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Evaluation of a Caregiver-Facing Digital Tool for Surrogate Decision-Making: A Pre–Post Study

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Abstract

Caregivers often feel unprepared to make surrogate decisions for seriously ill patients. To address this, we developed and evaluated a caregiver-facing, interactive website tailored to known surrogate decision-making needs. 42 active caregivers used the website for 7-10 days, with data collected through pre-post surveys, usage analytics, and optional follow-up interviews (n=6). Participants showed significant improvements in engagement with advance care planning (ACP) behaviours across knowledge, contemplation, and readiness domains. Usage patterns suggested that the values elicitation segments were the most beneficial. Participants also showed reduction in decisional conflict and improved perceptions towards ACP conversations, although barriers to initiate conversations remained. Interviews highlighted the website's informativeness and support for clinician interactions, while highlighting the need for more personalisation, peer witness, and applicability to real-world decisions. These findings offer early evidence that a caregiver-facing digital intervention can enhance surrogate decision-making preparedness in real-world conditions, with potential for scalability and long-term impact to be tested in future studies.

Key words: caregivers, medical decisions, values, surrogate decision making, digital health, advance care planning

Introduction

In advanced illness, decisions often shift from cure to aligning care with patient values. When patients lose capacity or are unwilling to decide, caregivers frequently serve as surrogate decision-makers (SDMs) [1, 2, 3] , a role needed in up to 50% of hospitalizations [4] and increasingly near end of life [5].

In a review of decision-making studies, Laidsaar et al. [6] suggests that the nexus of decision-making can shift dynamically between patient, clinician, and caregiver. For example, in situations with less patient involvement, clinicians often expect caregivers or next-of-kin to know the patient's values and make surrogate decisions accordingly. This responsibility may fall to single caregivers taking up a lead facilitator role [7] or a spokesgroup consisting of several caregivers who influence the decision-making process [8, 9]. Research originating in Asian, more collectivist societies indicate that family-based decision-making is preferred, sometimes over a patient-centred approach [7, 1]. Yet, caregivers are often unaware of the patient's preferences, or their preferences may differ from the patient's, which leads to higher perceived caregiver burden [10] and decreased agreement on decisions [11]. Caregivers who are involved in decision-making may therefore face significant emotional and practical demands, as they must balance the patient's preferences, clinical recommendations, and the family's sometimes conflicting priorities. [12, 2]. Consequently, multiple studies suggest that open conversations about future care preferences could help in facilitating consensus [11, 13].

Given these challenges, many caregivers feel unprepared for this responsibility. Asking experienced surrogate decision makers (SDM) on what advice they would give other surrogates, Bakke et al. [14] found challenges with lack of preparation, initiating advance care planning (ACP) conversations, patient value elicitation, conducting conversations with clinicians and finally how to make surrogate decisions.

While previous digital values elicitation tool exist for patients (e.g. STAMP [15] and PREPARE [16]), caregivers have unique needs as surrogate decision makers (SDMs). Documentation, the aim of many current ACP programs, also might not fully reflect the preferences of patients and surrogates due to unpredictable illness trajectories [17] and patient preference instability [18]. Furthermore, patients often want surrogates to be flexible rather than follow fixed instructions [19]. Hence, researchers are now

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calling for integrating ACP conversations into ongoing patient care [17].

However, for caregivers unfamiliar with the topic and possibly facing medical trauma themselves, initiating these difficult conversations can be challenging. They may lack motivation, prioritize "practical" issues such as cost or medical details, or not realize that decisions will increasingly depend on personal values [20]. Previous work attempted to address this by designing collaborative interfaces with a trained facilitator or clinician to lead the conversation [21]. Volandes and colleagues demonstrated that video decision aids improved patient–surrogate concordance [22], and the PARTNER trial found that a family-support intervention enhanced communication and family-centeredness in the ICU, though it did not reduce long-term distress [23]. Yet these approaches depend heavily on provider presence, limiting scalability and accessibility.

To respond to these challenges, we developed *Careverse*, a self-guided website created specifically for caregivers in the role of surrogate decision makers. The website's design and content were co-developed with clinicians, allied health professionals, patients, and caregivers through iterative pilot testing and refinement, ensuring that the guidance offered was both clinically informed and attuned to caregivers' needs for clarity, relevance, and usability [7]. Careverse builds on our earlier exploratory project focused on digital values elicitation tools [20], but extends beyond values to integrate motivational elements, informational articles, and interactive tools that respond to caregiver challenges identified in prior literature, including preparation, communication, and decision-making support as suggested by Bakke et al. [14].

The intervention map outlines the website's content, organized around four **Guides** that address caregiver challenges identified by Bakke et al., framed as questions to the patient, caregiver, and clinician, and culminating in a final section on making informed decisions (Figure 1). Guide A includes *Values Tool* for clarifying patient values, Guide B includes the *Meaning Tool* for reflecting on the caregiving role, Guide C includes the *Voice Your Concerns Tool* for raising questions with clinicians, and Guide D contains a *Case Study Tool* for practicing decision-making scenarios.

At the time of Careverse's development, no digital tools directly addressing caregivers' challenges as SDMs. The subsequent release of *Prepare for Their Care* and its pilot test further validates the importance of digital interventions for surrogates [24]. Whereas *Prepare for Their Care* offers a linear, video-based program to build readiness and self-efficacy, Careverse complements this approach by by offering a broader, modular ecosystem including articles and interactive tools tailored to diverse caregiver needs.

In this paper, we examine whether one week of independent use can enhance caregivers' preparedness for surrogate decision-making, from understanding their role, self-efficacy, to engagement in ACP conversations. We then discuss future directions for designing interactive tools to support caregivers as SDMs. Details of the intervention and study design are provided in the Methods section.

Methods

This section outlines the intervention design and how it addresses the key goals, followed by details on study design, measures used, and analyses done.

