Supportive Care in Cancer (2025) 33:444
https://doi.org/10.1007/s00520-025-09478-7

RESEARCH

Perceived impact of a decision-aid and planning tool for family building after cancer for young adult female cancer survivors

Annemarie D. Jagielo[1,2] · Jacqueline Shanley[1,2] · Michael A. Diefenbach[3] · Jennifer S. Ford[4] · Lidia Schapira[5] · Catherine Benedict[2,5]

Received: 23 August 2024 / Accepted: 18 April 2025 / Published online: 3 May 2025

Abstract

Purpose Young adult female (YA-F) cancer survivors report fertility-related uncertainty and distress. Roadmap to Parenthood ("Roadmap") is a web-based decision aid and planning tool for family building after cancer. This study examined the perceived impact of Roadmap, encompassing aspects of website utility and its effects on confidence and motivation, identified factors related to the perceived impact of Roadmap, and evaluated whether the perceived impact related to changes in psychosocial outcomes.

Methods Secondary analyses of a single-arm pilot study were conducted. Participants completed a baseline survey (T1), accessed Roadmap, and completed a survey 1 month post-baseline (T2). The eHealth Impact Questionnaire (eHIQ) measured the perceived impact of Roadmap. A linear regression model evaluated associations between baseline factors and the eHIQ. Linear regression models evaluated relationships between the eHIQ and decisional conflict, unmet information needs, fertility self-efficacy, and self-efficacy for managing fertility-related negative emotions at T2, controlling for baseline (T1) levels of each outcome.

Results Among participants ($N = 98$), 93% reported accessing Roadmap. A more positive perceived impact of Roadmap was related to younger age ($\beta = -.348$ $p = .002$), lower household income ($\beta = -.321.$ $p = .021$), greater health literacy ($\beta = .326$ $p = .004$), and dissatisfaction with post-treatment fertility discussions ($\beta = -.279$ $p = .029$). Those who reported a more positive perceived impact of Roadmap reported lower decisional conflict ($\beta = -.368$, $p < .001$) and unmet information needs ($\beta = -.515$, $p < .001$); self-efficacy outcomes were not related.

Conclusion A web-based decision aid for family building after cancer effectively supports important survivor subgroups. Future directions include assessing the needs of those with low health literacy and improving patient-provider communication.

Keywords eHealth · Decision aids · Decision-making · Oncofertility · Survivorship

Introduction

Fertility is a significant concern among young adult female (YA-F) cancer survivors [1]. Gonadotoxic cancer treatments may result in decreased ovarian reserve, infertility, and/or challenges with conceiving and pregnancy [2, 3]. Family building may require assisted reproductive technology, such as in vitro fertilization or surrogacy (using frozen, fresh, or donated gametes), adoption, or fostering. When fertility and family-building concerns go unaddressed, survivors' decision-making and quality of life suffer [4–6]. Indeed, survivors report high levels of unmet decision support needs when considering family-building options after cancer [7]. Roadmap to Parenthood ("Roadmap") is a decision aid (DA) and planning tool developed to support YA-F survivors in making decisions about

✉ Annemarie D. Jagielo
ajagielo@stanford.edu

[1] PGSP-Stanford Psy.D. Consortium, Palo Alto University, Palo Alto, CA, USA

[2] Department of Psychiatry and Behavioral Sciences, School of Medicine, Stanford University, Stanford, CA, USA

[3] Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Manhasset, NY, USA

[4] Hunter College and The Graduate Center, City University of New York (CUNY), New York, NY, USA

[5] Stanford Cancer Institute, Stanford, CA, USA

family-building options after cancer and to guide them in preparing for potential barriers [7–9]. In a single-arm pilot study, Roadmap demonstrated feasibility and acceptability and led to improvements in decisional conflict, unmet information needs, self-efficacy for managing fertility-related issues and fertility-related negative emotions, and increased planning behaviors related to future family building [8]. The current study builds on these findings to further understand survivors' perceptions of Roadmap and factors related to key psychosocial outcomes.

Prior research suggests that young adult cancer patients who are younger and have lower levels of health literacy and lower socioeconomic status (SES) may experience greater decisional conflict when making reproductive and family-building decisions [10–12]. Although DAs are often not tailored to socially disadvantaged populations, these tools have been shown to improve knowledge, patient-provider communication, and decision quality among patients of ethnic, racial, and gender minority groups, those of lower SES status, and individuals with low health literacy [13–15]. Consistent with patient-centered care [16], DAs should be designed to be understandable, user-friendly, and responsive to patients' needs [17, 18]. Roadmap was systematically and iteratively developed based on user-centered design principles [9]. The eHealth Impact Questionnaire Part 2 [19] assesses the self-reported or "perceived" impact of websites on users by examining website attributes such as usability, functionality, and content [20], which are crucial considerations for website evaluation. Here, the perceived impact refers to (1) the ease of website use, trustworthiness, and suitability of website content, (2) the extent to which users identify with other website users and gain confidence to discuss and manage their health, and (3) the extent to which users understand their health condition better and feel motivated to act [19]. Understanding the perceived impact of Roadmap is important for assessing its utility and value as a decision support resource.

The present study aims to characterize YA-F cancer survivors' use and perceived impact of Roadmap. Predictors of website impact were examined, including age, health literacy, household income, and pre- and post-treatment fertility-related discussions with providers. We also examined whether the perceived impact of using Roadmap was related to changes in primary psychosocial outcomes of interest (decisional conflict, unmet information needs, fertility self-efficacy, and self-efficacy for managing fertility-related negative emotions).

