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Development of an online tool to support financial and legal planning in dementia

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ABSTRACT

Objective: To develop, assess, and refine an online educational tool, Plan for Clarity, to support financial and legal planning in dementia.

Methods: A Delphi mixed-method study with three rounds of anonymous review by lay and professional stake-holders was designed to reach consensus about the content of the online tool and explore the socio-cultural and behavioral factors that could affect access and use.

Results: Consensus showed that the online tool covered key information, knowledge, and communication skills for financial and legal planning. Study themes: 1) the online tool had to be easy to navigate with relevant, easily understood information; 2) people with early signs of memory difficulties would be able to use the tool; 3) a referral from a trusted source is a primary way to facilitate access and use of the tool; and 4) discussions about financial and legal issues should be held early, ahead of barriers that can block discussion.

Conclusion: These data suggest this online tool is relevant and feasible for dementia care and support as well as aging more generally.

Innovation: Plan for Clarity is innovative as an evidence and theory-driven online education tool to address financial and legal planning for dementia care, particularly among underserved older adults.

1. Introduction

Individuals with Alzheimer's disease and related dementias and their caregivers face enormous disease-associated financial and legal risks for which most are unprepared. Difficulty managing finances is one of the earliest signs of dementia, and most people will lose the capacity to independently manage finances or make related legal decisions within a few years of its development. [1,2] There is significant need to support patients and caregivers in understanding, planning for, and navigating financial and legal decisions throughout the course of dementia. [3-5] This need has been recognized as part of quality clinical care by the Centers for Medicare and Medicaid Services [6] and, accordingly, should be more widely incorporated into clinical practice. [7,8] However, to address this requirement, tools are needed that are 1) evidence-based, 2) culturally competent [9], and 3) usable by people with low health and legal literacy. Protocols and tools that have been developed to support dementia care [9] and medical advance care planning can inform development of financial and legal planning tools for this population.

We drew upon our experience developing the *Care Ecosystem* [10] and *PREPARE* [11,12] programs, two highly-researched interventions in the dementia and medical advance care planning fields, to initially inform our development of such a tool.

Our aim is to develop an evidence-based, culturally competent [9], highly accessible tool that supports financial and legal planning as part of quality dementia care. The tool, called Plan for Clarity, is a patient and caregiver-facing **website**. Table 1 shows the core components and content of the website. The overall design of the website is guided primarily by social behavior and communication theories [13,14]. Table 2 shows the theoretical concepts that inform the design of the website.

While the content is relevant to everyone who will age someday, the goal is to promote accessibility for diverse older adults who have historically lacked access to legal and financial planning support, typically those with lower-income and literacy. [15] For instance, the website emphasizes the role of public benefit programs in supporting long term care and provides connections to free community resources, rather than centering investing or financial products as a primary concern or skill.

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Table 1
Core components and content of Plan for Clarity.

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Components	Content
Why Plan	Why making legal and financial plans is important, when to plan, key planning steps, and who should be involved in planning.
Naming Financial and Legal Caregivers	The roles of financial and legal caregivers, including detailed state-specific information about the different types of legally recognized caregivers that can be named, how to select financial and legal caregivers, and ways to prevent and mitigate the risks of exploitation and abuse.
Planning for Your Future Care	The types of long-term care that may be needed and how they may be financed, covering state-specific requirements and services, with case studies and planning tools.
Getting Legal Help	The different types of legal and financial professionals, how to select ones that meet specific needs, and how to work with them.
Talking with Others	Why and how to talk about plans with others, including a diverse set of videos demonstrating communication with family and friends, healthcare providers, and lawyers.
Other Resources	Vetted third-party information and support resources that address needs of specific populations and special topics beyond the core financial and legal issues covered by the website.

 Table 2

 Theoretical Concepts Informing the Design of Plan for Clarity.

