are in line with other research findings showing that women often overestimate the advantages of mammography screening [53,54].

The main goal of the study was to investigate to what extent patients' attitudes toward mammography screening and their decisions whether or not to participate in that procedure were influenced by the interplay between the salience of patients' needs and a physician's ability to be more or less responsive to these needs in an online consultation. Regarding attitude change and decision modification, we found that those participants whose needs were salient in the consultation responded to the physician's communication style, while participants without salient needs did not. With a need-oriented communication style, those participants whose needs for clarity and well-being had been made salient showed an attitude change in a positive direction (corresponding to their high valuation of the advantages of mammography screening), while they changed their attitude in a negative direction when given a purely fact-oriented communication style. The same pattern of development applied to decision modification. These results are even more remarkable since the information provided in the online role play was balanced, and only one tailoring strategy

was used (a meta-analytic review [46] pointed out that tailoring using several different strategies tends to be more effective than using just one strategy). It seems that women were more sympathetic to mammography screening and its advantages regardless of the physician character's effort to provide both advantages and disadvantages of this procedure. It appears that this positive evaluation of the procedure rubbed off on the modification of their attitudes and decisions when their needs were addressed by the physician—otherwise they developed in the opposite direction.

### Limitations and Future Work

A limitation of this study is that generalization of the findings to the whole population of women and to real (online) consultations must be handled with care. We cannot be certain to what extent women would decide in the same way if they were really faced with the decision whether or not to take part in mammography screening. In addition, we cannot know from the current findings to what extent women would react the same way if they were not confronted with a purely text-based consultation but with a richer [58] online communication, allowing the transfer of more social context cues [10]. It would also be interesting to test a similar setting in a face-to-face situation, in particular since there is evidence that tailored health messages are also an effective approach in face-to-face communication [59].

Another limitation is that we focused only on the needs for clarity and for well-being. It is possible that taking other personal needs into account would yield quite different results. In future studies it would be interesting to compare attitude change and decision modification of women of differing ages and to consider other personal needs that might be relevant to medical consultation and decision-making. In addition, it would be worthwhile to take people's knowledge acquisition into



account as well, in order to test whether their decision is an informed decision based on appropriate knowledge about the risks and benefits of a medical treatment.

The automatic response system that we developed for the study reported here might not have been entirely adequate as a representation of a real online consultation. Perhaps the participants experienced the communication as artificial or felt constricted in their choices to express their concerns and requests. However, participants were able to put themselves properly into the situation. Even so, the informative value of this one-item measurement needs to be handled with care. It would be interesting to replicate this study with real synchronous online communication. This might even increase the effects reported in this article.

## Conclusions

The interaction effects of patients' need salience and physicians' communication style yield remarkable results, because they point out the importance of communicating in a need-oriented style with patients or advice seekers who are mindful of their personal needs in a given situation. When their personal needs were made salient, it seemed to be especially important to participants to have these needs met. Apparently, the needs for

clarity and for well-being were not necessarily consciously accessible and were only relevant in an online consultation situation when they were activated (ie, made cognitively accessible) in advance.

So we conclude that physicians' sensitivity to their patients' currently relevant needs is essential. This is true not only because need-oriented communication resulted for people with highly salient needs in a more positive attitude toward the content of the consultation and a higher willingness to participate, but also because ignoring the needs of those people had the opposite effects. Communication style had a particularly strong effect when needs were currently relevant but were then disregarded by the physicians. In a counselling situation, one way for a physician to become aware of the needs of patients or advice seekers is to ask them for their expectations about the consultation and a medical intervention that might potentially result. The very same approach would also raise the patients' or advice seekers' awareness of their own needs and would make these needs more salient accordingly. In this way, it is possible for health care professionals to recognize which needs are currently relevant for a patient and to address these needs in their communication.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Sequences of interactions in the online role play.

[[PNG File, 137KB - cancer\\_v1i2e10\\_app1.png](#)]

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Original Paper

# Effect of Web-Based Versus Paper-Based Questionnaires and Follow-Up Strategies on Participation Rates of Dutch Childhood Cancer Survivors: A Randomized Controlled Trial

Ellen Kilsdonk<sup>1</sup>, MSc; Eline van Dulmen-den Broeder<sup>2</sup>, PhD; Helena J van der Pal<sup>3</sup>, MD, PhD; Nynke Hollema<sup>4</sup>, MSc; Leontien C Kremer<sup>5</sup>, MD, PhD; Marry M van den Heuvel-Eibrink<sup>6</sup>, MD, PhD; Flora E van Leeuwen<sup>7</sup>, PhD; Monique W Jaspers<sup>1\*</sup>, PhD; Marleen H van den Berg<sup>2\*</sup>, PhD

<sup>1</sup>Centre for Human Factors Engineering of interactive Health Information Technology (HIT-lab), Department of Medical Informatics, Academic Medical Center, Amsterdam, Netherlands

<sup>2</sup>Department of Pediatrics, Division of Oncology-Hematology, VU University Medical Center, Amsterdam, Netherlands

<sup>3</sup>Late Effects Outpatient Clinic for Adult Survivors of Childhood Cancer, Department of Medical Oncology, Academic Medical Center, Amsterdam, Netherlands

<sup>4</sup>Dutch Childhood Oncology Group – Late Effects Registry, The Hague, Netherlands

<sup>5</sup>Department of Pediatric Oncology, Emma Children's Hospital/Academic Medical Center, Amsterdam, Netherlands

<sup>6</sup>Department of Pediatric Oncology/Hematology, Sophia Children's Hospital/Erasmus Medical Center, Rotterdam, Netherlands

<sup>7</sup>Department of Epidemiology, Netherlands Cancer Institute, Amsterdam, Netherlands

\*these authors contributed equally

**Corresponding Author:**

Ellen Kilsdonk, MSc

Centre for Human Factors Engineering of interactive Health Information Technology (HIT-lab)

Department of Medical Informatics

Academic Medical Center

PO Box 22660

Amsterdam, 1100 DD

Netherlands

Phone: 31 205666204

Fax: 31 206919840

Email: [e.kilsdonk@amc.uva.nl](mailto:e.kilsdonk@amc.uva.nl)

## Abstract

**Background:** Questionnaires are widely used in survey research, especially in cohort studies. However, participation in questionnaire studies has been declining over the past decades. Because high participation rates are needed to limit the risk of selection bias and produce valid results, it is important to investigate invitation strategies which may improve participation.

