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Stakeholder Engagement to Enhance Interventions for Family Caregivers of People with Dementia: A Case Study of Care to Plan

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Abstract

Family members are prominent providers of necessary care to persons with dementia. The psychological, emotional, and social costs of care have led to the development of interventions to support these families. Although evidence supports the effectiveness of dementia caregiver interventions, few have been implemented into practice. Stakeholder involvement may increase the potential for interventions to be integrated into community contexts. Utilization of community advisory boards (CABs) have been identified as a successful strategy to engage stakeholders in research and intervention development. Yet, little is known about the use of CABs when developing and refining interventions in dementia care. This article presents a case study of a CAB intended to inform the development and translation of an online dementia caregiver resource: Care to Plan. Qualitative thematic analysis of transcripts from seven CAB meetings over a 3-year period identified two major categories. First, the CAB process: who participated, how meetings were conducted, and issues that arose. Second, Care to Plan improvement: how CAB members provided key stakeholder perspectives resulting in changes in language, functionality, substance, and dissemination. Findings demonstrate how CABs can inform gerontological social work when facilitating the development, translation, and implementation of meaningful, community-based resources for dementia caregivers.

Keywords

Stakeholder engagement; community advisory boards; dementia; Alzheimer's; caregiving; knowledge translation; thematic analysis

Introduction

The number of Americans living with Alzheimer's disease, the most common form of dementia, is projected to increase from 5.3 million to 13.8 million by 2050. The majority (92%) rely on help from unpaid caregivers such as family and friends (The Alzheimer's Association, 2018). As a result, an increasing number of caregivers will be required to provide support and assistance to those living with dementia. It is well-documented that dementia caregiving imposes a range of physical, emotional, psychological, and financial demands on family caregivers (Brodaty & Hadzi-Pavlovic, 1990; Goren, Montgomery, Kahle-Wroblewski, Nakamura, & Ueda, 2016; Pinquart & Sörensen, 2006; Schulz & Beach, 1999; The Alzheimer's Association, 2018; Vitaliano, Zhang, & Scanlan, 2003). These and other trends, such as a decrease in the number of potential family caregivers and a geriatric workforce shortage, lend urgency to the need to develop resources and interventions that support dementia family caregivers (Gaugler & Kane, 2015).

Researchers have developed and tested numerous interventions to support family caregivers, many of which have shown promise for improving caregiver outcomes. In a review of 24 meta-analyses and systematic reviews, Gitlin and Hodgson (2015) identified more than 200 dementia caregiver interventions that have been tested in randomized controlled trials and found to be effective. Examples include Resources for Enhancing Alzheimer's Caregiver Health II (REACH II), which improved caregiver quality of life, and The Savvy Caregiver, which improved outcomes such as coping, caregiving competence, and depression (Belle et al., 2006; Hepburn, Lewis, Sherman, & Tornatore, 2003; Kally et al., 2014; Sepe-Monti, Vanacore, Bartorelli, Tognetti, & Giubilei, 2016).

Although evidence supports the effectiveness of dementia caregiver interventions, few of these interventions have been implemented into practice. Using a rapid review process, Gitlin, Marx, Stanley, and Hodgson (2015) found that only six out of more than 200 efficacious studies reported the translation of dementia caregiver interventions into practice. The limited implementation of evidence-based interventions in community settings is concerning. Many of these interventions continue to be developed in largely academic and scientific settings that do not incorporate the experiences or viewpoints of intended recipients. The lack of stakeholder engagement is thought to contribute to the minimal "uptake" by dementia caregivers in the community or the organizations who serve them (Wethington & Burgio, 2015). As a result, a number of potentially beneficial interventions remain inaccessible to individuals with dementia and their caregivers. Ongoing stakeholder involvement in all phases of the research process may increase the potential for interventions to be integrated into community practice (Gitlin et al., 2015). As such, stakeholder involvement has been identified as a priority for future research in dementia caregiving and other areas of health and community-based services research (Esposito, Heeringa, Bradley,

Croake, & Kimmey, 2015; Landry & Keller-Allen, 2017; Patient-Centered Outcomes Research Institute & Leaders Engaged on Alzheimer's Disease, 2017).