Theoretical concepts	Plan for Clarity Features
Social Learning theory (SLT)	
Behavioral capability – knowledge and skills to influence behavior	Information about key knowledge and skills related to financial and legal planning, including videos modeling skills in planning and communication
Self-Efficacy – confidence in the ability to take action	Worksheets designed to support taking small steps for making behavior change
Observational learning – observation of the actions of others like self	Videos modeling others taking action, and promoting and improving communication, among family, and health and legal professionals
Health Belief Model (HBM)	
Perceived susceptibility to, and severity of, not taking action	Stories and narratives about the consequence of not planning ahead
Perceived benefits of taking action	Content describing and demonstrating the benefits of taking action for planning
Perceived barriers to action	References to specific resources, worksheets supporting planning steps, and videos modeling successful planning interactions addressing the barriers to taking action

The website visuals and videos aim to model successful planning activities by elders from communities of color, and to address common cultural considerations relevant to planning, such as nontraditional family structures in LGBTQi communities. The website is available in English and Spanish, with additional languages planned.

Functional elements of the website have been designed for use by older users and people with mild cognitive impairment, with features including simple language, informational graphics, animation of key concepts, videos that model planning and communication, and print-based worksheets for offline planning [16]. Downloadable worksheets and other printable/exportable tools help users focus on the most relevant content, record their progress and decisions, and perform planning activities outside of the website. Individualized content is delivered based on the personal characteristics of the user, making it more relevant and immediately applicable.

This paper presents findings from a Delphi study [17] to determine feasibility of the Plan for Clarity website and gain input about specific content and features from potential users themselves as well as other stakeholders. We discuss how these findings were used to iteratively

develop and refine the online tool to ensure its usefulness. We also discuss broader implications of the findings for additional study and clinical practice.

2. Methods and materials

2.1. Design

A Delphi Panel mixed-methods research strategy [17] was used to reach consensus about the content of the website and explore the socio-cultural and behavioral factors that could affect its access and use, among individuals with knowledge about, or experience with, dementia and memory loss. Panel members included individuals from five key stakeholder groups: 1) individuals self-reporting memory difficulties, 2) caregivers of people with any stage of dementia, and professionals with expertise in dementia and/or aging, which included 3) medical professionals, 4) legal professionals, and 5) advocacy professionals. Three rounds of anonymous review of website content were conducted followed with completion of a quantitative and qualitative survey. At each follow-up round, a summary of the previous round's findings along with expanded design documents were sent to study participants for further review and survey completion.

2.2. Recruitment and enrollment

Participants from the five stakeholder groups were recruited over 6 months from November 2021 to April 2022. Patients with early-stage dementia and caregivers of people with dementia at any stage from a memory clinic were informed about the study through written information, as were individuals self-reporting memory difficulties through community outreach efforts. Members of the study team identified and directly contacted seven medical professionals with expertise in neurology, geriatrics, primary care, and nursing, eleven advocates from organizations focused on older adults, and seven legal professionals with expertise representing older adults in elder law and estate planning matters. All potential participants were directed to a web page to learn more about the study. Participants could submit an online form indicating their interest in being a member of the Delphi panel, identifying themselves as either a person with memory difficulties (abbreviated "PWMD" in this report), a caregiver of a person with dementia at any stage, or a medical, legal or advocacy professional. Interested individuals were then contacted by a member of the study team to confirm and complete enrollment. Twenty individuals completed the enrollment form, and nineteen (95%) subsequently enrolled: 11 professionals who serve diverse low-income older adults (4 legal, 4 medical, & 3 advocates) and 8 lay persons (4 caregivers, 4 PWMD). Participants were from eight different states and consisted of 12 women and 7 men ranging in age from 29 to 87, with 37% identifying as Black, Asian and/or Latino.

2.3. Data collection

Successively more comprehensive website designs and content were reviewed and a survey completed in each of the three rounds over a 10-month period from February 2022 to November 2022. Before each round participants received an email with a link to a website where they would complete the review and survey within the next two weeks. In each round, 14 participants (73.7% of those enrolled) completed surveys. An incentive of \$100 was given to participants for each round of survey they completed. The study was designated as exempt from IRB review based on DHHS exemption categories 2 and 3. [18]

2.4. Study measures

In the first round, participants viewed an outline of the website design, content, and intended usage. Participants then ranked their level of agreement with the completeness and relevance of the website I. Tessaro et al. PEC Innovation 5 (2024) 100312

content and the perceived accessibility and usability of the website for PWMDs and caregivers. Qualitative measures explored factors affecting website use, including barriers and facilitators and communicating about financial and legal matters. In the second round, participants viewed expanded and more detailed design documents and sample content, with consensus rankings and other questions constructed from qualitative patterns found in the first round. In the third round, participants viewed a prototype website and responded to questions about the content, format, images, and their overall impression of the website. In all rounds a comment could be provided for each ranking.