**Objectives:** The purpose of this study is to investigate the effect of Web-based versus paper-based questionnaires on participation rates in a questionnaire survey on late effects among childhood cancer survivors (CCSs).

**Methods:** A total of 750 CCSs were randomized across 3 study arms. The initial invitation in study arms 1 and 2 consisted of a Web-based questionnaire only, whereas in study arm 3 this invitation was complemented with a paper-based version of the questionnaire. The first postal reminder, sent to the nonresponding CCSs in all 3 study arms, consisted of either a reminder letter only (study arms 1 and 3) or a reminder letter complemented with a paper-based questionnaire (study arm 2). The second postal reminder was restricted to CCSs in study arms 1 and 2, with only those in study arm 1 also receiving a paper-based questionnaire. CCSs in study arm 3 received a second reminder by telephone instead of by mail. In contrast to CCSs in study arm 3, CCSs in study arms 1 and 2 received a third reminder, this time by telephone. Results: Overall, 58.1% (436/750) of the CCSs participated in the survey. Participation rates were equal in all 3 study arms with 57.4% (143/249) in arm 1, 60.6% (152/251) in arm 2, and 56.4% (141/250) in arm 3 ( $P=.09$ ). Participation rates of CCSs who received an initial invitation for the Web-based questionnaire only and CCSs who received an invitation to complete either a paper-based or Web-based questionnaire did not differ ( $P=.55$ ). After the first postal reminder, participation rates of CCSs invited for the Web-based questionnaire only also did not differ compared with CCSs invited for both the Web-based and paper-based questionnaires ( $P=.48$ ). In general, CCSs preferred the



paper-based over the Web-based questionnaire, and those completing the paper-based questionnaire were more often unemployed ( $P=.004$ ) and lower educated ( $P<.001$ ).

**Conclusion:** Invitation strategies offering a Web-based questionnaire without a paper-based alternative at first invitation can be used without compromising participation rates of CCS. Offering the choice between paper- and Web-based questionnaires seems to result in the highest accrual participation rate. Future research should look into the quality of the data delivered by both questionnaires filled in by respondents themselves.

**Trial Registration:** International Standard Randomized Controlled Trial Number (ISRCTN): 84711754; <http://www.controlled-trials.com/ISRCTN84711754> (Archived by WebCite at <http://www.webcitation.org/6c9ZB8paX>)

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## KEYWORDS

childhood cancer survivors; follow-up strategies; participation rates; questionnaires; questionnaire mode

## Introduction

Owing to better stratification and advances in treatment regimens, childhood cancer survival rates have substantially increased in recent decades, resulting in a growing absolute number of childhood cancer survivors (CCSs). At present, approximately 75-80% of patients are expected to survive at least 5 years postdiagnosis [1]. Unfortunately, childhood cancer and its treatment can significantly impair long-term health and cause substantial excess morbidity [2-4] and mortality [5-9] even many years after treatment.

To gain insight into the long-term outcomes of children with cancer, patient-reported outcomes collected by questionnaires are essential. In the Netherlands, the Dutch Childhood Oncology Group Late Effects Group (DCOG LATER) initiated the “DCOG LATER” study, a nationwide study investigating late effects among these patients. As part of this retrospective cohort study, CCSs will be asked to complete a general health and lifestyle questionnaire to identify late effects not yet recognized and to define CCSs groups at high risk of developing such late adverse effects. In such studies, high participation rates are crucial for the validity of the results [10]. However, participation rates in questionnaire studies have been declining over the past 30 years, mainly due to an increase in the proportion of individuals declining participation or not responding at all [11]. Several studies have shown that participation rates of CCSs invited to questionnaire studies vary between 50% and 90% [12-19].

One proven way of increasing participation rates is to use reminders by regular mail or telephone calls [20-23]. In addition, recent studies have shown that using paper-based as well as Web-based questionnaire modes in the same study might increase response rates [11,23,24]. Web-based questionnaires are preferred by investigators because there are no printing and mailing costs involved and the time spent on data entry is minimized [25]. However, it is known that participant characteristics may influence the questionnaire mode preferred by participants [11,23,25,26]. For example, men tend to respond to Web-based questionnaires at a higher rate than women [25,27] and older participants seem to prefer paper-based over Web-based questionnaires [11,27-29]. A mixed-mode rather than a single mode design may overcome these limitations by

providing survivors the opportunity to choose their preferred mode [23].

Other childhood cancer survivor studies have raised concerns about selection bias due to nonparticipation of CCSs not suffering from late effects [7,10,30,31]. High participation rates are required to limit the risk of selection bias and increase statistical power. Therefore, it is important to evaluate which invitation strategy leads to the highest participation rate; however, current studies focused on strategies to improve participation of CCSs in questionnaire surveys are lacking. The purpose of this study is to answer 2 questions. The first is do participation rates of CCSs who are invited to complete a Web-based questionnaire only differ from CCSs who are invited to complete either a Web-based or paper-based questionnaire? And second, what is the effect of adding a paper-based questionnaire to a postal reminder on participation rates? In addition, the reasons for nonparticipation, differences in participants' questionnaire mode preferences, and their satisfaction with the different questionnaire modes was addressed. In this trial, CCSs were randomized to 1 of 3 study arms with different questionnaire modes and reminders.