Methods

Secondary analyses of a single-arm pilot study of a DA for family building after cancer (NCT04059237) were conducted. The study procedures were approved by the Stanford University Institutional Review Board and the Stanford Cancer Center Scientific Review Committee (#52143). Data were collected between February 2020 and December 2022.

Participant eligibility

Inclusion criteria included the following: assigned female at birth, ability to speak and read English, aged 18–45 years, completed cancer treatment with gonadotoxic risks, a desire to have a child or uncertain about family-building plans, access to the Internet and use of a computer, tablet, or smartphone, and living in the USA. Participants on long-term adjuvant or maintenance therapies were eligible.

Study procedure

Recruitment was conducted via social media advertising, in partnership with young adult cancer organizations (e.g., Stupid Cancer, Cactus Cancer Society), and through clinician referral at Stanford Health Care. Prospective participants completed an eligibility screener and were contacted by the study team to confirm eligibility and complete informed consent.

After completing the baseline survey (T1; pre-intervention), participants were emailed a website link to access Roadmap. Follow-up surveys were completed at 1 month and 3 months post-baseline (T2 and T3), respectively. Participants could access Roadmap for the duration of the study. Secondary analyses were conducted using T1 and T2 survey data only.

Description of the Roadmap to Parenthood decision aid and planning tool

Roadmap to Parenthood is an interactive, web-based DA and planning tool for women who have completed gonadotoxic cancer treatment (disease-agnostic) [8, 9, 21]. The tool provides information about cancer treatment effects on fertility and family-building options if natural conception (unassisted reproduction) is unlikely or not possible. It includes a 4-step self-assessment exercise that emphasizes value clarification, along with peer stories and suggestions for seeking support from family, friends, community, and professional counseling. Guidance for "next step" action planning is provided, including financial planning, questions for providers, and recommendations for communicating with a partner about family-building decisions. Links to access more detailed information about certain topics are provided, such as same-sex family-building laws, state-by-state surrogacy regulations, and ways to connect with relevant organizations. The tool was created to be used by single or partnered women. It is inclusive of all sexual orientations and suitable for all stages of decision-making preparedness. Roadmap was developed based on pilot work [7, 22] and went through extensive usability and pilot testing [21]. Guidelines by the International Patient Decision Aids Standards (IPDAS) [17, 18] and the Ottawa Decision Support Framework were followed [23, 24]. Roadmap was written at a 7th grade reading level [25].

Study assessments

Participants completed baseline demographic and medical history questionnaires. Items assessing oncofertility experiences were developed by study investigators based on prior research [26] and clinical experience and assessed patient-provider fertility-related discussions before and after treatment. Pre-treatment fertility discussions were assessed with a single item, “Did your oncologist, nurse, or other healthcare professional discuss fertility with you?” Responses included “Yes,” or “No/I don’t remember.” Post-treatment infertility/premature menopause discussions were assessed with a single item, “Has your oncologist or other health care professional discussed risk for infertility or premature menopause with you during follow-up care?” Responses ranged from “Yes, I was satisfied with the amount of information I received,” “Yes, but I was not satisfied with the amount of information I received,” and “No, it was not discussed at all.” Health literacy was measured using the Health Literacy Screening Questionnaire (HL-SQ), an 8-item measure with higher scores indicating greater health literacy (Cronbach’s alpha = 0.86) [27].

Website use

Website use was assessed at T2 with four items that asked participants to report whether they had accessed the website, the number of times they accessed it, the time in minutes spent on the website during their initial visit, and the total time spent on the website.

Website impact

The eHealth Impact Questionnaire Part 2 (eHIQ) measures the impact of using health-related websites [19], and items were adapted to refer to the Roadmap website. Participants completed it at T2, after viewing Roadmap. The eHIQ contains three subscales: Information and Presentation, Confidence and Identification, and Understanding and Motivation. The Information and Presentation subscale assessed perceived trust and suitability of the website content (range 8–40). The Confidence and Identification subscale measured the extent to which respondents identified with others using the website and whether the website affected their confidence in discussing and managing their fertility and family-building issues (range 9–45). The Understanding and Motivation subscale assessed understanding and motivation to manage fertility/family-building issues after viewing Roadmap (range 9–45). Items are answered on a 5-point Likert scale ranging from “1 = strongly disagree” to “5 = strongly agree.” Subscale means were calculated. Subscales were then combined to generate a total eHIQ score; higher scores indicate a more positive impact of using Roadmap. The measure demonstrated good internal consistency (Cronbach’s alpha = 0.94).

Decisional conflict

The Decisional Conflict Scale (DCS) assesses uncertainty in making health decisions and was adapted to refer to family-building decisions after cancer [28, 29]. This 16-item, well-validated measure was administered at T1 and T2 and includes five domains: feeling uncertain, feeling uninformed, feeling unsupported, feeling unclear about values, and ineffective decision-making. Total scores range from 0 to 100, where higher scores indicate greater decisional conflict. Scores > 37.5 reflect clinically significant decisional conflict [29]. The measure demonstrated strong internal consistency across time points (Cronbach’s alphas = 0.94 to 0.96).