All surveys were pre-tested with two caregivers who were not part of the panel to ensure that the materials were understandable, and that the survey questions were clear in their meaning with appropriate wording and language. Medical and legal consultants, identified through the professional networks of study staff, provided feedback on initial study measures and survey instruments.

2.5. Data analysis

Quantitative: Consensus was reached if the level of agreement for a statement was rated 4 (agree) or 5 (strongly agree) on a 5-point Likert scale by >70% of participants, --70-75% is a consensus threshold commonly used in Delphi studies. [19] Qualitative: All responses to open-ended questions and comments were imported into a qualitative data management software program (ATLAS.ti 8.0) to organize and categorize the data for analysis. Descriptive exploratory methods which systematically search for patterns, themes, and regularities in the data for a descriptive summary of results, were used in analyzing the data [20]. Responses were initially categorized (coded) for questions about access and use, and concepts from the theoretical framework (deductive), and further coded when regularities emerged in the data for additional viewpoints, experiences, and explanations brought up by participants (inductive) [21]. Study themes built on the frequency and consistency of qualitative responses by stakeholders, and consensus for the follow-up quantitative responses [22]. Supporting quotations from the qualitative data illustrate study findings.

3. Results

3.1. Round 1

There was consensus that the website could increase awareness and understanding of financial and legal issues, help users gain skills and confidence in making financial and legal decisions and preventing problems, and improve communication with family, friends, and health and legal professionals (see Table 3, Round 1).

3.1.1. Usability

While there was consensus that people with dementia could access and use the website, this was qualified with comments that only those with mild or early memory difficulties could use it.

"People with dementia level of impairment, by definition, will likely be unable to navigate any type of website. However, I believe that people with mild cognitive impairment due to an underlying or degenerative disease may still be able to use this website." (Medical Professional).

The website was also viewed as beneficial for individuals with early memory difficulties no matter the cause, and for people as they age. Caregivers were considered in a position to likely want to use the website.

"it would be very beneficial to make this website available to people with cognitive disorders generally, not only memory impairment, as early as possible"

(Medical Professional)

Table 3 Consensus findings for each round of data (N = 14).

Consensus Measure	Percent Agreement
Round 1	
This website can help increase awareness and understanding of financial and legal issues that may occur for people with dementia/memory problems.	92.9
This website can help people with dementia learn ways to prevent financial and legal issues.	100
This website can be a resource for people with dementia/memory problems and their caregivers to get the information they need to make financial and legal decisions.	100
This website can be a resource to learn to talk about making financial and legal decisions for people with dementia/memory problems and their caregivers.	92.9
The skills learned from the website would make someone feel more confident making financial and legal decisions.	85.7
The sections of this website cover key financial and legal information for people with dementia/memory problems and their caregivers.	100
Knowledge and communication skills learned from this website can improve talking with family and friends about financial and legal issues.	92.9
Knowledge and communication skills learned from this website can improve talking with health and legal professionals.	92.9
People with dementia/memory problems who can use websites could access and use this website.	78.6
Round 2	
Clarity can be beneficial to anyone with memory difficulties no matter what the cause.	85.7
Clarity can be beneficial to anyone as they age and begin to consider the possibility of future memory difficulties.	100
People with memory difficulties and caregivers would be likely to use Clarity if it was recommended by a trusted source.	100
People with memory difficulties would feel more confident in using Clarity with someone they trusted.	92.9
People with memory difficulties and caregivers would be more likely to continue using Clarity if it included links to other information of importance. Round 3	71.4
People with memory difficulties who use websites are likely to	92.8
use this website if they know about it. People with memory difficulties who are not necessarily	100
proficient in using websites, could use this website with the help of someone they trust.	100

"A caregiver would want to get an idea as to where to start the process to get the person with dementia affairs in order before it is no longer possible." (Legal Professional)

To access and use the website it needed to be easy to use and navigate, with simple wording and supportive visual, video, and audio content; contain information that is relevant and easy to understand, with links that direct people to other relevant resources, particularly to support caregivers.