## Methods

### Eligible Population

This study was conducted in 3 of the 7 Dutch Pediatric Oncology Centers (EKZ/AMC Amsterdam, Erasmus MC Rotterdam, and VUmc Amsterdam). Ethical Review Board approval was obtained in each participating center. We randomly selected 750 adult CCSs from the DCOG LATER cohort, which includes patients diagnosed with a malignancy (or a few specific benign disorders) before the age of 18 years between January 1, 1962, and December 31, 2001, alive 5-years postdiagnosis, and treated in one of the 7 Dutch pediatric oncology and stem cell transplant centers. Inclusion criteria for this study was CCSs currently alive, aged 18 years or older, and living in the Netherlands.

### Study Design

CCSs were randomly allocated to 1 of 3 study arms in a 1:1:1 ratio using computer software (jQuery version 7). Stratified sampling was used to achieve balanced representation of subgroups defined by gender and study center. The invitation strategies which were used in the different study arms combined 2 questionnaire modes and 2 reminder strategies (Table 1). In

the first reminder strategy (study arms 1 and 2), 2 postal reminders and 1 telephone reminder followed the initial invitation, whereas in the second reminder strategy (study arm 3), only 1 postal reminder and 1 telephone reminder followed the initial invitation, with a period of 3 weeks between each

reminder. Invitations and reminders were sent during September 2012 and June 2013. Questionnaires of CCSs were accepted until September 1, 2013, so that the study lasted exactly 1 year (International Standard Randomized Controlled Trial Number 84711754).

**Table 1.** Study arms.

	Study arm 1 n=249	Study arm 2 n=251	Study arm 3 n=250
Initial invitation	Web-based questionnaire	Web-based questionnaire	Web- and paper-based questionnaire
First reminder (after 3 weeks, in case of no response to initial contact)	Web-based questionnaire	Web- and paper-based questionnaire	Web based and option to apply for new paper-based questionnaire
Second reminder (after 3 weeks, in case of no response to 1st reminder)	Web- and paper-based questionnaire	Web-based and option to apply for new paper-based questionnaire	Telephone contact
Third reminder	Telephone contact	Telephone contact	

All CCSs received a postal package including a cover letter signed by the local physician responsible for CCSs follow-up care in which the login procedure for the Web-based questionnaire was explained and login details were given. In addition, an information sheet on the DCOG LATER study, an information sheet on the questionnaire study, an informed consent form, a refusal form for declining participation, and a prestamped return envelope were included. On the informed consent form an additional option was depicted to ask consent for linking data from the questionnaire to medical registries and information from the general practitioner (GP). On the refusal form, CCSs were asked if they could be contacted for a shortened telephone survey to ascertain baseline characteristics and health status and to ask consent for medical record release to collect information from a survivors' GP or other treating physician and medical registries.

Paper-based questionnaires were added to the invitation at various time points depending on the study arm. CCSs either received the paper-based questionnaire at first contact (study arm 3), second contact (study arm 2), or third contact (study arm 1). All CCSs receiving the Web-based questionnaire at any of the time points had the option to apply for a copy of the paper-based questionnaire by contacting the study coordinator through email or telephone. The study coordinator also followed up the CCSs via phone calls (telephone reminders), which were performed at various time points (morning, afternoon, evening) and days. In case of a successful contact, CCSs were asked if they were willing to complete the questionnaire, either on paper or through the Internet. Survivors also had the option to complete a shortened telephone survey of 16 questions instead of completing the entire questionnaire. In case they indicated that they were not willing to participate, they were requested to return the refusal form.

If a survivor responded to the study invitation or one of the reminders, the survivor was considered a responder. If there was no response whatsoever, the survivor was considered a nonresponder. Responding CCSs could be further divided into participants and nonparticipants. A survivor was considered a participant when the paper- or Web-based questionnaire (with at least two thirds of the questions completed) was sent back.

Nonparticipants included CCSs responding by answering the shortened telephone survey or by returning the refusal form with or without consent for medical record release.

CCSs who completed the telephone survey or returned the refusal form were asked about their reasons for not participating. CCSs had the option to choose between one or more of the following options: (1) I have already participated in many studies, (2) I do not want to be confronted with the past, (3) I think the questionnaire is too long, (4) I find the information about the study unclear, (5) I have no time to fill out the questionnaire, (6) I have no interest in this study, and (7) other reasons.

### Questionnaire

A paper- and Web-based questionnaire for CCSs were developed to collect information on general health and lifestyle. Both similarly collected information on education, socioeconomic status, medical history, disease symptoms, medication use, lifestyle, and quality of life. Different versions were used for male and female CCSs to account for differences in questions about reproduction and sexuality. The questionnaires for male and female contained 97 and 112 questions, respectively. The paper- and Web-based questionnaires were identical in number, type, wording, and order of questions posed. In the paper-based version, CCSs were explicitly instructed where they were allowed to skip questions that were not relevant to them (based on specific answers). In the Web-based version, these questions were automatically skipped. In general, it was possible for CCSs to leave questions open. Survivors had the option to save and log out of the Web-based questionnaire, and to log in again at another time. The time to complete the questionnaire was estimated to be 30 minutes.

To assess satisfaction of CCSs with the questionnaire, 4 questions were added to the standard questionnaire. The first question inquired the reason for choosing the paper-based instead of the Web-based questionnaire and vice versa. Furthermore, it was inquired whether any questions in the questionnaire had been difficult to answer and how much time it took to complete the questionnaire. Finally, CCSs were asked to indicate their agreement with 5 statements concerning their

satisfaction with the questionnaire, which they had to answer on a Likert scale from 1 (strongly disagree) to 5 (strongly agree).