Stakeholder engagement meaningfully involves organizations and individuals with a stake in increasing the quality, quantity, and timeliness of useful and trustworthy information. Stakeholders can include caregivers, clinicians, healthcare delivery systems, patients, and policymakers. These stakeholders often have insights and perspectives unique from researchers that are necessary to help translate research into practice in community settings. For example, stakeholders can identify supports and barriers to implementation given their firsthand experience and contextual knowledge (Esposito et al., 2015; Patient-Centered Outcomes Research Institute, 2015). Incorporating stakeholders in the intervention development process is also essential when attempting to improve intervention efficiency, identify participant benefits, and evaluate implementation readiness and program utilization. Stakeholder involvement enhances the integration of programs into the community and can play a key role in exploring sustainable payment structures (Gitlin et al., 2015).

The emphasis on stakeholder engagement throughout social work (Keizer, 1987; Palinkas, He, Choy-Brown, & Locklear Hertel, 2016; Washko, Campbell, & Tilly, 2012) and related disciplines has resulted in dialogues about best practices for stakeholder involvement. Community advisory boards (CABs) have been identified as a successful strategy to engage stakeholders in research and intervention development (Newman et al., 2011; Silvestre, Quinn, & Rinaldo, 2010). They reflect a community of interest, for which members share a common identity, experience, history, and/or culture (Israel, Checkoway, Schulz, & Zimmerman, 1994; Strauss et al., 2001) and act as a liaison between academic researchers and the community. They help researchers identify assets and barriers and provide an understanding of the social and political context of the community. CABs aim to facilitate collaborative and equitable involvement of stakeholders by providing an opportunity to express the interests, concerns, and priorities of their community (Doyle & Timonen, 2010; Fang et al., 2016; Newman et al., 2011).

Current literature on CABs largely highlights their role in identifying community needs (Doyle & Timonen, 2010) as well as in improving the research design and informed consent process (Dong, 2014; Saunders, Greaney, Lees, & Clark, 2003; Silvestre et al., 2010; Souder & Terry, 2009; Strauss et al., 2001). CABs have also been used to improve participant recruitment and retention (Dong, 2014; Souder & Terry, 2009) and to increase community awareness and ownership for projects (Saunders et al., 2003). These benefits have led some federal and state funding agencies, such as the Patient Centered Outcomes Research Institute, to require that CABs or similar stakeholder engagement strategies be incorporated into research protocols (Newman et al., 2011; Patient-Centered Outcomes Research Institute Methodology Committee, 2017; Silvestre et al., 2010; Strauss et al., 2001).

Given the increasing urgency to develop evidence-based interventions that are accessible to caregivers, it is essential that CABs or similar stakeholder engagement strategies be used to translate interventions into effective practice in dementia care. CABs foster the co-production of knowledge, acting as a cultural broker between academic researchers and caregivers, persons living with dementia, and health professionals. Such perspectives are

important to incorporate into intervention development and translation as they are representative of the intended users of such interventions. These stakeholder perspectives may provide insight into the best ways to adapt and streamline interventions for caregiver use, as well as identify potential barriers that could hamper intervention implementation (Doyle & Timonen, 2010; Fang et al., 2016; Gitlin et al., 2015; Saunders et al., 2003).

This article fills a void in the literature by describing how a CAB was used to facilitate the translation of a dementia caregiver intervention for implementation in a community setting. The Care to Plan (CtP) tool is an online resource that provides dementia caregivers with tailored support recommendations and guidance in selecting appropriate support based upon individual needs. The development of the CtP was done in four phases. Phase I, initial development, involved gathering a robust base of clinical recommendations. A total of 422 clinical professionals and scientific experts (including 153 social workers) reviewed and rated a series of hypothetical dementia caregiver scenarios, completing a total of 6,890 scenario ratings (Gaugler, Westra, & Kane, 2016). Scenarios represented dimensions of the validated Risk Appraisal Measure (Czaja et al., 2009). Experts assigned scores to seven intervention types according to what they thought would best help a caregiver in a given scenario. The seven intervention types were broadly aligned with attempts to categorize dementia caregiver interventions (Gaugler, Reese, & Tanler, 2016; Gitlin & Hodgson, 2015; Pinquart & Sörensen, 2006). The scenarios and ratings were then compiled into a web-based portal. During Phase II, the CtP prototype was tested for feasibility and usability among 21 dementia caregivers.

Phase III of development was the translational phase. A CAB was formed to provide stakeholder perspectives to inform the development and improve the translation potential of CtP. The CAB provided in-depth reviews of the tool during and immediately following Phase II prototype testing. As we discuss in the Results section, the CAB's feedback altered content of the CtP web-pages considerably.