Unmet information needs

Participants completed an investigator-designed 5-item measure at T1 and T2 that assessed whether respondents had adequate information regarding their risk of infertility following cancer, risk of premature menopause, options to assess fertility status, options to undergo fertility preservation post-treatment (if possible), and alternative options for family building after cancer. Responses were yes (0) or no (1). Scores ranged from 0 to 5, with higher scores indicating greater unmet information needs. We previously used this measure in several studies [4, 8, 26, 30]. It demonstrated good internal consistency across time points (Cronbach’s alphas = 0.70 to 0.84).

Self-efficacy

The Patient-Reported Outcomes Measurement Information System (PROMIS) General Self-Efficacy for Managing Chronic Conditions measures different aspects of self-efficacy [31]. The General Self-Efficacy short form (4 items) was adapted to assess fertility-related self-efficacy and assess confidence in managing difficult situations, problems, and events related to fertility/family building. The Self-Efficacy for Managing Negative Emotions was adapted to assess fertility-related negative emotions. The scale (4 items) asked respondents to rate their level of confidence in managing negative feelings, stress, feeling discouraged, and disappointment related to fertility/family building. All scales demonstrated good internal consistency across time points (Cronbach's alphas = 0.90 to 0.94).

Analyses

Descriptive statistics characterized the sample and outcome measures. Bivariate analyses examined relationships among study variables using Pearson's and Spearman's correlation and ANOVA. First, we sought to identify demographic and fertility-related factors that were related to the perceived impact of using Roadmap (eHIQ). A linear regression model was specified with the eHIQ as the dependent variable, and the independent variables included age, health literacy, household income, pre-treatment fertility discussions, and post-treatment infertility/premature menopause discussions. These variables were selected a priori based on conceptual relevance and literature review. Then, we sought to evaluate whether the perceived impact of using Roadmap was related to changes in key outcome variables of interest. Four linear regression models were specified with the eHIQ as the independent variable, and decisional conflict T2, unmet information needs T2, fertility self-efficacy T2, and self-efficacy for managing fertility-related negative emotions T2 as dependent variables. All models controlled for baseline (T1) levels of the outcome.

Results

Participant characteristics

Demographic and medical characteristics are provided in Table 1. The majority of participants ($N = 98$) self-identified as White ($n = 85$, 86.7%) and Non-Hispanic/Latinx ($n = 84$, 85.7%), and the mean age of the sample was 31 years (SD = 5.61, range 18–43). A range of annual household income was reported, such that 22% reported income < \$50,000, 37% reported income \$50,000–100,000, and 35% reported income > \$100,000. Health literacy levels were comparable to published means for females of this age group (HLSQ, $M = 28.24$, SD = 5.68) [26].

Most participants (82.5%) reported their healthcare providers discussed fertility with them prior to cancer treatment; 17.5% reported fertility was not discussed or they could not remember whether it was discussed. Following the completion of cancer treatment, 32.6% reported satisfaction with provider discussions of infertility/premature menopause, 35.8% reported dissatisfaction with provider discussions of infertility/premature menopause, and 31.6% reported these discussions were not had at all.

Use of roadmap

Among the participant sample ($N = 98$), 93% accessed the Roadmap website, and 40% reported using the website more than once (range 1–6×). Participants accessed the website two times on average ($M = 1.89$, SD = 1.4, median = 1). On average, participants spent 18 minutes on the website the first time they used it (range = 0–60 min, median = 20). The average total time spent on the website was 36 minutes (range = 0–200 min, median = 25). Accessing the website more times was associated with greater unmet information needs at baseline ($r = 0.27$, $p = 0.02$). Participants who spent more time on the website the first time they used it reported a greater perceived impact of using Roadmap (eHIQ; $r = 0.28$, $p = 0.02$).

Perceived impact of using roadmap

Subscale analyses characterized the perceived impact of using Roadmap (eHIQ; Fig. 1). For the Information and Presentation subscale, participants reported high levels of trust and suitability of the website content ($M = 33.55$, SD = 4.14), as evidenced by 56.7% of respondents who agreed across all items of the subscale. The most frequently endorsed item revealed that 95% of participants believed the language on the website made it easy to understand. For the Confidence and Identification subscale, participants reported the website improved their confidence to discuss and manage fertility-related health issues ($M = 35.95$, SD = 4.99). In total, 31.6% of patients agreed across all items of the subscale, and 70% believed the website gave them the confidence to manage what may happen related to family building. Finally, for the Understanding and Motivation subscale, many participants reported increased motivation to manage fertility and family-building issues after interacting with the website ($M = 35.62$, SD = 5.29). For example, 39.5% of participants agreed across all items, and 90% of participants believed the website helped them to have a better understanding of their family-building options.

Factors related to greater perceived impact of using roadmap

In bivariate analysis, greater perceived impact of using Roadmap (higher scores on the composite eHIQ) was related to younger age ($r = -0.349$, $p = 0.002$). Lower household income was related to greater perceived impact of using Roadmap, such that those with household incomes of \$50,000 or less reported greater perceived impact of using Roadmap than those with household incomes of \$50,000–100,000 ($F[2, 69] = 3.56$, $p = 0.034$). Those who had pre-treatment discussions about fertility reported

Table 1 Demographic and medical characteristics of the sample ($N = 98$)