Intervention Design

The design of Careverse was guided by several key principles and components intended to support caregivers throughout the decision-making process. This includes having guides as an organising principle, design elements to support independent use, and interactive tools with shareable outputs.

A key feature of the intervention is the set of four Guides designed to address caregivers' needs. Each Guide includes a curation of articles and one interactive tool (Figure 1). Articles provide foundational knowledge and context such as the role of a surrogate decision-maker, how to talk to loved ones about care preferences, and what to ask during doctor appointments. Tools offer customisable, step-by-step support for applying this knowledge in practice. The Guides are sequenced to reflect a typical decision-making journey. However, since caregivers may engage with the site at different points in their journey and face varying challenges, the Guides are modular and can be completed in any order, allowing users to focus on the sections most relevant to their situation. Logged-in users also have access to a personalised dashboard that provides an overview of all Guides and tracks their progress within each one (see Supplementary Figure 1)

As Careverse is designed as a self-guided tool, motivating independent use was a central priority. In our formative work, we recognized that values elicitation is more practical when situated within a broader set of caregiver needs [20]. We also identified the importance of providing a clear rationale for engaging in SDM preparation and incorporating collaborative features to support caregivers in their role. Accordingly, values elicitation was embedded within the broader context of medical decision-making and positioned in the first guide to emphasize its relevance to the surrogate role (Guide A from Figure 1) . This framing aimed to help caregivers understand how values inform preference-sensitive decisions. We also included informative content on illness trajectories ("Illness Journeys" article from Guide C in (Figure 1) and end-of-life choices ("7 Common Decisions" article from Guide B in Figure 1) to meet caregivers' expressed needs [20] and to build receptiveness toward the less familiar concept of values elicitation.

A persistent challenge in creating an online end-of-life planning interface is the lack of human touch. We thus made several empathetic design choices, such as soft visuals, honest language e.g. "Are there questions you are afraid to ask?" on the homepage banner (see Supplementary Figure 2) , and incorporating meaning-making themes to acknowledge emotional complexity while offering hope.

Lastly, Careverse provides tools that are structured, interactive, and adaptable, giving caregivers opportunities to apply knowledge to their own situations and personalize their responses. Each tool concludes with a shareable output, consistent with prior literature highlighting the importance of ongoing conversations among patients, caregivers, and clinicians [11, 13]. A key insight from our previous research was that caregivers often prefer to complete tools by themselves first before deciding whether — and how — to share the tool with others [20]. Accordingly, the website was designed primarily for single-user use rather than collaborative interfaces, with the downloadable summary providing flexibility for caregivers to share their outputs when they feel ready to initiate discussion (Supplementary Figure 3).

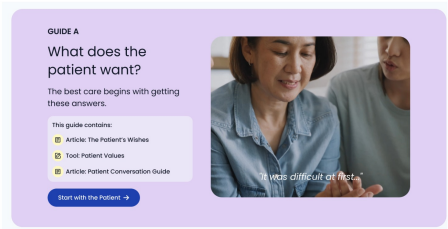
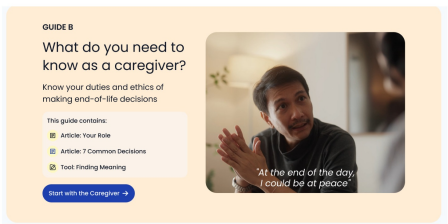
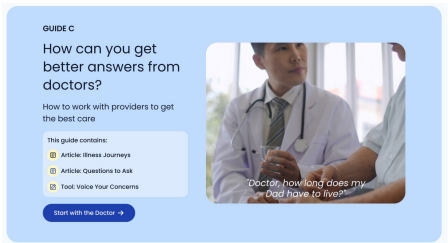
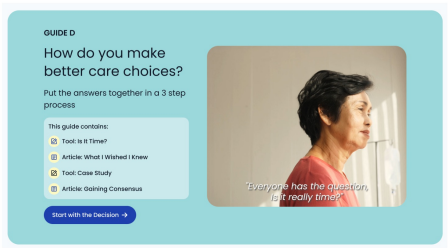
Guide	Need Addressed (adapted from Bakke et al., 2022)	Content
Guide A: "With Patients" 	• How to Initiate ACP Conversations • Motivate and guide SDMs to learn patient's values and preferences	**Articles** • Know Their Wishes • Plan A Talk • When You Disagree • Facing a Diagnosis **Tool** • Values Tool: Guided prompts to clarify and discuss what matters most to the patient
Guide B: "For Caregivers" 	• SDM's own preparation and guidance	**Articles** • Your Role • 7 Common Decisions • Your Concerns • Ethical Guidance • What Dying Looks Like • Resource List **Tool** • Finding Meaning Tool: A calming, visual aid to reflect on the caregiving journey.
Guide C: "With Doctors" 	• How to communicate with clinicians and advocate for patients	**Articles** • Illnesses • Questions to Ask • Talking to Doctors **Tool** • Voice Your Concerns Tool: Generates clear ways to express patients' and caregivers" concerns to clinicians.
Guide D: "Decisions" 	• How to make informed surrogate decisions	**Articles** • Is it Time? • What is Better Care? **Tool** • Case Study Tool: Real case studies alongside guided questions to clarify priorities for patients and caregivers in serious illness decisions.

Fig. 1: **Structure of the Careverse website and guides.** Overview of the website's four Guides, each mapped to surrogate decision-making (SDM) needs identified by Bakke et al. (2022). Each Guide combines short articles with an interactive tool designed to support caregivers in preparing for and engaging in advance care planning (ACP) conversations. *(Stock images licensed from iStock)*

Study Design

We employed a pre-post evaluation comprising a baseline survey, intervention, post-intervention survey, and optional follow-up interviews. The study was carried out in accordance with relevant guidelines and regulations, and approved by the NUS Institutional Review Board. Informed consent was obtained from all participants of this study.