Phase IV involved feasibility and usability testing of the CtP Beta version (n = 9 dementia caregivers). For more on how the CtP was developed, see Gaugler et al. (2016) and Gaugler et al. (2016). A beta version of CtP is available at <http://www.caretoplan.org>.

The purpose of this case study is to provide insight into how future gerontological social work research and practice can rely upon similar stakeholder engagement strategies to enhance the overall effectiveness and implementation potential of interventions, services and programs for older persons and their families. This purpose is accomplished by (1) describing the construction and orchestration of a CAB in order to serve as a guide for future translation efforts and (2) presenting observational evidence supporting the effectiveness of incorporating a CAB in the development of a dementia caregiver intervention.

Methods

Prior to obtaining funding to develop and initially evaluate CtP, the senior author sent email invitations to potential CAB members. A total of 62 professionals, community advocates, and family caregivers of persons with dementia were invited to participate in the CAB,

resulting in a 43.5% participation rate. The invitations were sent out 1–2 times prior to initiation of the CAB in late Fall 2012. An extramural grant (K18 HS022445) was subsequently awarded and began in Fall 2013, with the first CAB meeting held in November of 2013. The University of Minnesota’s Institutional Review Board provided approval for this project (Protocol no. 1305S33361). Informed consent was obtained from all CAB members.

CAB members included dementia family caregivers, long-term care administrators, health care providers, dementia researchers, persons in dementia-related organizations, and various other professionals (i.e., social workers, nurses, psychotherapists). Several members (73%) were currently or formerly providing care for a person with memory loss in both a personal and professional capacity. The majority of members were female (77.3%) and white (86.4%), with a mean age of 58 years (see Table 1).

The senior author led CAB meetings in an open dialogue format that allowed members to freely provide feedback. Meetings were held on the University of Minnesota’s campus and lasted 60–90 minutes. Data were collected from seven meetings that took place between 2013 and 2016. Each meeting was audio recorded (except for one meeting due to a technological challenge) and the senior author took detailed notes on each meeting. A professional service transcribed audio recordings verbatim. Meeting transcripts and notes were organized in NVivo 11 for thematic analysis by the first author and second author. The first and second authors applied Braun and Clarke’s (2006) six steps of thematic analysis. The first and second authors read all transcripts and meeting notes and then convened to compare interpretations and points of divergence in order to refine and clarify the coding structure. Two research questions guided the thematic analyses: (1) How did the CAB process unfold? and (2) How did the CAB affect the usability and feasibility of the CtP tool? Two major categories were identified: the CAB process and CtP tool improvement. The CAB process encapsulated who took part in the CAB, how the CAB was conducted, and issues that arose during the process. The category of CtP tool improvement described how the CAB strengthened the usability, feasibility, and sustainability of the tool (Table 2). After finalizing the codebook, the first author coded all material. The first and second authors reviewed all coding, then defined and named categories and themes. Audit trails and weekly debriefing between the first, second, and senior authors enhanced transparency and credibility (Marshall & Rossman, 2016). All names were changed to protect confidentiality when reporting our analytic results. This case study follows an instrumental case study design (Baxter & Jack, 2008; Stake, 1995). In an instrumental case study, the case is of secondary importance, playing a supportive role in facilitating the understanding of a broader issue of interest (the broader issue in the present study is the importance of a CAB in developing a dementia caregiver intervention).

Results

The CAB process

Participation—Three themes emerged from the CAB process: participation, facilitator, and issues. Participation included who was involved in the CAB, how they participated, and CAB members’ consistency of attendance. Eleven participants attended at least four of the

seven meetings in-person or by phone. CAB members represented a breadth of community stakeholders with backgrounds ranging from health service professionals to caregivers. This enabled the CAB process to achieve a more balanced blend of professional and personal perspectives (63.4% providing care in a professional capacity, 81.8% in a personal capacity; see Table 1).

Overall, participation was democratic, with no one person dominating the discussions. The CAB meetings also engendered a sense of camaraderie amongst members. For example, one member sought the opinions of his fellow CAB members who were happy to give their advice:

[My neighbor]'s having a tough time. And [his wife] came to me and said: "Is it possible that we could form a caregiver's support [group]? Not specific to a disease, but specific to a caregiver that's really feeling the stress? And [the facilitator] and I kind of kicked it around a little bit, and I asked [the facilitator if] I could at least have a couple minutes and get your opinion.