Patient demographics	Mean (SD)	Range
Age (years)	30.98 (5.61)	18–43
Age at diagnosis (years)	22.63 (11.36)	0–38
	n	%
Race		
White	85	86.7%
Black	4	4.1%
Asian/Pacific Islander	6	6.1%
Other	3	3.1%
Prefer not to answer	1	1.0%
Ethnicity		
Hispanic/Latinx	14	14.3%
Highest education		
High school	1	1.0%
Vocational training, other than high school	2	2.0%
Some college but no degree	16	16.3%
College degree	41	41.8%
Post-graduate degree	38	38.8%
Household income		
Less than $50,000	22	22.4%
$50,000–$100,000	36	36.7%
Greater than $100,000	34	34.7%
Unknown or prefer not to answer	6	6.12%
Cancer type*		
Breast	40	40.8%
Hodgkin's lymphoma	13	13.3%
Leukemia	12	12.3%
Cervical, ovarian, uterine, or endometrial	11	11.2%
Other	22	22.5%
Fertility-related information		
Nulliparous	72	73.5%
Pre-treatment fertility discussions		
Yes	80	82.5%
No/I do not remember	17	17.5%
Post-treatment infertility/premature menopause discussions		
Yes, I was satisfied with the amount of information I received	31	32.6%
Yes, but I was not satisfied with the amount of information I received	34	35.8%
No, it was not discussed at all	30	31.6%
Underwent fertility preservation before cancer treatment	27	27.6%
Oocyte cryopreservation ($n = 19$)		
Embryo cryopreservation ($n = 7$)		
Ovarian tissue cryopreservation ($n = 1$)		
Ovarian transposition ($n = 0$)		
Ovarian suppression ($n = 5$)		
Other ($n = 0$)		
Underwent fertility preservation after cancer treatment	7	7.1%
Oocyte cryopreservation ($n = 5$)		
Embryo cryopreservation ($n = 0$)		
Other ($n = 2$)		

*Not mutually exclusive; percents calculated for pre-treatment fertility discussions and post-treatment infertility/premature menopause discussions are based on valid percentages

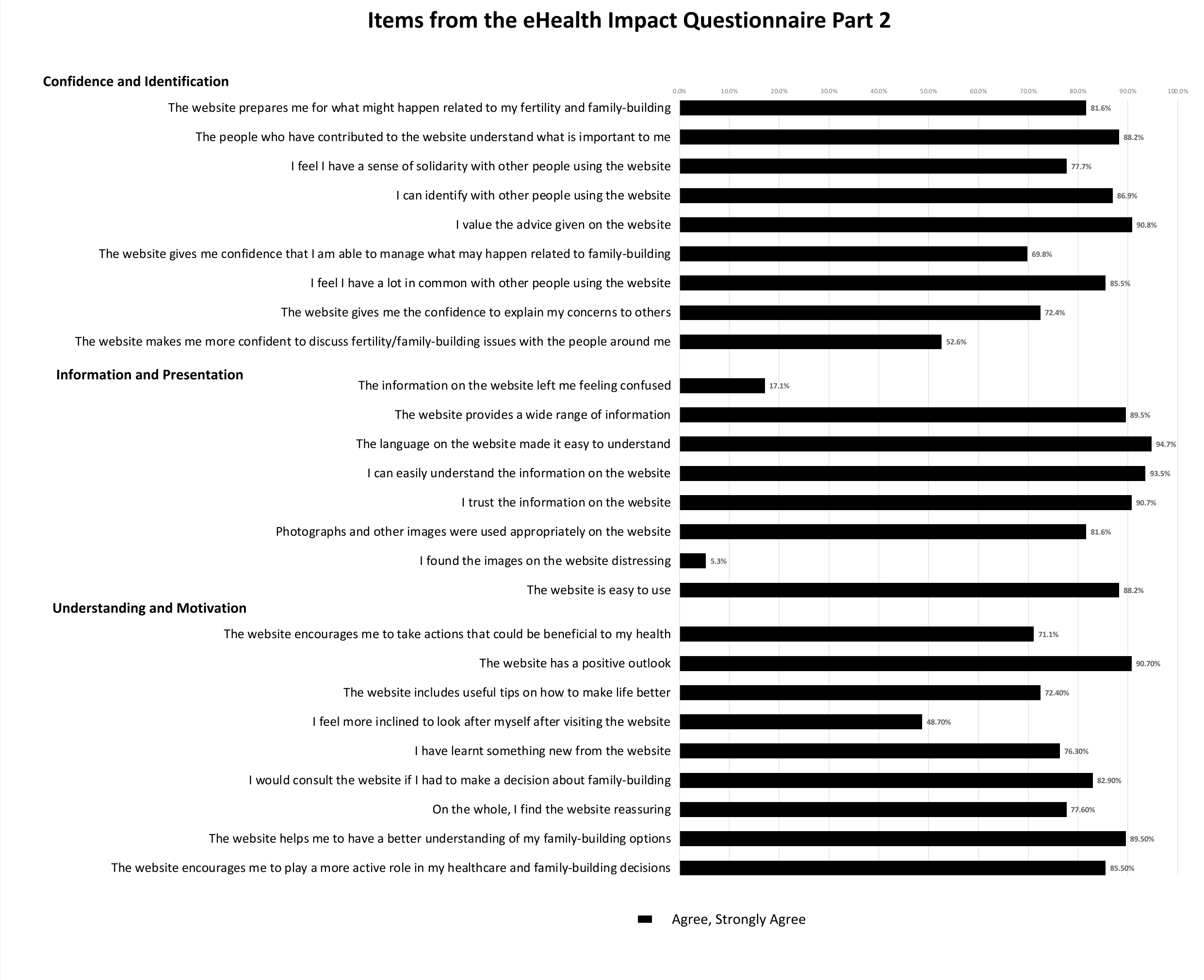

Fig. 1 Subscale analysis of the perceived impact of using the roadmap website as measured by the eHealth Impact Questionnaire Part 2 (eHIQ)

greater perceived impact of using the tool compared to those who did not have pre-treatment fertility discussions ($F[1, 74] = 8.27$, $p = 0.005$).