"It should be relevant and timely, and not just a rehash of information available elsewhere." (Caregiver).

"Simple words, big, bolded heading/topics, and I guess a way for them to quickly access their plan or information they'd put in, with links to relevant portions of the website so they're only accessing information that's pertinent to them." (Advocacy Professional).

3.1.2. Barriers to use

Frequently cited barriers to using the website were a lack of knowledge about the need for financial and legal planning, not knowing where to start, and the emotional and socio-cultural effects of dementia. Caregivers were busy with more immediate responsibilities, and a PWMD would be unable to understand and manage the website.

"They (PWMD) don't understand how to utilize it, they don't want to face the reality of their situation, they don't want to spend the time,

they don't feel it is beneficial. There are many more but you should get the idea." (PWMD).

"Assuming they [PWMD] have reliable internet and a working PC; domestic abuse, dementia too advanced, language barrier, self-denial, no family or love one support, pride/ignorance, stigma of dementia, pride, lack of trust, cultural prejudices, etc." (Caregiver).

3.1.3. Trusted source

A referral from a trusted source that the website was secure and beneficial was considered the primary way to help facilitate the use of the website for caregivers and PWMD. A trusted source was not only a personal relationship but medical, social service, and community-based groups and services.

"A referral from a trusted source will most likely be the impetus to use the website ... this does not however have to be a medical professional. For example, I can see this being an offering from a faith-based organization." (Medical Professional).

"Many people are hesitant to input personal details into the computer if they are not familiar with using the internet. If someone they trusted assured them that Clarity is safe and beneficial, they would most likely feel more confident using it". (Legal Professional)

3.1.4. Communicating about financial and legal matters

All participants agreed that the best time to start talking about financial and legal matters was early, when signs of memory difficulties were mild or before resulting cognitive and emotional changes become a significant barrier.

"As soon as there are symptoms of dementia! But that is problematic, especially if the person lives alone and has been independent. By the time family members realize there are issues, it may already be difficult to intervene. In my experience, a person with early dementia can do a very good job of concealing cognitive issues. Parents often want to remain independent and not burden their children. Children (even adult) often want to respect their parents' independence and privacy. By the time cognitive issues are addressed, there may be defensiveness, paranoia, and confusion about what decisions need to be made. So actually financial and legal concerns and decisions should ideally be discussed before there are signs of dementia, in the event that there is dementia." (Caregiver).

The emotional impact of dementia on the reluctance to discuss financial and legal matters with family and important others was noted by both caregivers and PWMD. One caregiver stated it was due to "stress, embarrassment, protect their love one's reputation, ignorance, lack of trust, lack of support"; another said, "motives of being looked upon as someone trying to take advantage." A PWMD stated the reluctance was due to "denial, embarrassment, concerns about their [family and important others] trying to infantilize, take advantage."

3.2. Round 2

Participants viewed updated and more detailed design documents and samples of videos and written content. Survey questions in this round were designed to explore consensus for patterns found in the qualitative data in round one. There was consensus among participants that the website can be beneficial for people with memory difficulties and anyone as they age, people would be likely to use it if recommended by a trusted source and would feel more confident using it with someone they trusted (see Table 2, Round 2).

3.2.1. Usability

After viewing four videos (Choosing a Financial Caregiver, Asking Someone to Be a Financial Caregiver, Starting the Conversation, and Durable Power of Attorney for Finances) and reading related written content, there

was strong agreement that the information was trustworthy (98.2%), easy to understand (91.1%), relevant (94.6%), and relatable (82.1%). Example comments about the *Starting the Conversation* video:

"Real relevant for everyone, whether you have memory difficulties or are a caregiver. Relevant for aging seniors, period." (Caregiver).

"The video provides a great example of how to approach this conversation without pushing any particular outcome or point of view." (Advocacy Professional).