(Henry, caregiver, corporate executive, 79 years old)

This led to a lengthy discussion amongst CAB members who were eager to share their professional advice and personal experiences. Other times, CAB members shared personal updates. One member, for example, was a caregiver for his wife. He was eager to share positive health updates to the support and encouragement of fellow CAB members.

Facilitator—This theme encompassed the different functions that the facilitator (the senior author) had in leading the meetings, how he exemplified appropriate meeting conduct, and handled logistics.

The facilitator provided leadership throughout the CAB process. Given the lengthy period between CAB meetings (5 months on average), the facilitator began each meeting by providing project updates, reviewing material covered in past meetings, and explaining goals for the present meeting. The facilitator welcomed members by name, answered their questions, gave context to the group discussions and probed for more information during meetings. The facilitator also addressed logistical issues at the start of each meeting and ensured that consent forms were signed, honoraria submitted, and refreshments provided. Prior to each meeting, the facilitator uploaded the meeting agenda and any other relevant material to a cloud-based, secure file folder for all members to access. The facilitator also followed-up each meeting by emailing a meeting summary to all members and uploading the audio recordings and transcripts for each meeting to the shared drive. Members were encouraged to view the transcripts and materials, and alert the facilitator if they felt anything was not accurate.

The facilitator set appropriate meeting conduct by demonstrating balanced communication and respect for all members. All viewpoints were given equal consideration. He detailed the mission and goals of the CAB so that the purpose and expectations were clear. The facilitator struck a balance between being agreeable and pushing back on suggestions. This allowed other members to be comfortable with healthy and respectful disagreement. For

example, after disagreeing on the language to use to disclose conflicts of interest to CtP users, the facilitator reassured members that disagreement can be productive:

That's good feedback. You see, that's part of the tension here. [Researchers] get feedback, and sometimes [we] don't want to do it, but then we come around eventually. (laughter) That tension is what makes [the CtP tool] better.

(Facilitator)

The facilitator assured CAB members that potentially dissenting and divergent views were welcome. He took steps to make sure that everyone felt at ease. This included repeated emphasis that if anyone felt uncomfortable contributing in a group setting, they could meet with him privately:

I realize sometimes when we're in really big meetings with lots of people, some people might not feel as comfortable voicing their opinions, their perceptions, their insights related to this project or really family caregiving issues in general. If that's the case, and if you ever wanted to set up an individual time to talk with me to share your insights regarding this project or anything else, let me know. Cause that certainly is a part of this. It's certainly a part of this community advisory board, and I really want to ensure that everyone's voice is heard and kind of has an equal place at the table.

(Facilitator)

The facilitator worked to democratize the process and broaden the role of experts by repeatedly offering members the opportunity to co-author manuscripts. He continually reminded CAB members how crucial their contributions were to the success of the CtP tool and he frequently expressed his gratitude for their work. For example:

Naomi (former caregiver, speaker/media host, 57 years old): You've really done a nice job simplifying this.

Facilitator: Naomi, this is so much due to what all of you [CAB members] have done. Again, I don't think I would have come up with this on my own.

Throughout the meetings, the facilitator was quick to praise CAB members for their feedback and he frequently mentioned the important role that CABs have in successfully translating research to practice in the community.

Issues—While the CAB meetings generally ran smoothly, minor issues occurred on occasion. The theme of issues included technology glitches, interruptions, and meeting conversations deviating from the intended purpose of the CAB.

Technology issues were more frequent during the first few CAB meetings. For example, malfunctions with the recording system resulted in the first meeting not being recorded. Issues with the conference call during one meeting caused CAB members on the phone to be cut off before the meeting ended. Every so often members who called in to meetings failed to mute their lines, resulting in a distracting echo. Technology issues were effectively addressed and were generally handled with humor.

In some instances CAB members would arrive or call in to the meeting late, which caused unintended interruptions. On one occasion the refreshments arrived late, resulting in a pleasant interruption for CAB members attending the meeting in person. These instances were handled good-natu-redly by the facilitator and other CAB members.