A linear regression model was conducted to understand factors (age, health literacy, household income, pre-treatment fertility discussions, and post-treatment infertility/premature menopause discussions) related to the perceived impact of using Roadmap (eHIQ; Table 2). Younger age and lower household income remained significantly related to the perceived impact of Roadmap in the expected directions. In addition, higher levels of health literacy and dissatisfaction with post-treatment fertility discussions were related to a greater perceived impact of using Roadmap. At the trend level, engaging in fertility discussions with healthcare providers prior to cancer treatment was related to a greater impact of using the website.

Impact of roadmap on psychosocial outcomes

Four linear regression models were conducted to assess the relationships between the perceived impact of using Roadmap (eHIQ) and decisional conflict, unmet information needs, fertility self-efficacy, and self-efficacy for managing fertility-related negative emotions at T2, while controlling for baseline levels of these outcomes (Table 3).

Decisional conflict

Controlling for baseline levels of decisional conflict, greater perceived impact of using the website (eHIQ) was related to lower levels of decisional conflict at T2 ($\beta = -0.368$, $p < 0.001$).

Table 2 Linear regression analysis to evaluate factors related to greater perceived impact of using the roadmap website

	R^2	*Adj*R^2	*B*	SE	β	*t*	*p*
Model 1							
DV: eHIQ, *F*(7, 58) = 5.502; *p* <.001	.399	.327					
Constant			115.5	9.92		11.64	<.001
Age			−.781	.245	−.348	− 3.18	.002
Household income							
Less than $50,000 (reference)							
$50,000–$100,000			− 7.84	3.30	−.321	− 2.38	.021
Greater than $100,000			− 9.41	3.52	−.380	− 2.68	.010
Pre-treatment fertility discussions							
No/I do not remember (reference)							
Yes			5.92	3.36	.191	1.76	.084
Post-treatment infertility discussions							
Yes, I was satisfied with the information (reference)							
Yes, but I was not satisfied with the information			− 6.99	3.11	−.279	− 2.24	.029
No, it was not discussed at all			− 3.57	3.20	−.141	− 1.12	.268
Health literacy (HLSQ)			.676	.223	.326	3.03	.004

Table 3 Linear regression analysis to evaluate the impact of the roadmap website on psychosocial outcomes

	R^2	*AdjR*^{2}	*B*	SE	β	*t*	*p*
Model 1:							
DV: decisional conflict T2, *F*(2, 57) = 22.42; *p*<.001	.440	.421					
Constant			75.04	17.28		4.34	<.001
eHIQ			−.561	.152	−.368	− 3.69	<.001
Decisional conflict T1			.413	.082	.507	5.07	<.001
Model 2:							
DV: unmet information needs T2, *F*(2, 49) = 11.59; *p* <.001	.321	.293					
Constant			8.47	1.86		4.56	<.001
eHIQ			−.064	.016	−.515	− 4.07	<.001
Unmet information needs T1			.102	.112	.115	.911	.367
Model 3:							
DV: fertility self-efficacy T2, *F*(2, 57) = 17.55; *p* <.001	.381	.359					
Constant			.516	.836		.617	.540
eHIQ			.012	.008	.162	1.55	.126
Fertility self-efficacy T1			.524	.094	.583	5.58	<.001
Model 4:							
DV: self-efficacy for managing negative emotions T2, *F*(2, 57) = 21.58; *p* <.001	.431	.411					
Constant			.114	.842		.136	.892
eHIQ			.009	.008	.117	1.16	.252
Self-efficacy for managing negative emotions T1			.686	.111	.626	6.17	<.001

Unmet information needs

Controlling for baseline levels of unmet information needs, greater perceived impact of using the website (eHIQ) was related to lower levels of unmet information needs at T2 ($\beta = -0.515$, $p < 0.001$).

Self-efficacy

Controlling for baseline fertility self-efficacy, the perceived impact of using Roadmap did not relate to fertility self-efficacy at T2. Similarly, controlling for baseline self-efficacy for managing fertility-related negative emotions, the perceived impact of using the website did not relate to self-efficacy for managing negative emotions at T2.

Discussion

The aim of the study was to evaluate YA-F cancer survivors' use and perceived impact of a web-based DA and planning tool for family building after cancer, Roadmap to Parenthood. After viewing Roadmap, YA-Fs reported high levels of trust and suitability of the website content, identification with others using the website, and increased confidence and motivation to manage fertility and family-building issues. These factors are crucial to the user experience [19], and perceptions of trustworthiness are closely associated with website engagement [32, 33]. Notably, in subscale analysis, 82% reported the website "prepares me for what might happen related to my fertility and family building," and 70% reported the website "gives me confidence that I am able to manage what may happen related to family building." However, there may have been other areas where the website underperformed. For example, only 53% of participants reported the website made them feel more confident to discuss fertility and family-building with the people around them. Roadmap is conceptually designed as a starting point for survivors to make decisions about family-building options and plan for the future including (potential) challenges. It provides resources for accessing more in-depth information about various topics, depending on a user's circumstance, and for accessing support resources such as mental health counseling and patient communities. It may be that some users would have benefitted from more intensive support, such as one-on-one counseling and personalized guidance for discussing fertility/family-building issues with others. Findings highlight the importance of monitoring the impact and consequences of engaging with health-related websites [19] in order to adapt these tools based on patient assessment and preferences.