Participants were asked when a PWMD and a caregiver would most likely consider using Plan for Clarity (see Table 4). The choice most selected for a PWMD was "after a discussion with a health or legal professional" with all caregiver participants choosing this option.

(For a PWMD) "Most people are in denial when it comes to this sort of thing. But advice coming from a health/legal professional would probably yield the best results."

(Caregiver)

3.2.2. Trusted source

Participants were asked who a PWMD and a caregiver would most likely trust for a referral to Plan for Clarity (see Table 5). The responses were often qualified with "depending on the relationship the person had with these different sources."

"I think caregivers are likely to trust medical professionals or community-based services. More than anything I think they will trust someone who can vouch for Clarity, so for example, another caregiver who has used it, or doctors who can vouch that their patients have benefited from it." (Advocacy Professional).

"I was between medical/legal pro vs. community-based org...I finally chose community because they are probably most equipped to have the time to help walk through this site with the dementia person/caregiver, provide support, and get through language/cultural barriers and fears." (Caregiver).

3.3. Round 3

There was consensus that PWMD who use websites would be likely to use it if they knew about it, and those who were not proficient in using websites would be able to use it with the help of someone they trusted (see Table 3, Round 3).

Participants viewed a prototype of the website, which included the *Welcome* page and two of the six content areas—the *Why Plan* and *Naming a Caregiver* topics. There was strong agreement (>85%) that the format, information, and videos on the *Welcome* page would engage the user, that the overall format would make users feel capable of using the website and comfortable with the information presented, and that the information in the two content areas was credible, easy to read and understand, and presented in a logical order (>92%).

All participants had a favorable impression of the website. Corresponding comments indicated it was easy to navigate, the content was easy to read and understand, and there was a logical flow to the information.

Table 4 Usability.

When would (a PWMD, a caregiver) most likely consider using Plan for Clarity?	A PWMD N %	A caregiver N %
After a discussion with a health or legal professional	8 (57)	5 (36)
After talking with a family member or significant other	5 (36)	4 (28)
On their own if they knew about it	0	1 (< 1)
Other – wake up call, all of above	1 (<1)	4 (28)

Table 5
Trusted Source.

Who would (a PWMD, a caregiver) most likely trust for a recommendation to Plan for Clarity?	A PWMD N %	A caregiver N %
A Medical or legal professional	6 (43)	7 (50)
Individual family member or significant other	6 (43)	2 (14)
Community-based group or service	2 (14)	3 (21)
Organization/agency dealing with health issues/aging	0	2 (14)

"Very clear and user friendly, especially for older adults. I love that it has large text, audio read-alongs, clear buttons for print/download/share, very clear layout, and easy-to-follow flow. That great web design is coupled with clear plain language text. This is a site that I'd refer people to." (Advocacy Professional).

"I probably would have found this helpful years ago as it makes me think as to where I've been, where I am, and where I might be going and what actions I should be taking to have a life that I can enjoy. "(PWMD).

Table 6 shows the overall themes from the three rounds of data and their implications for the development of the Plan for Clarity website.

3.4. Professional practice

All professional participants agreed they would be likely to recommend the website to their patients with dementia who can use websites and their caregivers. The most important aspects of the website they felt could support their practice was its ease of use, accessibility, simple wording, having comprehensive information in one place, and improved communication.

"I think this project could fill what I perceive to be a gap in this space for clinicians. In other words, throughout my clinical practice I have not come across a website that comprehensively covers all of these topics tailored to persons with neurocognitive disorders and their families and caregivers." (Medical Professional).

Table 6
Study themes and implications for the development of Plan for Clarity

dudy themes and implications for the development of Plan for Clarity.		
Themes	Design Implications	
Ease of Use: The website needs to be very easy to navigate, with relevant, easily understood information.	Further simplify the writing and interface. Ensure that content is understandable to readers with limited financial and legal literacy and those who speak a language other than English.	
Early Use: Clarity could be used by individuals with early signs of memory difficulties due to any cause, and anyone as they age.	Include content focused on why and when to plan, including planning prior to memory problems.	
Trusted Source: A trusted source can help facilitate the use of Clarity by PWMD and caregivers, and PWMD can use the website with trusted others.	Highlight the Clarity team's expertise and trusted sources of Clarity's information.	
Early Communication: Discussions about financial and legal issues are best held	Include content and functionality that encourage and support dyadic usage. Include content (including demonstrations) to encourage, address	

barriers to, and develop skills in

Include content to help professionals

implement strategies, including to

communicating with others.