### Data Analysis

Data were analyzed using the statistical program R (version 2.15.1). Descriptive statistics were used to describe (1) differences between CCSs allocated to the different study arms, (2) response characteristics with respect to the different study arms, reminders, and questionnaire modes, (3) reasons for not participating, (4) participant characteristics in relation to questionnaire mode preference, and (5) participants satisfaction with the paper- and Web-based questionnaire. It was determined whether these differences were statistically significant using Kruskal-Wallis tests for continuous data and Pearson chi-square tests for categorical data. As the randomization to study arms was stratified by center, it was important to take the clustering of CCSs within centers into account [32]. Hence, for each Kruskal-Wallis and Pearson chi-square test, test statistics and associated degrees of freedom for each single center were calculated. The results were summed and *P* values were obtained using the summed test statistics and a chi-square distribution with the summed degrees of freedom [33]. *P* values less than .05 were regarded as statistically significant. However, for post hoc tests on all pairs of differences between the 3 arms of the study, the Bonferroni correction was implemented and *P* values less than .0167 (0.05/3) were regarded as statistically significant [34]. The agreement of CCSs to 5 different statements on a 5-point Likert scale were categorized into the following 3 categories: “Agree” with the statement (points 4 and 5), “Neutral” (point 3), or “Disagree” (points 1 and 2).

CCSs who completed the questionnaire were inquired on their highest achieved educational level. The International Standard Classification of Education (ISCED) was used to classify educational level [35]. The ISCED comprises 8 educational levels, which were further categorized to low (early childhood education, primary education, lower secondary education, ISCED levels 0-2), medium (upper secondary education, postsecondary nontertiary education, short-cycle tertiary education, ISCED levels 3-5), and high (bachelor or equivalent education, masters or equivalent education, doctoral or equivalent education, ISCED levels 6-8).

## Results

Overall, 750 survivors were randomly selected from a total of 2958 eligible adult CCSs from the 3 participating centers. The sociodemographic and treatment-related characteristics of the survivors in each of the 3 study arms are shown in Table 2. The randomization, stratified by gender and study center, resulted in representative cohorts in the study arms.

### Participation Rates per Study Arm

The participation rates for all contact moments in each study arm are summarized in Figure 1. Overall, 58.1% of CCSs (436/750) completed the questionnaire, and participation rates were similar in all study arms with 57.4% (143/249) in study arm 1, 60.6% (152/251) in study arm 2, and 56.4% (141/250) in study arm 3 (*P*=.09).

In study arm 1, 64 (25.7%, 64/249) CCSs completed the Web-based questionnaire after the initial invitation. Nonresponding CCSs were reminded by a postal letter to complete the Web-based questionnaire, after which an additional 49 (19.7%, 49/249) completed the questionnaire. The second reminder consisted of a mixed-mode invitation (containing both the Web- and paper-based questionnaires). An additional number of 21 CCSs (8.4%, 21/249) completed the questionnaire after this reminder. A final telephone contact yielded an additional participation of 9 (3.6%, 9/249). Overall, 143 (57.4%, 143/249) CCSs completed the questionnaire, with 35 (14.1%, 35/249) completing the paper-based questionnaire and 108 (43.4%, 108/249) completing the Web-based questionnaire.

In study arm 2, 75 (29.9%, 75/251) CCSs completed the Web-based questionnaire after the initial invitation. Nonresponding CCSs received a mixed mode invitation as a first postal reminder. An additional 38 (15.1%, 38/251) CCSs completed the questionnaire after this reminder. Nonresponding CCSs received an additional second postal reminder following which 27 (10.8%, 27/251) CCSs completed the questionnaire. After a final telephone call, an additional 12 (4.8%, 12/251) CCSs completed the questionnaire. In total, 152 (60.6%, 152/251) CCSs completed the questionnaire, with 60 (23.9%, 60/251) CCSs completing the paper-based questionnaire and 92 (36.7%, 92/251) CCSs the Web-based questionnaire.

CCSs in study arm 3 initially received a mixed-mode invitation. After this invitation, 60 (24.0%, 60/250) CCSs completed the questionnaire. Nonresponding CCSs received a postal reminder, after which 51 more CCSs (20.4%, 51/250) completed the questionnaire. In addition, 30 (12.0%, 30/250) CCSs completed the questionnaire after telephone contact. A total number of 141 (56.4%, 141/250) CCSs participated, 101 (40.4%, 101/250) CCSs by completing the paper-based questionnaire and 40 (16.0%, 40/250) CCSs by completing the Web-based questionnaire.

In total, we attempted to contact 261 CCSs through a telephone reminder. Of these CCSs, we were unable to reach 67 CCSs (25.7%, 67/261) from all attempted reminders; and 38.5% (67/174) of CCSs remained nonresponders at the end of study. Approximately 40 hours were spent calling these CCSs (telephone reminder) with an average of 3 attempts per survivor (approximately 783 in total) and 3 minutes per attempt.

**Table 2.** Sociodemographic and treatment-related characteristics of the CCSs in each study arm.

Characteristic	Study arm 1	Study arm 2	Study arm 3
Number of survivors, n	249	251	250
Median current age (years), range	29 (18-58)	30 (18-61)	31 (18-60)
Median age at childhood cancer diagnosis (years), range	6 (0-17)	6 (0-17)	6 (0-17)
Median time since diagnosis (years), range	23 (10-46)	23 (10-49)	23 (10-49)
<b>Gender, n (%)</b>			
Male	122 (49.0)	127 (50.6)	124 (49.6)
Female	127 (51.0)	124 (49.4)	126 (50.4)
<b>Study center, n (%)</b>			
EKZ/AMC	114 (45.8)	111 (44.2)	112 (44.8)
Erasmus MC	80 (32.1)	83 (33.1)	82 (32.8)
VUmc	55 (22.1)	57 (22.7)	56 (22.4)
<b>Diagnosis, n (%)</b>			
Central nervous system tumor	31 (12.5)	38 (15.1)	38 (15.2)
Leukemia	77 (30.9)	66 (26.3)	58 (23.2)
Lymphoma	41 (16.5)	43 (17.2)	48 (19.2)
Renal tumor	27 (10.8)	38 (15.1)	32 (12.8)
Other	73 (29.3)	66 (26.3)	74 (29.6)
Chemotherapy, n (%)	199 (79.9)	187 (74.5)	191 (76.4)
Radiotherapy, n (%)	95 (38.2)	86 (34.3)	98 (39.2)
Surgery, n (%)	162 (65.1)	176 (70.1)	174 (69.6)
Other therapy, n (%)	135 (54.2)	129 (51.4)	128 (51.2)
Recurrence of disease, n (%)	39 (15.7)	30 (12.0)	31 (12.4)
Recent visit to late effect outpatient clinic (<2 years), n (%)	87 (34.9)	103 (41.0)	98 (39.2)