We found dissatisfaction with provider discussions about infertility/premature menopause risks in post-treatment survivorship contributed to a greater perceived impact of using Roadmap. Survivors who were dissatisfied with provider discussions may have been made aware of possible risks and challenges associated with family building after cancer but lacked adequate information or access to support. Roadmap may have filled an important gap in care for these patients and was perceived as particularly useful. Conversely, among those who did not have fertility-related discussions, awareness of the (potential) barriers to family building may have been low, and thus, Roadmap may have been perceived as irrelevant. Research suggests provider discomfort and lack of knowledge about oncofertility are barriers to fertility-related conversations in cancer care [34], despite survivors' desire for ongoing fertility-related information throughout survivorship [7]. Additionally, providers report a need for information and logistical support to better navigate fertility-related discussions throughout the cancer trajectory [35]. Provider-facing resources have been developed to meet this need, such as the Enriching Communication skills for Health professions in Oncofertility (ECHO) program [36] and electronic medical record (EMR) interventions to standardize provider referrals to reproductive specialists [37]. Future directions should focus on how these tools may be used in conjunction with patient-facing resources such as DAs.

Younger women and those with lower household incomes reported greater perceived impact of using Roadmap. This is notable as younger survivors and those with lower incomes are at greater risk for using avoidance as a coping strategy when faced with cancer-related fertility distress [38, 39]. Moreover, socioeconomic disparities exist in patient-provider communication such that patients with lower incomes are less likely to actively participate in treatment decision-making and are provided with less detailed information about their illness by their healthcare teams compared to those with high incomes [40, 41]. These subgroups of patients may have had more limited access to a trusted provider to address fertility-related questions or concerns and found Roadmap particularly useful. Research suggests DAs may help mitigate health disparities to some extent [42]. Future research with larger, more diverse samples is necessary to confirm these results and explore mechanisms through which DAs exert their effects.

At the same time, higher levels of health literacy related to greater perceived impact of using Roadmap. Effective use of DAs can be partially determined by one's health literacy abilities [25]. Special attention was paid to health literacy in the development of Roadmap, including attention to issues of comprehension (functional health literacy) and values clarification in the decision-making process (communicative health literacy) [25]. Nevertheless, it may be that those with lower levels of health literacy still had difficulty applying specific informational content to their circumstances. For example, research has found health literacy impacts the quality of medical decision making [43, 44]. It may be that a "stepped up" intervention model is needed to provide more support to subgroups of survivors to help them apply information, engage in high-quality decision making, and translate a decision into action. Further research is needed to test Roadmap across all health literacy groups and determine whether a stepped care approach is warranted.

Findings revealed that a more positive perceived impact of Roadmap translated to lower levels of decisional conflict and unmet information needs at T2. These results expand on our prior work, highlighting ways in which Roadmap may impact users and subsequently lead to improvements in these key outcomes. Although Roadmap led to improvements in self-efficacy and self-efficacy for managing negative emotions related to fertility/family building (as previously reported [8]), in the present analyses, this did not relate to participants' perceived impact of the website as measured by overall eHIQ scores. While the eHIQ is important for monitoring website impact and engagement [19], it may not necessarily translate to self-efficacy. With respect to self-efficacy for managing fertility-related negative emotions, research suggests addressing and regulating emotions through online platforms presents many difficulties [45] and may require more personalized interventions than an online tool can provide. Future research should explore the relationship between the perceived impact of fertility-related DA tools and self-efficacy constructs.

Our findings are limited by the study cohort of mainly White and fairly well-educated participants, which limited our ability to assess subgroup differences based on racial/ethnic identity and educational attainment. Patient-provider discussions of fertility and infertility were provided through self-report items. Longitudinal follow-up of psychosocial outcomes was limited to a one-month time period. To generalize findings, testing of Roadmap in larger, more diverse samples is underway.

Findings suggest that the Roadmap may be particularly beneficial to certain subgroups of YA-F cancer survivors, including those of lower SES status, younger age, and individuals who are dissatisfied with post-treatment provider discussions about infertility/premature menopause risks. Those who reported a greater perceived impact of using the website demonstrated improvements in key psychosocial outcomes related to fertility and family building.

Author Contribution All authors made substantial contributions to the conception and design, acquisition of data, or analysis and interpretation of data. The first draft of the manuscript was written by A.D.J. and C.B., and all authors reviewed and edited the manuscript. All authors provided final approval of the manuscript.

Funding This work was supported by a grant from the National Cancer Institute (K07 CA229186, PI: Benedict).

Data availability The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate The study procedures were approved by the Stanford University Institutional Review Board and the Stanford Cancer Center Scientific Review Committee (#52143). Informed consent was obtained from all participants included in the study. The study was performed in accordance with the Declaration of Helsinki.

Consent for publication N/A.

Competing interests Catherine Benedict has served on the board of directors for Stupid Cancer, as a member of the research advisory board for Cactus Cancer Society, and as a research advisor to Gryt Health. There are no other financial or non-financial conflicts of interest to disclose.