Our hypotheses were:

- H1: The participants' knowledge of serving as a surrogate decision-maker will be higher after the intervention

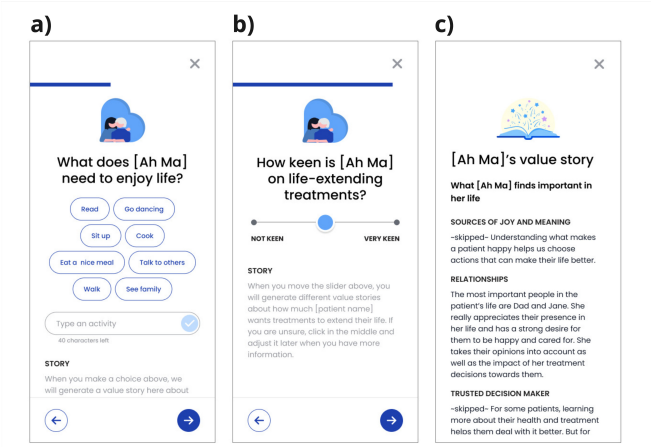


Fig. 2: **Example of an interactive tool.** Shown here is the Values Tool, which is designed to elicit patient preferences. The first two screens are samples of input steps, and the last screen shows the generated output to support caregiver reflection and facilitate advance care planning conversations. (a) Caregivers could select activities important for the patient's quality of life (e.g., cooking, walking, spending time with family). (b) Slider interface allowing caregivers to indicate the patient's preferences for life-extending treatments, ranging from "not keen" to "very keen." (c) Automatically generated "value story" summarizing what the patient finds important These outputs are designed to support caregiver reflection and facilitate advance care planning conversations.

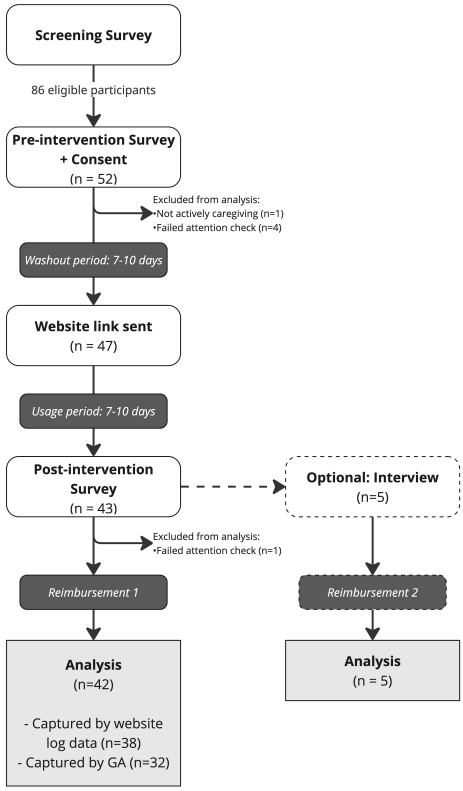


Fig. 3: **Participant flow diagram.** Flowchart summarizing recruitment across two periods.

- H2: The participants' intention to have an informal ACP conversations within the next month will be higher after the intervention
- H3: The participants' readiness to arrange a formal ACP conversation will be higher after the intervention
- H4: Increasing engagement with the content is associated with an increase in the SDM-17 score.

Participants were recruited through a social media (Telegram) channel for research participation. To be eligible, participants had to be *actively caregiving* for a target patient, which we defined as someone who is significantly involved in (taking on at least 50% of) any of these care roles: (1) physical care; (2) financial support; (3) emotional support and (4) decision-making for said patient. The target patient also has to be previously hospitalized for at least 7 days (in total). Participants also had to be 21 years or older, residing in Singapore, proficient in English, and comfortable accessing a website via computer or mobile phone.

Participants were excluded if they were current or former healthcare or palliative care workers, or if they declined audio-recording of the interview.

Interested participants completed a 5-minute screening survey. Those who passed were sent a pre-intervention survey, which included consent and demographic questions. After 7–10 days, they received login details for the website. Participants were told they could explore the site freely for one week, with strong encouragement—but no requirement—to try at least one tool, to reflect real-world use.

After 7–10 days, we sent the post-intervention survey, with reimbursement of about 15 USD upon completion. We then invited all participants to an optional 30-minute interview (in-person or online), with a 7 USD reimbursement. Interviews began with the participant's caregiving background, followed by site usage and any feedback they might have about the website. These interviews were recorded and authors took turn to interview and notetake.

Due to high dropout in Round 1 of recruitment (Apr–May 2024, with 24 valid participants), we conducted a second identical round (May–Jun 2024, with 18 valid participants).

Measures

Our main outcome was ACP engagement among potential SDMs, assessed using the 17-item ACP engagement survey for SDMs [25], the only validated tool for this purpose adapted from a well-established patient ACP survey [26]. We took this measurement before and after using the website

In addition, we collected several secondary measures both before and after website use. These included the 10-item Decisional Conflict Scale (DCS) [27], presenting a scenario about treatment choices for a severely ill patient. As the DCS was originally patient-facing, we kept the original "you" phrasing (DCS-Y) and added adapted questions with "the patient" phrasing (DCS-P) when relevant. We also assessed intent to start an informal ACP conversations within the next month with a Theory of Planned Behaviour scale [28] while readiness to arrange a formal ACP

conversation was assessed using a 5-point Transtheoretical Model Stages of Change scale [29].

Further post-use measures captured participants' motivation to engage with the ACP topic with the Intrinsic Motivation Inventory (IMI) [30] . We also assessed website usability with the System Usability Scale (SUS) [31] and indication of overall satisfaction with the website through Net Promoter Score (NPS) [32]

Finally, behavioural data was tracked anonymously using website log data, and Google Analytics built-in and custom events.