### Effect of Mixed-Mode Questionnaires on Participation Rates

At the initial invitation, the Web-only invitation group consisted of all CCSs in study arms 1 and 2, and the CCSs in study arm 3 received a mixed mode invitation. Although the proportion of participants after initial invitation was lowest in study arm 3, it was not significantly different compared to study arms 1 and 2 (24.0% and 27.8%, respectively,  $P=.55$ ). To investigate the effect of adding a paper-based questionnaire to a postal reminder on participation rates, we compared the Web-only invitation group consisting of CCSs in study arm 1 with the mixed-mode invitation group consisting of CCSs in study arm 2. CCSs in study arm 3 were excluded from these analyses because they had already received the paper-based questionnaire with the initial invitation. Results show that the proportion of participants was not significantly different between the Web-only and mixed mode invitation group after the first postal reminder (19.7% in study arm 1 and 15.1% in study arm 2,  $P=.48$ ). When receiving the mixed-mode invitation, in all study arms more CCSs preferred completing the paper-based

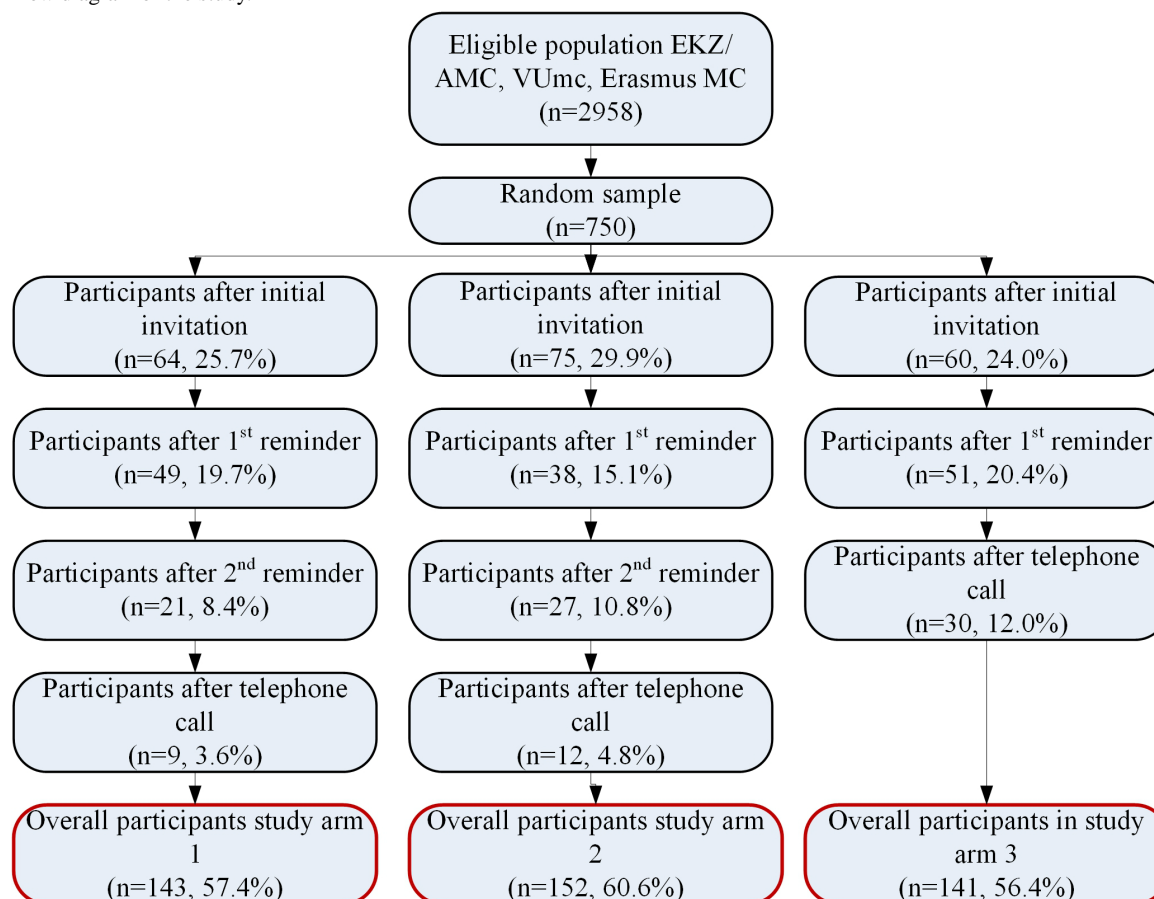
questionnaire over the Web-based questionnaire (17.2% vs 6.8% in study arm 3, 10.4% vs 4.8% in study arm 2, and 5.2% vs 3.2% in study arm 1).

### Characteristics of Nonparticipants

The number of nonparticipants across all study arms was 140 CCSs (18.7%, 140/750). The number of nonparticipants was highest in study arm 1 (21.3%, 53/249) compared with 18.7% (47/251) and 16.0% (40/250) in study arms 2 and 3, respectively. The proportion of nonparticipants did not differ significantly across study arms. There were 29 (3.9%, 29/750) CCSs who did complete a short telephone questionnaire, 50 (6.7%, 50/750) CCSs who provided consent for medical record release only, and 61 (8.1%, 61/750) CCSs who refused participation altogether.