References

1. Benedict C, Shuk E, Ford JS (2016) Fertility issues in adolescent and young adult cancer survivors. J Adolesc Young Adult Oncol 5(1):48–57. https://doi.org/10.1089/jayao.2015.0024
2. Coccia PF, Pappo AS, Beaupin L et al (2018) Adolescent and young adult oncology, version 2.2018, NCCN Clinical Practice Guidelines in Oncology. J Natl Compr Canc Netw 16(1):66–97. https://doi.org/10.6004/jnccn.2018.0001
3. Van Dorp W, Haupt R, Anderson RA et al (2018) Reproductive function and outcomes in female survivors of childhood, adolescent, and young adult cancer: a review. JCO 36(21):2169–2180. https://doi.org/10.1200/JCO.2017.76.3441
4. Benedict C, Thom B, Friedman DN, Pottenger E, Raghunathan N, Kelvin JF (2018) Fertility information needs and concerns post-treatment contribute to lowered quality of life among young adult female cancer survivors. Support Care Cancer 26(7):2209–2215. https://doi.org/10.1007/s00520-017-4006-z
5. Young K, Shliakhtsitsava K, Natarajan L et al (2019) Fertility counseling before cancer treatment and subsequent reproductive concerns among female adolescent and young adult cancer survivors. Cancer 125(6):980–989. https://doi.org/10.1002/cncr.31862
6. Canzona MR, Victorson DE, Murphy K et al (2021) A conceptual model of fertility concerns among adolescents and young adults with cancer. Psychooncology 30(8):1383–1392. https://doi.org/10.1002/pon.5695
7. Benedict C, Hahn AL, McCready A, Kelvin JF, Diefenbach M, Ford JS (2020) Toward a theoretical understanding of young female cancer survivors' decision-making about family-building post-treatment. Support Care Cancer 28(10):4857–4867. https://doi.org/10.1007/s00520-020-05307-1
8. Benedict C, Ford JS, Schapira L et al (2024) Preliminary testing of "roadmap to parenthood" decision aid and planning tool for family building after cancer: results of a single-arm pilot study. Psychooncology 33(4):e6323. https://doi.org/10.1002/pon.6323
9. Benedict C, Dauber-Decker KL, King D, Hahn A, Ford JS, Diefenbach MA (2021) Decision aid intervention for family building after cancer: developmental study on the initial steps to consider when designing a web-based prototype. JMIR Form Res 5(1):e20841. https://doi.org/10.2196/20841
10. Benedict C, Stal J, Davis A et al (2023) Greater fertility distress and avoidance relate to poorer decision making about family building after cancer among adolescent and young adult female survivors. Psychooncology 32(10):1606–1615. https://doi.org/10.1002/pon.6212
11. Mersereau JE, Goodman LR, Deal AM, Gorman JR, Whitcomb BW, Su HI (2013) To preserve or not to preserve: how difficult is the decision about fertility preservation? Cancer 119(22):4044–4050. https://doi.org/10.1002/cncr.28317
12. Nahata L, Anazodo A, Cherven B et al (2023) Optimizing health literacy to facilitate reproductive health decision-making in adolescent and young adults with cancer. Pediatr Blood Cancer 70(S5):e28476. https://doi.org/10.1002/pbc.28476
13. Nathan AG, Marshall IM, Cooper JM, Huang ES (2016) Use of decision aids with minority patients: a systematic review. J Gen Intern Med 31(6):663–676. https://doi.org/10.1007/s11606-016-3609-2
14. Ong C, Li AD, Marino JL, Peate M (2024) Interventions to improve oncofertility knowledge and decision-making in patients with low health literacy: a systematic review. Patient Educ Couns 119:108096. https://doi.org/10.1016/j.pec.2023.108096
15. Alam S, Elwyn G, Percac-Lima S, Grande S, Durand MA (2016) Assessing the acceptability and feasibility of encounter decision aids for early stage breast cancer targeted at underserved

patients. BMC Med Inform Decis Mak 16(1):147. https://doi.org/10.1186/s12911-016-0384-2