improve communication.

before there are signs of memory

before barriers can impede the

discussion.

difficulties, or when signs are mild and

4. Discussion and conclusion

4.1. Discussion

The Plan for Clarity online tool was developed with direct input from people self-reporting memory difficulties and their caregivers, as well as healthcare and legal professionals and advocates, with the goal of making it useful for all constituencies. Data from the three Delphi rounds have implications for the design of programs to address this need and were used to refine this online tool. While consensus through quantitative statements about topics of interest is a primary aim of a Delphi study, the qualitative data that explored the opinions of the key stakeholders was instrumental in helping to drive the key design decisions of the website.

The findings and experience of this study also have important practice implications for healthcare providers serving patients with dementia and their caregivers. They indicate that healthcare providers can play a key role as a trusted referral for patients in need of financial and legal planning, should address financial and legal planning needs early, when patients have minimal symptoms or just concerns, should consider the needs, and leverage the potential supportive role of trusted caregivers, and can be supported in their practice by patient- and caregiver-directed tools like this website.

A key limitation of our study is that most of the study panel members were from Eastern and Western US urban areas, and although Delphi panel members provided lived and professional expertise on the needs of diverse older adults with dementia and their caregivers, the sample was too small to characterize differences or make specific findings about Plan for Clarity's acceptability to specific cultural and demographic groups. Additional research is required to determine this.

4.2. Innovation

The Plan for Clarity website is innovative in several realms. Foremost, it is the first online financial and legal educational tool to be developed with and for patients, caregivers, clinicians, and legal professionals. Our formative research with all of these key stakeholders suggests Plan for Clarity can be used by patients in early stages of dementia and caregivers, as well as by clinicians to support patients and caregivers as part of dementia care.

The website is also unique among online financial and legal planning tools in its theory and evidence-driven development. Content and framing are grounded in social behavioral and communication theories, and ongoing formative research, as described here, is employed in most aspects of the website's development.

The overall design and specific content of Plan for Clarity are also informed by a diverse set of formative research participants who provided feedback about overall design and specific content. Content, framing, and media are crafted to be inclusive of a wide set of culturally-linked characteristics including racial, ethnic, sexuality, SES, and geographic characteristics. A diverse set of characters and situations demonstrate care planning needs and options and promote engagement between family, friends, health providers, and legal professionals. Through this process and resulting features, the website strives to have a high degree of cultural competence, making its information more engaging and resonant to audiences commonly under-represented in financial and legal planning tools.

Finally, Plan for Clarity is designed to be accessible to patients and caregivers with low to moderate literacy, cognitive barriers, and limited financial resources — characteristics that put most financial and legal planning tools out of reach. Plain-language writing, combined with an easy-to-use, media-rich interface designed with cognitive accessibility in mind make the website uniquely approachable and usable. Spanishlanguage parity further extends access for Spanish-speaking populations. A broad library of state-specific legal and financial information results in targeted information about legal needs and services,

particularly financial support services which vary considerably by state.

4.3. Conclusion

This study showed consensus among lay and professional stakeholders that the Plan for Clarity website is a feasible tool that covers the key information, knowledge, and communication skills needed for people with memory difficulties, caregivers, and others to engage in financial and legal planning. Although people with memory difficulties and caregivers face barriers to financial and legal planning, they can benefit from using tools that are carefully designed with and for them and that are used early and with trusted others.

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CRediT authorship contribution statement

Irene Tessaro: Writing – original draft, Visualization, Resources, Methodology, Investigation, Formal analysis. Sarah M. Hooper: Writing – review & editing, Conceptualization. Denise Watt: Writing – review & editing, Investigation. David Menestres: Writing – review & editing, Supervision, Project administration, Investigation. David Farrell: Writing – review & editing, Supervision, Funding acquisition, Conceptualization.

Declaration of Competing Interest

All authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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I confirm all personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

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