Analysis

We did not conduct a sample size calculation as there were no studies on equivalent digital interventions that facilitates independent caregiver preparation for serious illness decision-making.

Associations between SDM-17 and demographic variables were assessed using linear regression for continuous variables and ANOVA for categorical variables.

Changes in the scores of Surrogate Decision-Making (SDM-17), Decision Conflict Scale (DCS) and Theory of Planned Behaviour (TPB) from baseline to post-intervention were analysed using the Wilcoxon signed-rank two-tailed test.

We conduct a Repeated-Measures ANOVA to compare differences across SDM-17 subscales, along with Games-Howell post-hoc pairwise comparisons adjusted for variances and homogeneity across groups.

We used Pearson's correlation to calculate the pairwise correlation between SDM-17 subscales and DCS, TPB, TTM and IMI measures.

We used Fisher's exact test to calculate the odds ratio of starting and completing each tool and guide, comparing participants in the top half versus bottom half of the SDM-17 and TPB score changes. This analysis aimed to evaluate the impact of engagement with the website.

Our criteria for statistical significance is a p-value of less than 0.05, although do note that some of the analyses were more exploratory in nature due to the small sample sizes.

All statistical analyses were conducted using Python and JASP (Version 0.18.3)

Two authors analysed the interview notes using affinity diagramming [33]. Key points from the interview notes were annotated and then grouped into higher-order themes based on similarity.

Results

Participants

Out of the 52 participants that completed the baseline survey, 5 participants were excluded due to failing attention checks, 4 were lost to follow up, and 1 was excluded due to not being an active caregiver. (Figure 3). In summary, we collected valid quantitative data from 42 participants, of whom just six took part in optional follow-up interviews (see Supplementary Table 1 for more details on interviewees).

Overall, the participant pool was mostly representative of the Singapore caregiver demographics (Table 1) [34], though respondents were more likely to be university graduates (71.4% vs. 58.8% nationally), younger (23.8% and 38.1% respondents in the 21-25 and 26-35 years old groups respectively as compared to the national 10.3% and 21.3%) and less likely to be married (61.9% vs. 36.3% nationally). Among the demographic factors, only gender influenced SDM-17 outcomes, with female participants showing greater improvement.

	Respondents (n=42)	**Caregiver Population Demographics**
Age		
21-25 years	10 (23.8%)	(21-24 years) 10.3%
26-35 years	16 (38.1%)	(25-34 years) 21.3%
36-45 years	10 (23.8%)	(35-44 years) 19.0%
46-55 years	5 (11.9%)	(45-54 years) 19.3%
66-75 years	1 (2.4%)	(65 years and above) 4.2%
Gender		
Female	23 (54.8%)	47.3%
Male	19 (45.2%)	52.7%
Marital Status		
Divorced or Widowed	1 (2.4%)	6.8%
Married	15 (35.7%)	56.9%
Unmarried	26 (61.9%)	36.3%
Highest Education		
A Levels or Diploma	12 (28.6%)	38.9%
Bachelors Degree	26 (61.9%)	58.8%
Post-graduate (Masters or PhD)	4 (9.5%)	
Race		
Chinese	38 (90.5%)	80.7%
Indian	1 (2.4%)	4.8%
Malay	3 (7.1%)	12.5%
Religion		
Buddhism	8 (19.0%)	34.1%
Catholicism	3 (7.1%)	4.5%
Christianity	11 (26.2%)	19.3%
Islam	3 (7.1%)	14.8%
No Religion	13 (31.0%)	19.9%
Taoism	4 (9.5%)	3.9%
Income		
Less than $30,000	8 (19.0%)	18.3%
$30,000 - $49,999	5 (11.9%)	13.5%
$50,000 - $99,999	14 (33.3%)	28.3%
$100,000 - $149,999	8 (19.0%)	24.1%
$150,000 - $199,999	4 (9.5%)	10.0%
$200,000+ per year	3 (7.1%)	5.8%

Table 1. Participant characteristics (n = 42). Caregiver demographics compared to national statistics. Income shown in Singapore dollars (SGD)

Subscale	Baseline Score (SD)	Post-Intervention Score (SD)	Difference (SD)	95% Confidence Interval	Effect size	p-value
Overall	3.02 (2.89)	3.44 (2.89)	0.42 (2.36)	[0.24, 0.60]	0.18	< 0.001***
Knowledge about serving as SDM	3.11 (1.87)	3.63 (1.77)	0.52 (1.87)	[0.30, 0.74]	0.28	< 0.001***
Contemplation	2.82 (1.73)	3.26 (1.93)	0.44 (1.83)	[0.12, 0.58]	0.24	0.003**
Readiness	3.05 (2.16)	3.35 (2.06)	0.29 (1.67)	[0.08, 0.51]	0.18	0.008**

Table 2. Primary outcome: SDM-17 pre- and post-intervention results. Advance Care Planning Engagement Survey for Surrogate Decision Makers (SDM-17) overall results and reported by sub-scales of knowledge about serving as a surrogate decision-maker, contemplation and readiness.

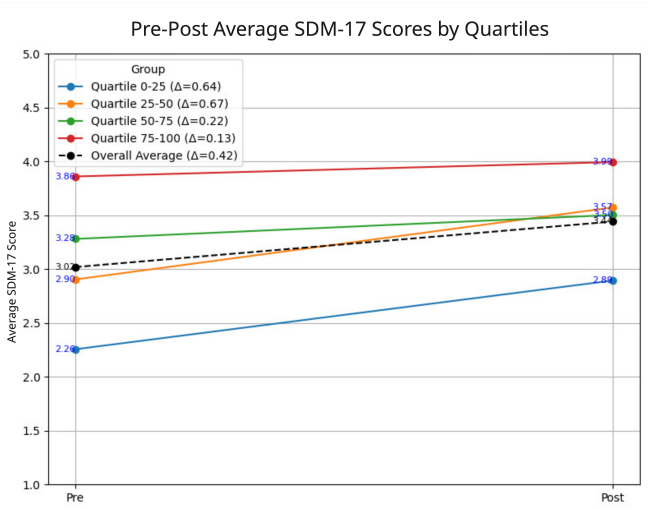


Fig. 4: **Improvements in ACP engagement by baseline quartile of SDM-17 scores.** Average pre- and post-intervention scores on the 17-item Advance Care Planning Engagement Survey for Surrogate Decision Makers (SDM-17) are shown, grouped by baseline quartile. Caregivers in the lowest quartile (Q1) and second quartile (Q2) demonstrated the largest improvements compared to higher quartiles (Q3–Q4).

