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“Safety in Dementia’: Development of an online caregiver tool for firearm, driving and home safety”

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Introduction

Unintentional and intentional (e.g., suicide) injury and death are risks among individuals with cognitive impairment. Firearm access is a particular concern for individuals with ADRD (Alzheimer’s disease and related dementias), given firearms’ lethality. The convergence of increased rates of ADRD, associated injuries,¹ and firearm ownership represent a public health concern,² with firearms present in an estimated 40-60% of homes

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Conflict of Interest

The authors do not have any other conflicts of interests to disclose.

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of people with ADRD. While existing literature addresses safety in dementia,³⁻⁵ there is a paucity of practical tools for ADRD caregivers regarding firearms access.

Decision aids (DAs) support patient-centered decision-making by presenting available options – their benefits, risks, and areas of uncertainty – in an unbiased fashion. DAs also draw upon individual values, beliefs, and preferences in order to facilitate discernment and action.⁶ “Safety in Dementia” (SiD) (www.safetyindementia.org) is an online DA designed for ADRD caregivers (or individuals with mild ADRD) to support decision making surrounding firearm access for a person with ADRD. Additional decisions, added later in the development process based on stakeholder feedback, are “When is it time for the person with ADRD to stop driving?” and “What else can I do to improve home safety?” The goal of SiD is to improve knowledge, preparation for decision-making, action planning, and health-promotion behaviors to prevent injuries or death among people with ADRD and those around them.

Methods

SiD was developed through iterative refinement based on feedback from stakeholder interviews and focus groups (October 2018 to October 2019) with: medical providers (geriatricians, neurologists); dementia caregivers (previous or current); firearm owners; members of dementia/ADRD organizations; and, professionals (gun shop owners, lawyers, and medical reporters who work on firearms and dementia). Participants were recruited via the research team’s networks, social media advertisements, snowball sampling (i.e., through contacts suggested by interviewees), and postings on the Alzheimer Association’s Trial Match registry and ResearchMatch. Telephone interviews sought input on the educational needs, language, messaging, design, and implementation of the prototype tool. Interviews were recorded with permission, professionally transcribed, and coded for qualitative analysis. Interviewees received a \$25 gift card after completing an online survey to assess SiD acceptability using standardized measures.⁷

SiD was designed to address decisional needs and facilitate decision quality (i.e., alignment of decisions with the values of well-informed caregivers), while encouraging movement from pre-contemplation to contemplation and/or action.⁸ Weekly development meetings reviewed stakeholder feedback, resulting in iterative refinement of SiD’s content, design, structure, organization, and layout. A third-party usability testing service evaluated site stability, workflow, and logic.

Results

Over the course of SiD development, participants completed interviews (n=24) or joined focus groups of older veterans (n=7) or ADRD caregivers (n=12). Participants were predominantly white (n=19) and female (n=16) and represented various stakeholder groups, including: those with personal/professional experience with ADRD (n=12), firearms owners/enthusiasts (n=5), and healthcare professionals (n=7).

After early interviews and team discussions, the decision was made to focus on ADRD caregivers, with the potential for them to involve individuals with early or mild ADRD in

decision making. A public-facing website was created to optimize usability and acceptability, albeit with recognition that some priority populations may lack internet accessibility. We included information about driving and general home safety to make the tool useful to a broader audience of caregivers, enhance acceptability of firearm safety messaging (by contextualizing it with other safety topics), and to acknowledge similarities in decision making across the topics of firearms, driving, and home safety (see Table 1 for further descriptions). Content for the driving and home safety sections was largely based on an existing driving decision aid⁹ and home safety materials.¹⁰

Acceptability

Of those who completed the post-interview survey, 72% indicated the tool had about the right amount of information; 85% said the options were completely balanced. Participants responded that most (71%) or all (29%) the content was clear, and the tool was somewhat (50%) or very (50%) helpful. The majority (85%) said they would definitely recommend the tool.

Discussion

The SiD decision aid is the first comprehensive tool to help caregivers of those with dementia understand various strategies to improve safety, offering both information to make decisions and practical suggestions for next steps. Additional testing of SiD is needed to evaluate its effects on behavior change and outcomes for both caregivers and people with dementia, as well as to identify the best methods for dissemination to at-risk populations. The development of tools like SiD offer the potential to support caregivers, the people they care for, and the community in promoting health while respecting independence and individual rights.

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Table 1.

“Safety in Dementia” components, with key elements

Section	Imagery	Messaging	Key Points	Rationale
Home	Distinct colors Large font Clear images and links to content	Reassure and validate difficulties of caregiving Provide information on stages of disease and safety considerations	Identify 3 areas of decision-making (firearms, driving, home issues) Provide rationale for changes	Engage user Explain what decisions exist (and why)
About	Clear sections describing <i>Situations</i> and <i>Solutions</i> Additional information on site creation	Further describe difficulties of decision-making as caregiver Provide details on site use and its creation	Explain <i>Situations</i> and <i>Solutions</i> sections and how to use them Detail creation of site	Ground content into two main sections and explain their use Explain site origins to provide legitimacy
[Section]: Home	Header image to describe section Four composite quotes centered to draw user’s attention	Present composite “real-life” examples that demonstrate fear, confusion, grief, and concern about present home safety issues	Showcase potential parallels to caregivers’ own experiences with these safety concerns	Connect with user emotionally or intuitively Validate their experience Encourage user to view themselves in cases provided Normalize decisions and actions
[Section]: Situations	Questions stated plainly with large, bold buttons prompting user input; <i>Why This Matters</i> text explains rationale for each question	Present questions that impact the overall decision in neutral, value-based format	Questions based on: Legal ownership of items; Confidence in ability to make safety changes; Comfort in current circumstances; Short and long-term plans; Thoughts on how changes impact the person with dementia	Compartmentalizes a larger decision into smaller, more manageable questions Value-based, moral, or legal concerns help better inform user preferences and decisions
[Section]: Solutions	Stylized table split into two categories based on each section Describes solutions with pros and cons, alongside iconography to act as visual cues	Display common and practical solutions Neutral language and consideration of personal choice and values	Solutions for each section: Are quick to read; Provide pros and cons; Offer enough flexibility for user to choose based on personal circumstances and beliefs	By viewing specific solutions, users are more likely to engage with at least one option that aligns with their intuition, circumstances, or lifestyle
[Section]: FAQs	FAQs separated by strict lines to enhance readability	Normalize questions about how to make and implement these decisions	Address questions or concerns about practical options Provide further assurances to user about validity of their decisions and plans	Allow more detailed explanations of conceptual issues while keeping earlier sections focused on facilitating decisional clarity and reducing fatigue