The reasons for nonparticipation are shown in Table 3. There were 2 main reasons for nonparticipation: CCSs did not want to be confronted with their past (26.4%, 37/140) and/or they indicated to have already participated in many other studies in the past (24.3%, 34/140). Another important reason was that CCSs found the questionnaire too long (10.7%, 15/140).



**Figure 1.** Flow diagram of the study.**Table 3.** Reasons for declining to complete the questionnaire (N=140).

Reasons	Telephone survey or refusal, n (%)
Unknown	18 (12.9)
I do not want to be confronted with the past	37 (26.4)
I have already participated in many studies	34 (24.3)
I think the questionnaire is too long	15 (10.7)
I have no time to fill out the questionnaire	11 (7.9)
I have no interest in this study	11 (7.9)
I have had bad experiences in the past with research/care	6 (4.3)
I am currently unable to fill out the questionnaire	5 (3.6)
The answers to the questions are already available at the clinic	4 (2.9)
I am unable to answer the questions due to a mental handicap	4 (2.9)
I find the information about the study unclear	0 (0.0)

### Questionnaire Mode Preferences

The differences in characteristics of the survivors completing the paper-based questionnaire compared to survivors completing the Web-based questionnaire are shown in Table 4. Gender, age at start of the study, age at diagnosis, years since diagnosis,

follow-up center, diagnosis, treatment, marital status, and whether or not the survivor had recently visited a follow-up clinic did not have a significant effect on the survivors' choice of questionnaire mode. CCSs who completed the paper-based questionnaire were more likely to be unemployed (20.9% vs 10.5%,  $P = .015$ ) and lower educated (17.9% vs 7.1%,  $P = .008$ ).



**Table 4.** Differences in participant characteristics between paper-based and web-based questionnaires.

	Paper-based questionnaire	Web-based questionnaire	<i>P</i> value
Survivors, n	196	240	
Median age, range	30 (18-61)	31 (18-57)	.73
Median age at diagnosis, range	6 (0-17)	6 (0-17)	.88
Median number of years since diagnosis, range	23 (10-49)	23 (11-45)	.52
<b>Gender, n (%)</b>			.96
Male	93 (47.4)	109 (45.4)	
Female	103 (52.6)	131 (54.6)	
<b>Follow-up center, n (%)</b>			
AMC	104 (53.1)	104 (43.3)	
Erasmus	50 (25.5)	84 (35.0)	
VUmc	42 (21.4)	52 (21.7)	
<b>Diagnosis, n (%)</b>			.40
Central nervous system tumor	26 (13.3)	24 (10.0)	
Leukemia	50 (25.5)	57 (23.8)	
Lymphoma	39 (19.9)	48 (20.0)	
Renal tumor	29 (14.8)	38 (15.8)	
Other	52 (26.5)	73 (30.4)	
Chemotherapy, n (%)	153 (78.1)	192 (80.0)	.91
Radiotherapy, n (%)	81 (41.3)	90 (37.5)	.40
Surgery, n (%)	133 (67.9)	173 (72.1)	.73
Other therapy, n (%)	104 (53.1)	124 (51.7)	.81
Recurrence of disease, n (%)	26 (13.3)	33 (13.8)	.70
Recent visit to late effect outpatient clinic (<2 years), n (%)	92 (46.9)	99 (41.2)	.76
<b>Marital status, n (%)</b>			.28
Single	72 (36.7)	77 (32.1)	
In a relationship	68 (34.7)	85 (35.4)	
(Ever) Married	56 (28.6)	78 (32.5)	
<b>Employment status, n (%)</b>			.02
Student	29 (15.2)	45 (18.8)	.83
Employed	122 (63.9)	169 (70.7)	.24
Unemployed	40 (20.9)	25 (10.5)	.015
Unknown	5	1	
<b>Educational level, n (%)</b>			.001
Low <sup>a</sup>	35 (17.9)	17 (7.1)	.008
Medium <sup>b</sup>	107 (54.6)	135 (56.2)	.67
High <sup>c</sup>	54 (27.6)	88 (36.7)	.04

<sup>a</sup>Low educational level: ISCED levels 0 to 2.<sup>b</sup>Medium educational level: ISCED levels 3 to 5.<sup>c</sup>High education level: ISCED levels 6 to 8.

There were 248 participating CCSs who had received a mixed-mode invitation with the initial invitation (56.9%, 141/248; study arm 3) or with one of the reminders (43.1%, 107/248; study arms 1 and 2) (Figure 1). Furthermore, 27 (3.6%, 27/750) CCSs who received a Web-only invitation requested the paper-based questionnaire from the study personnel; among these 27, 4 (14.8%) CCSs had also completed the Web-based questionnaire. A total of 275 CCSs thus had the choice to complete either the paper- or Web-based questionnaire. Of these, 79 (28.7%, 79/275) chose to complete the Web-based questionnaire compared to 196 (71.3%, 196/275) who chose the paper-based questionnaire. These CCSs were also asked about their reason for choosing the particular questionnaire mode (see [Multimedia Appendix 1](#)). The question was not answered by 8 CCSs (4 who completed the paper-based questionnaire and 4 who completed the Web-based questionnaire). For both paper- and Web-based questionnaires, the main reason was that CCSs found the questionnaire mode easier to use: 62.0% (119/192) of CCSs completed the paper-based questionnaire and 84% (63/75) completed the Web-based questionnaire. Other reasons for those CCSs who completed the paper-based questionnaire include practical reasons (14.6%, 28/192) and length of the questionnaire (9.4%, 18/192). For those CCSs who chose the Web-based questionnaire additional reasons were that they did not need to leave the house to go to the mailbox to send the questionnaire (25%, 19/75) and because of the length of the questionnaire (15%, 12/75).