Primary Measure: ACP engagement survey for SDMs (SDM-17)

We observed significant improvements in the overall score of the 17-item ACP engagement survey for Surrogate Decision Makers (SDM-17) from a baseline mean of 3.02 (SD = 2.89) to 3.44 (SD = 2.89) post-intervention, showing a mean difference of 0.42 (95% CI [0.24, 0.6], $p < 0.001$) (Table2). Participants in lower baseline quartiles showed greater improvements (+0.64 for Q1 and +0.67 on Q2) than those in the higher quartiles (+0.22 for Q3 and +0.13 for Q4) (Figure 4).

All subscales of SDM-17 showed significant improvement, with the largest in *Serving as Surrogate Decision Maker* (+0.52, SD = 1.87, $p < 0.001$), followed by *Contemplation* (+0.44, SD = 1.83) and *Readiness* (+0.29, SD = 1.67, $p = 0.008$). The difference between subscales was significant ($F(2, 82) = 4.4543$, $p = 0.015$), with post-hoc Games-Howell tests showing that the *Serving* subscale improved more than both *Contemplation* (p = 0.048) and *Readiness* (p = 0.058), with no significant difference between the latter two (p = 1.000).

Going by item, Q2 "knowledge about what makes a good decision maker" (+0.67 points) and Q5 "confidence in talking to the patient about their care preferences" (+0.64 points) under the *Serving* subscale showed the greatest increases while Q17 "ready to ask the doctors questions to help you make a good medical decision for the patient" had the least increase (+0.12 points).

Next, we examine the secondary measures to understand the correlates of this outcome.

Secondary Measures

Participants showed significant reductions in decisional conflict regarding the extent of intervention when the patient is severely ill with the Decision Conflict Scale with 'you' phrasing (**DCS-Y**) score decreasing by 14.52 points (SD = 17.73, $p < 0.001$) and the Decision Conflict Scale with 'the patient' phrasing (**DCS-P**) by 13.57 points (SD = 18.55, $p < 0.001$), with no significant difference between the two scores (p = 0.186).

Participants also showed a significant increase on overall Theory of Planned Behaviour Scale (**TPB**) score on starting **informal** ACP conversations within the next month (mean difference = +0.3, 95% CI [2.14, 6.06], $p < 0.001$) and across the subscales of *Attitude* (mean difference = +0.4, 95% CI [0.94, 2.68], $p < 0.001$), *Subjective Norms* (mean difference = + 0.2, 95% CI [0.03, 1.40], $p < 0.03$), and *Perceived Behavioural Control* (mean difference = +0.3, 95% CI [0.37, 1.97], $p < 0.01$). However, the increase in *Intention* was non-significant (mean difference = +0.13, 95% CI [-0.22, 1.03], $p = 0.21$).

The Transtheoretical Model of Change (**TTM**) score, which represents the caregiver's readiness to arrange a **formal** ACP conversation with the patient in the next month, showed a significant overall increase from mean=2.6 (SD = 1.2) to mean=2.9 (SD = 1.0) with a mean difference of 0.3 (95% CI [0.04, 0.53], $p < 0.03$)

Although the secondary measures showed improvements individually, none of them had a correlation higher than 0.3 with SDM-17 (Figure 5) with the exception of the SDM-17 Contemplation subscale with the TTM score.

The Intrinsic Motivation Inventory (**IMI**) measures are only weakly correlated with SDM-17, suggesting that positive perceptions of the topic or website were not strongly linked to outcomes.

Secondary Measures	Subscale	Baseline Score (SD)	Post-Intervention Score (SD)	Difference	95% Confidence Interval	Effect Size	p-value
Decisional Conflict Scale (DCS)	DCS-Y ("you")	35.24 (21.86)	20.71 (19.9)	-14.52 (17.73)	[-20.05, -9]	-0.82	< 0.001***
	DCS-P ("the patient")	35.24 (22.2)	21.67 (20.65)	-13.57 (18.55)	[-19.35, -7.79]	-0.73	< 0.001***
Theory of Planned Behaviour Scale (TPB)						0.65	< 0.001***
	Attitude	3.44 (1.43)	3.8 (1.1)	+0.36 (1.25)	[0.94, 2.68]	0.65	< 0.001***
	Norm	3.07 (1.21)	3.25 (1.13)	+0.18 (1.11)	[0.03, 1.4]	0.32	0.03*
	Perceived Behavioural Control	3.16 (1.24)	3.45 (1.21)	+0.29 (1.28)	[0.37, 1.97]	0.45	< 0.01**
	Intention	3.29 (1.49)	3.43 (1.53)	+0.13 (1.16)	[-0.22, 1.03]	0.2	0.21
Transtheoretical Model of Change Scale (TTM)		2.62 (1.25)	2.9 (0.98)	+0.29 (0.77)	[0.04, 0.53]	0.37	0.03*
Intrinsic Motivation Inventory (IMI)			5.33 (2.99)				
	Enjoyment		5.06 (2.12)				
	Effort		4.9 (2.26)				
	Usefulness		5.91 (1.89)				
System Usability Scale (SUS)			72.38 (12.23)				

Table 3. Secondary outcome measures results. Results for Decisional Conflict Scale (DCS), Theory of Planned Behaviour (TPB), Transtheoretical Model of Change (TTM), Intrinsic Motivation Inventory (IMI), and System Usability Scale (SUS).