16. Rathert C, Wyrwich MD, Boren SA (2013) Patient-centered care and outcomes: a systematic review of the literature. Med Care Res Rev 70(4):351–379. https://doi.org/10.1177/1077558712465774
17. Sepucha KR, Borkhoff CM, Lally J et al (2013) Establishing the effectiveness of patient decision aids: key constructs and measurement instruments. BMC Med Inform Decis Mak 13(S2):S12. https://doi.org/10.1186/1472-6947-13-S2-S12
18. Durand MA, Witt J, Joseph-Williams N et al (2015) Minimum standards for the certification of patient decision support interventions: feasibility and application. Patient Educ Couns 98(4):462–468. https://doi.org/10.1016/j.pec.2014.12.009
19. Kelly L, Ziebland S, Jenkinson C (2015) Measuring the effects of online health information: scale validation for the e-Health Impact Questionnaire. Patient Educ Couns 98(11):1418–1424. https://doi.org/10.1016/j.pec.2015.06.008
20. Allison R, Hayes C, McNulty CAM, Young V (2019) A comprehensive framework to evaluate websites: literature review and development of GoodWeb. JMIR Form Res 3(4):e14372. https://doi.org/10.2196/14372
21. Benedict C, Dauber-Decker KL, Ford JS et al (2022) Development of a web-based decision aid and planning tool for family building after cancer (roadmap to parenthood): usability testing. JMIR Cancer 8(2):e33304. https://doi.org/10.2196/33304
22. Benedict C, Nieh JL, Hahn AL, McCready A, Diefenbach M, Ford JS (2021) "Looking at future cancer survivors, give them a roadmap": addressing fertility and family-building topics in post-treatment cancer survivorship care. Support Care Cancer 29(4):2203–2213. https://doi.org/10.1007/s00520-020-05731-3
23. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, Van Der Weijden T (2013) A systematic development process for patient decision aids. BMC Med Inform Decis Mak 13(S2):S2. https://doi.org/10.1186/1472-6947-13-S2-S2
24. Decision aid toolkit - patient decision aids - Ottawa Hospital. Research Institute. https://decisionaid.ohri.ca/resources.html. Accessed 10 May 2024
25. McCaffery KJ, Holmes-Rovner M, Smith SK et al (2013) Addressing health literacy in patient decision aids. BMC Med Inform Decis Mak 13(S2):S10. https://doi.org/10.1186/1472-6947-13-S2-S10
26. Kelvin JF, Thom B, Benedict C et al (2016) Cancer and fertility program improves patient satisfaction with information received. JCO 34(15):1780–1786. https://doi.org/10.1200/JCO.2015.64.5168
27. Abel T, Hofmann K, Ackermann S, Bucher S, Sakarya S (2015) Health literacy among young adults: a short survey tool for public health and health promotion research. Health Promot Int 30(3):725–735. https://doi.org/10.1093/heapro/dat096
28. O'Connor AM (1995) Validation of a decisional conflict scale. Med Decis Making 15(1):25–30. https://doi.org/10.1177/0272989X9501500105
29. O'Connor AM (1993) User manual. Decisional conflict scale. https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf. Accessed 1 June 2024
30. Benedict C, Thom BN, Friedman D et al (2016) Young adult female cancer survivors' unmet information needs and reproductive concerns contribute to decisional conflict regarding posttreatment fertility preservation. Cancer 122(13):2101–2109. https://doi.org/10.1002/cncr.29917
31. Gruber-Baldini AL, Velozo C, Romero S, Shulman LM (2017) Validation of the PROMIS® measures of self-efficacy for managing chronic conditions. Qual Life Res 26(7):1915–1924. https://doi.org/10.1007/s11136-017-1527-3
32. Sillence E, Briggs P, Harris PR, Fishwick L (2007) How do patients evaluate and make use of online health information? Soc Sci Med 64(9):1853–1862. https://doi.org/10.1016/j.socscimed.2007.01.012
33. Rains SA (2007) Perceptions of traditional information sources and use of the world wide web to seek health information: findings from the health information national trends survey. J Health Commun 12(7):667–680. https://doi.org/10.1080/10810730701619992
34. Quinn GP, Vadaparampil ST (2009) Fertility preservation and adolescent/young adult cancer patients: physician communication challenges. J Adolesc Health 44(4):394–400. https://doi.org/10.1016/j.jadohealth.2008.08.014
35. Stalls JM, Dorfman CS, Divakaran S et al (2024) Unmet reproductive health care information needs of female young adult survivors of childhood cancer: oncology providers' perspectives. J Adolesc Young Adult Oncol. https://doi.org/10.1089/jayao.2024.0025
36. Pecoriello J, Klosky JL, Augusto B et al (2023) Evolution and growth of the ECHO (Enriching Communication skills for Health professionals in Oncofertility) program: a 5-year study in the training of oncofertility professionals. J Cancer Surviv 17(4):1184–1190. https://doi.org/10.1007/s11764-021-01139-y
37. Sena LA, Sedhom R, Scott S et al (2022) Trainee-led quality improvement project to improve fertility preservation counseling for patients with cancer. JCO Oncol Pract 18(3):e403–e411. https://doi.org/10.1200/OP.21.00479
38. Jagielo AD, Davis AM, Pons D et al (2024) Cancer and fertility: exploring uncertainty management strategies of young adult female survivors. J Adolesc Young Adult Oncol. https://doi.org/10.1089/jayao.2024.0015
39. McCloud RF, Jung M, Gray SW, Viswanath K (2013) Class, race and ethnicity and information avoidance among cancer survivors. Br J Cancer 108(10):1949–1956. https://doi.org/10.1038/bjc.2013.182
40. McVea KLSP, Minier WC, Johnson Palensky JE (2001) Low-income women with early-stage breast cancer: physician and patient decision-making styles. Psychooncology 10(2):137–146. https://doi.org/10.1002/pon.503
41. Siminoff LA, Graham GC, Gordon NH (2006) Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. Patient Educ Couns 62(3):355–360. https://doi.org/10.1016/j.pec.2006.06.011
42. Yen RW, Smith J, Engel J et al (2021) A systematic review and meta-analysis of patient decision aids for socially disadvantaged populations: update from the International Patient Decision Aid Standards (IPDAS). Med Decis Making 41(7):870–896. https://doi.org/10.1177/0272989X211020317
43. Seo J, Goodman MS, Politi M, Blanchard M, Kaphingst KA (2016) Effect of health literacy on decision-making preferences among medically underserved patients. Med Decis Making 36(4):550–556. https://doi.org/10.1177/0272989X16632197
44. Amalraj S, Starkweather C, Nguyen C, Naeim A (2009) Health literacy, communication, and treatment decision-making in older cancer patients. Oncology (Williston Park, N.Y.) 4:369–375
45. Bettis AH, Burke TA, Nesi J, Liu RT (2022) Digital technologies for emotion-regulation assessment and intervention: a conceptual review. Clin Psychol Sci 10(1):3–26. https://doi.org/10.1177/21677026211011982