### Questionnaire Satisfaction

Results show that, after correction for educational level, CCSs completing the Web-based questionnaire more often indicated that the questions were difficult to answer compared to CCSs completing the paper-based questionnaire (74.3% vs 62.8%,  $P=.02$ ). Furthermore, CCSs spent more time (42.6 vs 37.7 minutes,  $P=.05$ ) completing the Web-based questionnaire than the paper-based questionnaire. Although this trend was not statistically significant, when CCSs were asked whether they preferred to complete the other questionnaire mode next time, 18% (31/177) of participants of the paper-based questionnaire answered affirmatively, as compared to 10% (23/236) of participants of the Web-based questionnaire ( $P=.08$ ). The proportion of survivors agreeing on statements assessing CCS's satisfaction with the questionnaire for both questionnaire modes is summarized in [Multimedia Appendix 2](#).

## Discussion

### Principal Findings

This is one of the first studies examining the influence of Web-based versus paper-based questionnaire on participation rates of CCS. Although the study had sufficient power to detect a difference of 15%, no differences in participation rates were found between the 3 study arms. The results also showed no difference in participation rates of CCSs who received an initial invitation for the Web-based questionnaire only versus CCSs who received an initial invitation to complete either a paper- or Web-based questionnaire. Furthermore, adding a paper-based questionnaire to a first postal reminder did also not result in

higher participation rates compared to a reminder consisting of a Web-based questionnaire only.

In addition, when offered the choice to complete either the paper- or the Web-based questionnaire, most CCSs chose to complete the paper-based questionnaire. Furthermore, a significantly larger proportion of unemployed and/or low educated CCSs completed the paper-based questionnaire, although these results may have been influenced by different reminder strategies used in the different study arms. Most CCSs preferred the paper-based over the Web-based questionnaire as they considered the paper-based questionnaire more easy to use (60.7%, 119/192), yet the same reason was given by CCSs who completed the Web-based questionnaire (80%, 63/75). However, CCSs completing the Web-based questionnaire more often rated questions difficult to answer (74.3%, 176/237) compared to CCSs completing the paper-based questionnaire (62.8%, 118/188) and they also took on average 5 minutes more to complete the questionnaire.

### Comparisons With Other Studies

Previous questionnaire studies conducted among CCSs have yielded participation rates between 50% and 90% [12-19]. The overall participation rate in this study was within this range, and although we consider it rather low (58.1%, 436/750), it is in line with recent trends in epidemiological studies [11]. Decreases in participation rates in these types of studies can partly be explained by an increase of individuals explicitly declining participation. In this study, 140 invited CCSs (18.7%, 140/750) declined to complete the questionnaire, compared with about 5% in previous studies among CCSs [36,37]. An explanation for the increase in individuals declining participation is that there has been an increase in the number of requests to participate in scientific research for individuals over the past decades [11]. This increasing number of requests may become an intrusion on personal lives, limiting the willingness of individuals to participate. A quarter of the CCSs declining participation in this questionnaire study indicated that the reason for declining is that they had already participated in many other studies or that they did not want to be confronted with their past. It is conceivable that this leads to participation bias as evidence points out that individuals are much more likely to participate when the study concerns a topic which they consider of great importance to their lives [11]. As such, CCSs not suffering from severe late effects or having bad experiences with medical follow-up may be less inclined to participate in research on long-term effects, which would most certainly lead to an overestimation of the prevalence of late effects among the CCSs population [30]. Fortunately, in the Netherlands, obtaining information about nonresponders is allowed. As such, we are currently gathering data on health status and risk factors of nonresponding CCSs and CCSs that consented for medical record release by sending a questionnaire to their GP. This GP questionnaire will make it possible to compare outcome measures of the questionnaire among different response categories, except for CCSs declining participation and medical record release (8.1%, 61/750). Because data on nonparticipants are usually lacking, this will provide unique opportunities to measure and quantify selection bias.

Edwards et al [21] reviewed randomized controlled trials assessing methods to increase participation rates of paper-based and Web-based questionnaires. The probability of participation increased by more than a quarter with a follow-up contact after the initial invitation. In our study, we found a similar increase in participation rates with, on average, a 25% increase after the first postal reminder and an overall increase of 20% after the second postal and third telephone reminder. Although a combined strategy of postal and telephone reminders substantially improved CCSs participation rates, caution should be taken when interpreting results as different questionnaire modes were used within the study arms.

Previous studies showed ambiguous results regarding participants' preferences for questionnaire modes. In a meta-analysis by Shih et al [23], higher participation rates of participants were found for paper-based than for Web-based questionnaires. However, no differences in participation rates were found between these questionnaire modes when offered in a mixed-mode invitation. In a recent study by Van den Berg et al [24], no differences were found in participation rates of female CCSs invited to complete either a paper- or a Web-based questionnaire. However, the CCSs who were invited through a paper-based questionnaire preferred completing the paper-based over the Web-based version. Our study confirms these results, although this study also showed that offering a paper-based questionnaire with a reminder contact ultimately does not influence the participation rate. In general, CCSs prefer to complete a study questionnaire on paper, even at a relatively young age, where a tendency toward preferring Web-based questionnaires was expected [11,27,29]. This may be explained by the fact that the questionnaire used in this study contained multiple questions on a medical history, requiring CCSs to take the questionnaire to their parents' home for further inquiries; a paper-based version may be more suited for this purpose.