The website's average System Usability Score (**SUS**) was 72.4, higher than the digital health app average of 68 [35].

The average Net Promoter Score (**NPS**) is 8.0, which translates to "Passive"

Website Activity

The website logs captured data from 38 participants while Google Analytics captured 32. The incomplete data is likely due to restrictive browser settings, such as ad blockers. During data analysis, we found that the built-in Google Analytics events were incorrectly captured, so we only retained the custom events.

As participants were free to explore any part of the website at their convenience, engagement greatly varied across articles (Figure 6), as well as guides and tools (Table 4)

Looking at the effect of starting and completing guides towards outcome measures, we observed that participants who started Guide A were significantly more likely to show greater SDM-17 improvements (OR = 7.65, p = 0.030) (Table 4). Starting Guide B's Finding Meaning Tool also showed a positive trend approaching significance for TPB Intention (OR = 7.80, p = 0.059).

In terms of the efficacy of tools, we found that participants who started the Values Tool were significantly more likely to have higher SDM-17 improvements (OR = 5.71, p = 0.036). As the Values Tool is part of Guide A, this aligns with Guide A having the most effect on the primary outcome.

Guide/Tool	Odds of Higher SDM-17 Improvement	p-value	N	95% CI Lower	95% CI Upper
Started					
Guide A	7.65	0.029	27	1.37	42.71
Guide B	1	1	28	0.24	4.24
Guide C	0.34	0.191	17	0.09	1.27
Guide D	0.3	0.17	13	0.07	1.23
Values Tool	5.71	0.036	19	1.16	28.07
VYC Tool	0.46	0.444	9	0.09	2.29
Case Study Tool	0.67	0.712	10	0.15	3.04
Meaning Tool	3.67	0.156	16	0.85	15.84
Completed					
Guide A	2.19	0.476	11	0.52	9.27
Guide B	0.7	1	7	0.13	3.68
Guide C	0.7	1	7	0.13	3.68
Guide D	0.3	0.604	4	0.03	3.14
Values Tool	3.93	0.087	18	0.88	17.56
VYC Tool	0.46	0.444	9	0.09	2.29
Case Study Tool	0.87	1	9	0.19	4.11
Meaning Tool	3.6	0.153	14	0.83	15.63

Table 4. Caregiver engagement with Careverse guides and tools. Analysis of caregiver engagement with Careverse guides and tools, displaying odds of SDM-17 improvement along with participant counts for starting and completing each guide and tool

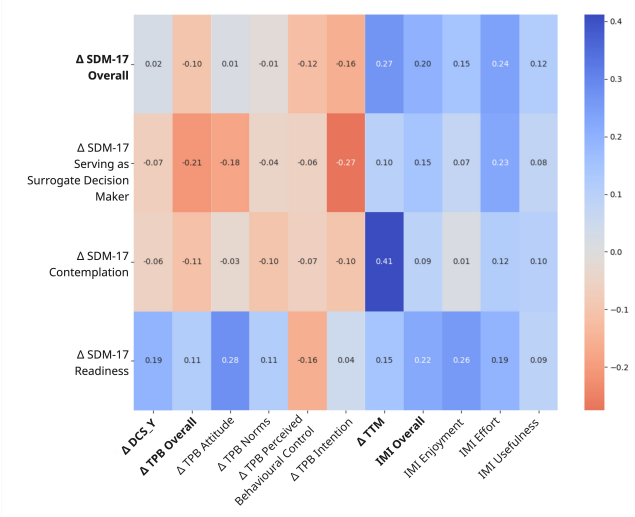


Fig. 5: **Correlations between primary and secondary study outcomes.**Correlation matrix showing relationships between the primary outcome (SDM-17 scores) and secondary outcomes, with relevant subscales: Decisional Conflict Scale (DCS), Theory of Planned Behaviour (TPB), Transtheoretical Model (TTM), and Intrinsic Motivation Inventory (IMI). Darker shading indicates stronger correlation coefficients.

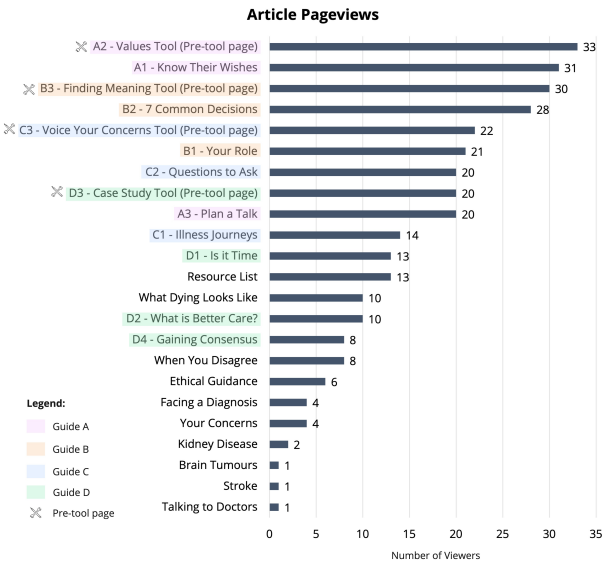


Fig. 6: **Distribution of article pageviews within the Careverse website.** Bar chart showing the number of pageviews across different Careverse articles, showing how caregivers navigated different parts of the site.

However, these associations should be interpreted with caution given the small sample size and wide confidence intervals. The observed patterns suggest promising directions, yet the odds ratios should be viewed as exploratory signals to be explored in larger trials.

Completing any one guide or tool was not significantly associated with outcome measures (Table 4).