Infrequently, the conversation of the CAB drifted off-topic. For example, during one meeting CAB members insisted on providing recommendations for improving a scale that had already been validated. The scale was not within the scope of the CAB's charge since its validity had been established and could not be changed. This resulted in a conversation that had limited relevance and practical implications to the CtP online platform. Generally, the facilitator let these tangents run on for a brief period of time, waiting for the conversation to progress before subtly bringing the conversation back in line with the purposes of the CAB.

CtP tool improvement

Four major themes emerged from the category of CtP tool improvement: language, functionality, substance, and dissemination. These themes demonstrate how CAB members provided key stakeholder perspectives that were vital to improving the CtP tool.

Language—Language encompassed the ways in which the CAB shaped the wording used in the CtP tool. CAB members were instrumental in naming the tool and ensuring that terminology was appropriate and non-threatening. In one instance, members pointed out the need to alter the text on the opening screen to appear less academic and more inviting to caregivers:

Hillary (former caregiver, dementia consultant, 72 years old): That [wording] scares people off.

Danna (former caregiver, academician, 61 years old): [In this instance] I put my [self] as a caregiver, and I say: "So these researchers are telling me what?" 100 percent [the wording] has to be more talking to me as a caregiver.

CAB members provided advice regarding word choice, such as connotations associated with "psychotherapy" and "respite." They advised that "psychotherapy" be changed to "troubleshooting" and "respite" be changed to "take a break." Members also raised concerns with using the term "loved one." One member advised that many people with memory loss do not appreciate this term. Other members pointed out that caregivers do not necessarily love the person they are caring for. These suggestions resulted in the term "loved one" being dropped from all text.

The CAB also provided guidance on the readability and literacy level of the language used in the CtP tool. For example, members recommended displaying introductory text more succinctly in bullet points. In another instance, CAB member Janette advised changing the perspective to first-person and lowering the literacy level of the text:

Put [the text] in first-person to the person that's hearing [it]. Instead of saying, "explain to the person your role", say, give the example of: "I'm here as a guide to walk you through this". Just try to get the literacy level down and make it very easy.

Cause as we know, caregivers are stressed, and we don't want to have them trying to figure out what you're talking about.

(former caregiver, program administrator, 61 years old)

These suggestions helped ensure that the tool was accessible and relevant to the broadest audience possible.

Functionality—Functionality included how the CAB helped design the operability, navigation features, and appearance of the CtP tool. CAB members made a number of suggestions that were instrumental to ultimately shaping the beta version of the online care planning tool. For example, CAB members determined how best to display the recommendations. They suggested using a video or audio presentation to communicate recommendations. Members also provided important feedback regarding the appearance of the tool.

Naomi (former caregiver, speaker/media host, 57 years old): I don't know if it's just my old eyes— but I don't think the contrast is enough, in the writing or the type. [The font] needs to be a little bit bigger...

Janette (former caregiver, program administrator, 61 years old): If people are printing this not in color, [Naomi]'s making a [fair] point. You want to get those colors [down].

Facilitator: If you print this not in color, it's going to be in white background... That will print out you'll have greyscale in the back but with white type. I mean you'll be able to see it visibly.

Janette: Well, you're using a lot of black ink. But you're not going to be printing this page, would you?

Vic (caregiver): You gotta remember that you're addressing an older age here that's got diabetes and stuff like that. Colors do not come across the same.

Suggestions during conversations such as these resulted in larger font size, a high-contrast and print-friendly color scheme (relying on guidance from the National Institute on Aging; see National Institute on Aging, 2002), and navigation features such as a "back" and "next" button on each page in order to make the tool more user-friendly.

Substance—Substance included how CAB recommendations contributed to the content of the CtP. Members provided crucial feedback that was ultimately incorporated into the online tool. This included personalizing the tool, providing links to relevant resources, stating the amount of time the questionnaire would take to complete, and adding progress indicators. CAB members also noted the importance of emphasizing that the tool is not a commercial entity but that there may be potential costs associated with recommended services. Several members provided the critical viewpoint of a caregiver, pointing out aspects that researchers might miss. For example, one CtP question item asked about the care recipient's stage of dementia. Members expressed concern that caregivers might not know the answer. They suggested briefly explaining the stages of dementia along with the question, rather than including a hyperlink to a Mayo Clinic article. Many members pointed out that expecting

caregivers to read the article to determine the appropriate stage of dementia of their care recipient was a burden.