One concern with using multiple modes for data collection is the possibility that the results from different data collection modes are not comparable because participants across modes differ in certain characteristics [25,27,38]. It is thus important to investigate potential differences in participant characteristics opting for different questionnaire modes. Previous studies have shown that gender, age, educational level, and socioeconomic status can influence questionnaire mode preferences [11,24,25,27-29,38,39]. Participants of Web-based questionnaires more often are male, younger, higher educated, and employed. In this study, a lower proportion of unemployed and low educated CCSs completed the Web-based questionnaire compared with the paper-based questionnaire. One explanation for this finding may be that CCSs suffering from severe cognitive late effects, such as brain tumor or central nervous system-irradiated leukemia survivors, need help from a parent or other relative in completing the questionnaire. In 63% (32/51) of the low educated and 46% (30/65) of the unemployed survivors, a third party had indeed supported them in completing the questionnaire, whereas only 16% (62/380) of the higher educated and 18% (64/360) of the employed CCSs were assisted by a parent or relative. Hence, it seems that a paper-based questionnaire is more suitable when completing the questionnaire with help of other persons. Another explanation

could be the lack of access of lower educated or unemployed CCSs to a computer or the Internet. In general, higher educated and employed people more often have access to the Internet at home than less educated, unemployed persons [40]. In this study, a higher proportion of low educated and unemployed CCSs from the Web-only group contacted the study office to request a paper-based questionnaire because they did not have regular access to a computer or the Internet. Of the participants, 11.9% (52/436) had a low education and 14.9% (65/436) is unemployed. There were 27 CCSs who had received an invitation to complete the Web-based questionnaire only and requested a paper-based questionnaire. Of those, 15% (5/27) completed the Web-based questionnaire anyway. Out of the 23 CCSs who completed the paper-based questionnaire, 26% (6/23) had a low education and 36% (8/23) were unemployed (4%, 1/23, unknown), which are higher than the percentages of low educated and unemployed in the participant group.

### Limitations

There are a number of factors limiting the generalizability of our study results to patient populations other than CCSs. First, the most ideal study design to evaluate the effectiveness of a combination of follow-up strategies and paper- versus Web-based questionnaires would have been a sequential multiple assignment randomized trial [41]. However, because our study was set up as a pilot study aiming to determine the most appropriate invitation strategy for the entire Dutch cohort of survivors, the decision for choosing the current certain study design was mostly based on practical considerations. By choosing a study design as mentioned above we would have to include even more study arms and a larger study group, thereby hampering the goal of this study to select the most appropriate strategy for the entire Dutch cohort.

Second, the CCSs population is a unique study population often confronted with (severe) long-term side effects, varying in need and type of follow-up care from other patient populations. Therefore, their involvement in research studies may differ from other patient populations. In addition, some CCSs in our study had already been frequently invited for scientific research in the past decade. This can be an advantage, because CCSs know what to expect, but it could also hamper the study as CCSs are less willing to participate due to the high frequency of such studies. The latter is an important issue for research groups that initiate nationwide late effects studies. Third, current CCSs represent a relatively young cohort, although the CCSs population will grow and age over the next decades. Fourth, this study was conducted among Dutch CCSs living in the Netherlands at the time of the study. Although Internet access at home is growing across European countries and the United States [42], the Netherlands is among the countries with the highest access rates [40]. This could have led to a relatively high proportion of participants that completed the Web-based questionnaire, making it difficult to generalize results to CCSs populations in other countries. Fifth, apart from an invitation to complete the questionnaire, CCSs were also asked to give consent to link questionnaire data with medical registries and GP information, which may potentially have influenced the participation rate.

CCSs represent a relatively young and mobile patient group [7], resulting in conceivably frequent changes in home address. Current addresses of CCSs in this study were all traced through the municipal registry system, but to trace CCSs telephone numbers we had to rely on data from the medical patient records from the participating long-term follow-up clinics. As such, we were unable to contact about one-third of the nonresponders by telephone because the telephone numbers appeared to be no longer in use (32%, 17/53 of nonresponders in study arm 1; 44%, 23/52 in study arm 2; and 38%, 26/69 in study arm 3).

Although we analyzed the effect of different questionnaire modes in combination with various follow-up strategies, there are other ways to improve participation rates of CCSs in questionnaire studies. For instance, it is known that prenotification of a study and incentives could further increase participation rates [43-45]. As participation rates may further decline in the coming years, future studies investigating other invitation and follow-up strategies to increase participation are of great importance.

## Conclusions

In this study, we found that invitation strategies offering a Web-based questionnaire without a paper-based questionnaire at the first invitation can be used without compromising participation rates of CCS. Research into invitation strategies that improve participation rates is important to limit the risk of selection bias and to increase statistical power. However, even if high participation rates are acquired, the results may still be subject to participation bias, as each invitation strategy has its own underlying self-selection mechanism. We showed that CCSs who were offered the choice between paper- and Web-based questionnaires preferred the paper-based questionnaire, especially those with lower education levels and being unemployed. Nevertheless, offering the choice between paper- and Web-based questionnaires will probably lead to the highest accrual participation rate. The results of this study are of great importance for gaining insight into selecting the best method for the accrual of CCSs in questionnaire-based studies and will be used to determine the strategy for the nationwide questionnaire survey of the DCOG LATER study. In further research, we will focus on investigating selection bias in the DCOG LATER questionnaire study.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Reasons for completing the paper- or Web-based questionnaire.

[PDF File (Adobe PDF File), 180KB - [cancer\\_v1i2e11\\_app1.pdf](#) ]

## Multimedia Appendix 2

Proportion of CCS agreeing on statements regarding satisfaction with the questionnaire.

[PDF File (Adobe PDF File), 180KB - [cancer\\_v1i2e11\\_app2.pdf](#) ]

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**Abbreviations**

**CCS:** childhood cancer survivor

**DCOG LATER:** Dutch Childhood Oncology Group Late Effects Group

**EKZ AMC:** Emma Children's Hospital Academic Medical Center

**Erasmus MC:** Erasmus Medical Center

**GP:** general practitioner

**VUmc:** Free University Medical Center

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