Interview Findings

We have organised feedback from follow-up interviews into key themes corresponding to caregiver needs from Bakke et al (2022) (Table 5). Despite being a small group, interviewees had diverse backgrounds and SDM-17 scores (Supplementary Table 1)

Theme	Description	Illustrative Quotes
How to Initiate ACP Conversations, Motivate and guide SDMs to learn patient's values and preferences		
Emotional and practical barriers to ACP conversations	Caregivers described several barriers. Some patients resisted the topic, and caregivers often hesitated to bring it up because of the emotional weight or concern they could not honour the wishes expressed. Others preferred keeping conversations casual rather than using structured tools, and some felt less urgency when they believed they already knew the patient's preferences or when the patient's condition had stabilised.	**P8**: *"It would be a very sensitive thing... Some people, they are ready, some they are not. Even at the very last minute. They are still not ready to talk."* **P44**: *"Exploring wishes is important, but I also am a little bit held back because if my mom gives me a full... wishlist, can I fulfill that?"* **P15**: *"The patient's progress was at a state where... everything started to... go back to normal, so I didn't really feel the need to look for that kind of caregiver (resources)."*
Some prefer facilitated conversations	Some expressed that they might need more help in having the conversation, for instance facilitation by a neutral third party.	**P13, whose wishes differ from the patient's**: *"Sometimes I have to admit my emotions run high... so if there's someone who can speak to (the patient), and help her on a more neutral basis... that'd be great."*
SDM's own preparation and guidance		
Informative Resource	Caregivers valued the website as an informative resource, especially for new caregivers. They appreciated its empathetic tone and how it caters specifically to their needs.	**P20, a university student**: *"It is a very informative website... personally I found that it was very useful... The guides... is a good thing to have (for) people who are very new to caregiving. But people who are already midway... wouldn't need the guides"* **P15**: *"It's helpful for both who are... newly trusted into the role as well as... people like me who have gone through it once before... I appreciate how there's a specific section for caregivers"*
Expectation for Website to be a comprehensive resource hub	Some caregivers wanted the site to function as a more comprehensive hub (e.g., mental health support, live chat), which sometimes clashed with the website's core focus on values clarification.	**P13 who has completed ACP and Lasting Power of Attorney (LPA) for her mom**: *"There wasn't very new information that I don't know already."* **P44, whose NPS is much lower than average**: *"If you need to talk to someone live... do you offer this kind of thing?... Does (the website) link you up with the appropriate platforms to seek help?"*
How to communicate with clinicians and advocate for patients		
Website as conversation support, especially with doctors	Guidance on phrasings and doctor conversations were particularly appreciated.	**P29**: *"I find the phrasing really good... if I run out of things to say during the consultation, at least I can actually use them... even when talking to my grandpa"*
How to make informed surrogate decisions		
Tools prompt reflection, but needs more actionability	Tools were appreciated for prompting reflection and advocating for patient's wishes, but more actionable next steps or new insights will be appreciated	**P29 on Values Tool**: *"It gave me a sense of goal in mind... I can always come back to this so-called value story.... and double confirm why am I doing this for him"* **P15, on Meaning Tool**: *"I'm not very clear... of the takeaway that I'm supposed to have... maybe (the tool can) include certain relevant resources based on that (caregiver) profile."*
Demand for peer witness content	Case Study Tool was often treated as peer witness stories rather than an interactive decision practice, with comments on scenario realism, and requests for real caregiver videos.	**P8, taking care of grandmother with dementia**: *"I would say, the goals of care is something we already know... but those stories... will be more helpful because it's... a very similar situation. And what people do."*
Hesitant to answer for patient	Caregivers expressed discomfort with speaking on the patient's behalfCaregivers expressed discomfort with speaking on the patient's behalfCaregivers expressed discomfort with speaking on the patient's behalf	**P13**: *"I didn't try (Values Tool), because it's from her perspective. I wouldn't want to answer on her behalf"*

Table 5. Themes from caregiver interviews. Summary of themes generated from caregiver interviews, with accompanying descriptions and illustrative quotes. Themes were organized based on caregiver needs identified by Bakke et al. (2022).

Discussion

This paper presents the design and evaluation of a digital tool to support caregivers in making preference-sensitive decisions for individuals with serious illness, guided by the unique challenges of surrogate decision-making. Results from both primary and secondary measures suggest that the website significantly improved caregiver preparedness to be surrogate decision-makers. We now examine each hypothesis in detail.

The findings supported H1, our first hypothesis, that participants' knowledge of surrogate decision-making will improve

post-intervention, as indicated by significant gains on the SDM-17 *Serving* subscale. Beyond our initial expectations, significant improvements were also seen in *Contemplation* and *Readiness* scores, suggesting that addressing caregiver-specific needs can enhance reflection and confidence in engaging in care planning conversation. These improvements seem robust despite the small effect size, which is notable given the brief, 1-week exposure to the website. Interviews further highlighted the informativeness of the website. In our context where death is often a taboo topic, perhaps the exposure to these new and tailored resource may have substantially boosted awareness and helped normalise the concept of having ACP conversations. It is also possible that just knowing that such support exists may have been reassuring in itself. Altogether, the results provide early evidence that a caregiver-facing digital intervention may enhance preparedness, with potential for scalability and impact.

However, the application of knowledge gains to real-world decision-making appears less consistent. Among the SDM subscales, *Readiness* scores lagged behind, and SDM-17 was weakly correlated with other decision-related measures (DCS, TPB, TTM). This suggests that despite having a stronger understanding of ACP concepts, caregivers may still struggle in translating these values into concrete decisions. The qualitative findings also showed that participants wanted more actionable guidance from the website and identified various social barriers to applying what they learned. Increased awareness might also have surfaced new uncertainties about complex care choices.