Dissemination—CAB members were instrumental to the successful dissemination of the CtP tool. The theme of dissemination demonstrated how the CAB provided recommendations to implement and evaluate the tool, and also identified resources to sustain the tool. Due to the wide variety of backgrounds represented by the CAB, members disseminated the tool to their own personal and professional networks. Additionally, they were crucial in identifying existing partnerships to aid in the dissemination of the tool. Tammy, for example, expressed:

We run community-based volunteer programs and caregiver support programs, and this tool seems like it would be a great way, if the caregiver found it on their own online, and then were referred to our program, it's something we could walk through with them and then provide them with caregiver support or refer them to a counselor. The other thing is, I could see us using this tool as our caregiver consultant sits down with caregivers and wants to make an assessment with them. You know, we've had a lot of different tools we've tried over the years, but some have been pretty complicated.

(service provider)

Another member suggested using social media to disseminate the CtP tool and several members with large social media platforms (e.g., one CAB member ran a popular blog on Alzheimer's disease) offered to use their digital influence to share the tool.

Discussion

Trends such as a geriatric workforce shortage and a decreasing number of potential family caregivers (Gaugler & Kane, 2015) along with the demands dementia caregiving imposes (Goren et al., 2016; The Alzheimer's Association, 2018) generate an urgency to develop resources and interventions that are accessible to dementia family caregivers. Although stakeholder engagement strategies such as CABs have been shown to increase the salience of interventions in the community, little is known regarding the use of a CAB to translate interventions into practice in dementia care. This paper addresses this gap in the literature.

The findings reported here can be used as a resource for future stakeholder engagement efforts in dementia caregiver intervention and resource development. The qualitative analysis described the process of the CAB as well as how it facilitated the development of a dementia caregiver intervention, CtP.

CAB members featured a blend of personal and professional perspectives, allowing the CAB to provide insights from these diverse contexts. Findings suggest that CAB meetings provided members with opportunities to emotionally connect and provide support to one another. This may be particularly apparent in CABs consisting primarily of caregivers, individuals living with dementia, or other such vulnerable populations. As such, implementing CAB protocols in research that involves these populations may offer members the rare opportunity to commune with others in similar circumstances, may contribute to

improved well-being among members, and in some respects may serve as an “intervention” in its own right for participants. Such mutual benefit is an important aspect of community-based participatory research models, especially among populations with potentially high levels of social isolation and stress.

The facilitator role was crucial to the success of the CAB by providing project updates, addressing logistics, and sharing meeting materials. In order to increase the transparency of the CAB process, audio recordings and transcripts along with all meeting materials were uploaded onto a shared, secure cloud-based server. The facilitator demonstrated respect toward all members and a commitment to mutual learning and understanding of CAB member perspectives. Such respect is important in order to deepen trust between researchers and community partners in efforts to address the health of older adults (Dong, 2014). The facilitator also encouraged members to agree to disagree, which Newman and colleagues (2011) identify as an important aspect of the CAB process. Further, the facilitator worked to broaden the role of experts by offering members the opportunity to co-author manuscripts. He ensured all members were given an equal voice by encouraging one-on-one meetings if members felt uncomfortable in a group setting. Minor issues such as technology glitches, meeting interruptions, and tangential conversations during CAB meetings were inevitable, but were managed in such a manner that they did not detract from the principal mission of the CAB.

The findings also depicted the CAB members’ involvement in the development and translation of CtP. The CAB was vital in shaping the language used in CtP and their input was instrumental in naming the tool, pointing out potentially problematic wording and suggesting appropriate alternatives, and ensuring appropriate literacy level of the text. Insight by CAB members also improved the functionality of CtP. Their feedback resulted in changes to the appearance of CtP, such as larger font size, higher-contrast color scheme, and navigation buttons. Members provided recommendations regarding the substantive content of CtP, such as personalizing the tool, providing links to relevant resources, and adding progress indicators. CAB members also pointed out potential barriers in the content of CtP that may hinder a caregiver’s ability or desire to use it. Finally, the CAB was instrumental in successfully disseminating the tool. Members volunteered to disseminate CtP throughout their personal, professional, and social media networks. They also provided recommendations for implementation and evaluation, as well as ideas about ways to sustain CtP. This reflects the results from previous community engagement projects that demonstrate how CABs generate community support and awareness by acting as a cultural broker between academic researchers and the community (Saunders et al., 2003).