Therefore, we propose that future iterations of caregiver-facing interventions integrate real-world examples explicitly linking values to decisions, to show how others have applied ACP concepts within the complex and nuanced context of everyday caregiving. One way to do this is by providing the highly-requested peer witness videos. We propose that such stories can give caregivers tangible ides of how to pursue what matters most to them while simultaneously fostering an empathetic connection.

Additionally, we can obtain more robust evidence by extending future interventions beyond one week. As this was an early-stage study, we focused on a short timeframe to first establish feasibility and detect signal outcomes. Assessing outcomes over one week allowed us to capture caregivers' immediate reflections before external events (e.g., new medical crises or shifting family dynamics) could introduce confounders, thereby isolating the website's proximal impact. However, decisional clarity may take time to develop following initial awareness. A longer timeframe also increases opportunities for caregivers to apply values to real decisions, while enabling examination of longer term outcomes such as aggressive care measures for the patient and impact on caregiver bereavement.

Moving onto the next hypotheses, H2 and H3 explored whether the website influenced caregivers' intentions to initiate informal and formal ACP conversations respectively.

Though participants reported stronger attitudes, social norms, and perceived behavioural control regarding informal ACP conversations, this did not translate into intention to personally conduct an informal conversation within a month. Interviews corroborated this point by fleshing out common interpersonal challenges including emotional discomfort, unreadiness from the patient or caregiver, and lack of motivation. Some also felt the tools were too formal or better suited in crises situations, and preferred resources that were more immediately actionable.

Contrarily, intentions to seek **formal** ACP facilitation improved significantly. Participants seemed to feel that external support from facilitators can lessen the burden of leading the conversation or minimise the influence of personal biases. However, it is worth noting that the TTM score increased only to 2.9 on a 5-point scale, where a score of 3 reflects "thinking about doing it within the next six months", which does not suggest a strong preference for formal over informal conversations. We conclude that initiating both informal and formal ACP conversations remain a significant challenge.

We propose that future caregiver-facing digital interventions offer more scaffolding and conversational language to empower caregivers with the structure to carry out these conversations. Ideally, materials should be available in the patient's preferred language to encourage patient involvement. Building on what caregivers found helpful, encouragements from clinicians could also reinforce the relevance of these conversations to care decisions. When caregivers better understand their role in ACP conversations, they may feel more motivated to initiate these discussions and reassured that what they are doing is important. Caregivers may also benefit from learning how others have broached the conversations - not just during crises situations, but earlier, when patients can still participate meaningfully. An important element of these stories is to acknowledge the emotional difficulty yet while emphasizing the value of these conversations could further encourage caregivers to take the first step. Additionally, a longer study duration might allow the documentation of care planning conversation behaviour and not just the intention to carry it out.

Lastly, H4 asked whether engagement with website content was associated with increased ACP engagement. Among all tools, progress in Guide A and the Values Tool showed the strongest link with SDM-17 improvements. This suggests that reflecting on the patient's values, identity, and preferences may enhance caregivers' ACP engagement, perhaps allowing them to have more confidence to advocate for the patient's wishes. While encouraging, it is worth noting that these associations are based on small numbers with wide confidence intervals and thus warrant further testing in larger trials. It is also worth noting that there might be primacy effect at play here, as Guide A and Values Tool appeared first on the site and participants were instructed to complete at least one tool. While our current design uses a modular approach, future studies could explore if the ordering of the tools matter, and if a more guided sequence could strengthen user engagement.

For the other tools, participants seem to engage with them as informational resources rather than engaging with them as interactive tools as intended, and therefore felt that it's not very practical. Additionally, participants felt that the website could offer more personalisation. This suggests room for improvement in both usability and actionability of the tools. Future work in caregiver-facing digital tools could be tailored to generate more personalised prompts and phrasing aids, which can support real-world conversations with clinicians and patients. The tools also provide an opportunity to incorporate real-world use cases from other caregivers, consistent with the feedback received on the website as a whole.

Furthermore, our behavioural measurements were limited by data collection issues. Future implementations should include a more reliable and granular tracking —such as tracking pageviews and time spent on each section — to better assess engagement

patterns and evaluate the efficacy of various components in the site beyond the interactive tools.

In conclusion, this study contributes early evidence that a caregiver-facing digital intervention tailored towards caregivers' needs may enhance preparedness for surrogate decision-making. Importantly, this study demonstrates real-world patterns of usage beyond controlled environments by leveraging a combination of digital analytics and qualitative insights, Our findings suggest the need for digital tools to move beyond static content and documentation, toward more personalised, actionable, and contextually relevant experiences.

While short-term gains were observed, especially in knowledge, caregivers still struggled to apply them into real-world conversations and decisions. We recommend that that future interventions incorporate peer witness videos, emphasise the relevance of ACP conversations in care decisions, and provide clearer scaffolding to support application in everyday care contexts.

Future work should focus on larger, controlled trials with more robust tracking to better understand the drivers of meaningful engagement and long-term impact. Ultimately, we hope that caregiver-facing digital tools could complement in-person ACP systems and broaden access to timely, values-based care planning.

Data availability

The data in this study, encompassing all quantitative measures, behavioural measures, and interview data, could not be shared publicly to protect participants' privacy and confidentiality, to comply with the approved Institutional Review Board (IRB) protocol, but are available from the corresponding author on reasonable request.

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N. U. - Conceptualization, Methodology, Software, Formal analysis, Investigation, Resources, Data Curation, Writing - Original Draft, Visualization, Project administration. P. S. F. - Conceptualization, Methodology, Software, Investigation, Resources, Data Curation, Writing - Review and Editing, Funding acquisition. B. T. J. D. - Formal analysis, Data Curation, Writing - Original Draft, Visualization. C. F. - Conceptualization, Software, Resources. C. S. H. - Formal analysis, Investigation, Data Curation. T. N. L. and S. A. – Resources, Software. G. C. H. K. - Supervision, Funding acquisition

Competing Interests

None declared

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