A strength of this study is the inclusion of both caregivers and health professionals in the CAB. The inclusion of caregivers in the development and evaluation phases challenges top down approaches to research by placing stakeholder perspectives at the forefront (Fang et al., 2016) and aligns with international efforts to incorporate stakeholder perspectives in dementia research (Gove et al., 2017). Additionally, the project relied on the senior author’s existing partnerships with community members to serve on the CAB and to identify other potential members. Developing long-standing community partnerships prior to a scientific

project's initiation has been identified as an important part of successful community-based research (Brown et al., 2017).

While this study fills an important gap in the literature, there are several limitations. Although CAB members were diverse in terms of occupation and caregiving experience, members were primarily female, highly educated, and had limited racial and ethnic diversity. The inclusion of more members from diverse racial, ethnic, and socioeconomic backgrounds may have allowed the CAB to identify additional supports and barriers to the implementation of CtP in other communities. Another limitation is the extended length of time between CAB meetings (5 months on average), as CAB guides suggest meeting 9 to 12 times a year (Department of Children's Service, n.d.; Office of Adolescent Health, 2015). However, for this project, meetings were scheduled according to project milestones in order to minimize the burden of participation on CAB members. Additionally, this paper serves as a case study and results have limited generalizability to the development of other resources or interventions in other communities. CAB member participation was largely influenced by the senior author's extensive contacts and community engagement efforts. Other researchers and practitioners may have a more difficult time recruiting in regions with distinct healthcare and caregiving contexts. Finally, the CAB's influence on the CtP was not empirically tested, although observationally, CAB input seems to have improved the translational potential of the CtP. Despite these limitations, results should serve as a guide for future efforts to engage stakeholders in resource and intervention development.

Clinical implications for social work

Expanding the use of CABs holds clinical potential for gerontological social work research and practice, especially at the intersection of social work and dementia caregiving. While the effects of the CAB on the development and implementation of the CtP were not formally evaluated, what follows is an exploration of the potential implications of expanding the use of CABs.

Enhancing evidence-based interventions and programs that support family caregivers and persons living with dementia within healthcare and community-based settings is a priority in gerontological social work. While research supports the efficacy of various caregiver interventions (Gaugler, Reese, & Mittelman, 2015; Gitlin & Hodgson, 2015; Pendergrass, Becker, Hautzinger, & Pfeiffer, 2015), their implementation into clinical practice has been gradual. Involving stakeholders in the early stages of intervention design and implementation may minimize future challenges in translation and allow for more consistency in the delivery of evidenced-based interventions. CABs can provide researchers with contextual insights that are critical to facilitating translational efforts. For example, community stakeholders can emphasize the multidimensional factors that often need to be considered and addressed for effective implementation to occur (e.g., agency barriers, community dynamics). These firsthand insights provided by CABs can help reduce the imbalance often found between the dissemination of empirical outcome data and actual implementation, thus reducing the gap between best evidence and best practice. Additionally, feedback from community stakeholders can provide unique insights regarding

the needs for specific interventions, as well as feedback regarding the feasibility and functionality of programs and interventions.

Utilizing stakeholder engagement strategies such as CABs can help inform various staples of social work practice, including assessment, intervention, and ensuring client needs are being met through adequate resources. In particular, CABs can help inform accurate assessment of caregiver needs. Currently, caregiver burden and caregiver depression are the two most commonly assessed endpoints for caregivers in descriptive as well as intervention research (Cheng et al., 2017; Gaugler & Burgio, 2016; Losada et al., 2015; Pendergrass et al., 2015; van der Lee, Bakker, Duivenvoorden, & Drees, 2014). Because much heterogeneity exists within the caregiving career (e.g., demographics, family structure, concurrent roles), CABs can be a valuable resource in identifying additional endpoints that may otherwise be missed in the assessment process, particularly those that are more person-centered and relevant to diverse caregiving situations. Furthermore, multiple changes can occur within the caregiving trajectory that account for changing needs and resources that require ongoing assessment. CABs have the potential to serve as a valuable tool in helping to ensure that standardized assessment tools frequently used for caregivers and their care recipients are relevant or require modification when capturing their evolving needs and experiences.

CABs are also an ideal tool to capture changes in family structures. Caregiving in the twenty-first century is no longer illustrative of the traditional family unit. Increasingly common are blended families and multigenerational family units that pose unique complexities and challenges in the caregiving framework. As social workers often serve as a conduit for families and the utilization of community resources and services, community engagement feedback that is reflective of changing familial dynamics can help inform both social work research and practice of the familial needs that require specific assessment and intervention strategies.

Finally, CABs have the potential to emphasize factors that are often under-represented in the current caregiving literature. In particular, CABs can inform ongoing empirical efforts to better understand the needs and experiences of care-recipients. Currently, the majority of aging research, primarily intervention research, heavily focuses on caregiver experiences and outcomes (Heller, Gibbons, & Fisher, 2015). The use of stakeholder engagement through CABs can help inform gerontological social work research by highlighting the needs and priorities of the care-recipient. Additionally, CABs may help shed light on variables such as positive caregiving outcomes and the caregiving experiences of males, both of which can enrich the current caregiving literature that focuses primarily on the negative outcomes of caregiving and the experiences of female caregivers.

Future gerontological social work research can benefit greatly from stakeholder engagement strategies similar to those highlighted in the current study. Hallmark elements of social work, including assessment, intervention, and the enhancement of community resources, can all be enriched by the involvement of CABs which ultimately serve as agents for social change as it pertains to dementia, caregiving, and implementing appropriate evidence into practice.

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Table 1.

Community advisory board member demographics (N = 22).

Member characteristics	N (%)
Gender	
Male	4 (18.2)
Female	17 (77.3)
Missing	1 (4.5)
Age	
	Mean: 58.19 years
40–49	2 (9.1)
50–59	8 (36.4)
60–69	7 (31.8)
70–79	3 (13.6)
Missing	2 (9.1)
Ethnicity	
Hispanic/Latino	1 (4.5)
Not Hispanic/Latino	19 (86.4)
Race	
White	19 (86.4)
2 or more races	1 (4.5)
Missing	2 (9.1)
Education	
High school degree	1 (4.5)
Associate's degree (2-year college)	1 (4.5)
Some graduate courses	2 (9.1)
Graduate degree	17 (77.3)
Missing	1 (4.5)
Care for a person with memory loss in professional capacity	
Yes	14 (63.6)
No	8 (36.4)
Care for a person with memory loss in personal capacity	
Yes	18 (81.8)
No	3 (13.6)
Missing	1 (4.5)
Relationship to care recipient	
Spouse or partner	4 (18.2)
Daughter or son	9 (40.9)
Daughter-in-law or son-in-law	1 (4.5)
Other	5 (22.7)
Not applicable	3 (13.6)

Note: Missing data on five CAB members.

Table 2.

Qualitative thematic framework: categories and themes.

The CAB process	
Participation	<ul style="list-style-type: none"> • Who was involved in the CAB • Background of members (i.e., caregiver, health professional) • Level of participation (balanced input of all members vs. a few dominating voices) • Consistency of member attendance • Camaraderie amongst CAB members
Facilitator	<ul style="list-style-type: none"> • Functions of the facilitator leading meetings: giving updates, welcoming members, providing context, answering questions • Facilitator's handling of logistics: refreshments, honorariums, consent forms • Facilitator's transparency with CAB members: sharing of meeting minutes and recordings • How the facilitator engendered balanced communication and mutual respect, and exemplified meeting conduct • Facilitator's treatment of CAB members
Issues	<ul style="list-style-type: none"> • Technology problems: recording system glitches, conference call malfunctions • Interruptions to meetings: members or refreshments arriving late • Discussions not relevant to the purpose of the CAB
CtP tool improvement	
Language	<ul style="list-style-type: none"> • How the CAB influenced the wording of CtP • Naming CtP • Ensuring appropriate terminology and literacy level, and streamlining text
Functionality	<ul style="list-style-type: none"> • How the CAB affected the design, operability, navigation features, and functional appearance of CtP • CAB's influence on the layout and display features of the tool, font size, appropriate color contrast, use of bullet points, and graphics
Substance	<ul style="list-style-type: none"> • Ways the CAB influenced the content of CtP • CAB's recommendations on ways to personalize the tool and provide links to relevant resources • Recommendations to add or remove sections of text
Dissemination	<ul style="list-style-type: none"> • How the CAB aided in the dissemination of CtP • Members spreading it through personal and professional networks and utilizing existing partnerships • Suggesting when and how the tool can best be used by the community • Evaluating the tool and identifying resources such as funding, technology support and personnel needs to sustain the tool

CAB, community advisory board; CtP, Care to Plan.