

A multi-method co-design approach to develop CONTACT: A communication coaching tool for caregivers

Gail L Towsley PhD^{a,*}, Alexandra L Terrill PhD^b, Gregory Bayles MEAE^c

^aCollege of Nursing, University of Utah, Salt Lake City, USA; ^bOccupational & Recreational Therapies, University of Utah, Salt Lake City, USA; ^cDivision of Games, University of Utah, Salt Lake City, USA; *Corresponding author: gail.towsley@nurs.utah.edu

Abstract

Background: Care partners (CPs; relatives, and friends) are an integral part of the care team for persons living with dementia (PLWD) residing in long-term care facilities, where good communication is critical. Existing interventions to support CP communication skills while effective, are resource-intensive and often deploy a top-down approach, limiting uptake and sustainability.

Objective: To adapt our existing in-person coaching session intervention to an online CONversaTION cAre Coaching Tool (CONTACT), and obtain feedback on its acceptability, appropriateness, and feasibility.

Method: We developed and tested CONTACT using a multi-method approach in an iterative co-design process: (1) In-person coaching session content was adapted to an online platform (REDCap); (2) 3 professionals with clinical/research expertise in caregiving, nursing, social work, and gerontology provided feedback, which was incorporated into the next iteration; (3) CONTACT was tested by two cohorts of CPs, who then completed an online survey rating the tool's acceptability (4 items), appropriateness (4 items), and feasibility (4 items) on a scale of 1=strongly disagree to 5=strongly agree, and participated in a subsequent focus group session. Data were analyzed using summary statistics and content analysis.

Results: CPs (n=8) favorably rated the tool. Mean ratings for acceptability ranged from 4.13 – 4.25 mean ratings for appropriateness ranged from 3.88 – 4.43, and mean ratings for feasibility ranged from 4.13 – 4.57. CPs reported that the tool was clear, simple, informative, and logically organized and that it provided direction and structure for starting a conversation. They liked that instructions were provided via video and in writing, the definitions of terms, and large response buttons. CPs recommended additional videos depicting different scenarios.

Conclusion: Utilizing a collaborative co-design process to develop our tool empowered CPs to advocate for important features of CONTACT, including the type and method of providing information to foster communication skills that would support them in having conversations.

Keywords: caregivers, communication tool, long-term care

BACKGROUND

About half of the 2.2 million people residing in U.S. long-term care (LTC) settings such as nursing homes or assisted living facilities are living with Alzheimer's disease and related dementias (Harris-Kojetin et al., 2016). Care partners (CP; family members, friends, or neighbors) of persons living with dementia (PLWD) often serve as their proxy decision-makers. Yet, many LTC settings lack structure or resources to coordinate care routinely or effectively (Gilissen et al., 2017; Kemp et al., 2019), including discussions about end-of-life (Furman et al., 2007). For example, routine care plan meetings infrequently included discussions related to end-of-life care options, despite CPs expressing concerns about resident decline (Puurveen Cooke & Baumbusch,

2018). Excluding CPs from care conversations and decisions (Puurveen et al., 2018) can perpetuate feelings of uncertainty, lack of knowledge or confidence in healthcare settings, as well as discordance in an understanding of end-of-life (EOL) preferences between CPs and staff (Fetherstonhaug et al., 2019; Towsley et al., 2022). In the post-COVID-19 context where LTC settings struggle with staffing, the role of the CP has never been more crucial. Care partners often serve in the role of being an advocate or intermediary between the resident, staff, and other family members and friends, and effective communication is a critical skill. Communication skills of CPs vary and can influence the care of PLWD (Kemp et al., 2019). They constitute a necessary part of the care team and need to feel empow-

ered to have a voice. Unfortunately, CPs may feel unsure of their place in this type of setting, may lack confidence and be unsure how to be actively involved in care conversations, and may not be sure what to say or advocate for (Kemp et al., 2020; Keast et al., 2020). In fact, a recent review of online resources for informal CPs for PLWD found that although there is a lot of content on engaging in consultations, more emphasis is needed on resources for CPs to engage in timely conversations, advocate for PLWD preferences or continuity of care, foster communication and relationships among family and care teams (Gonella et al., 2019; Gonella et al., 2022; Kemp et al., 2020; Keast et al., 2020).

In-person or “live” family coaching sessions

We developed an intervention consisting of three iterative coaching sessions to empower CPs of residents in LTC to engage in and facilitate care conversations, where CPs reflect on their self-efficacy, knowledge, and competence as caregivers to act on a goal--to facilitate conversations about resident care preferences (Cattaneo & Chapman, 2010). To guide coaching session development, we used Cattaneo and Chapman’s (2010) Empowerment Process Model which includes 6 components consisting of setting a meaningful goal, taking action toward the goal, and reflecting on the impact of the action while drawing from one’s self-efficacy, knowledge, and competence. The focus is on change in human interactions while acknowledging that social context plays a role in the overall impact of the person’s experience (Cattaneo & Chapman, 2010). Each coaching session aligned with an empowerment model element (i.e., goals, actions, impact) and included a worksheet to record the session, including the proposed goal, barriers, facilitators to having conversations, caregiver’s strengths, and the steps planned to achieve the goal. The worksheet provided a list of “Conversation starters” and “Reflective listening skills” to facilitate supportive non-threatening conversations.

Coaching sessions included four steps: (1) education about LTC to clarify key terms and processes (e.g., care conferences, levels of care, and treatment preferences near EOL); (2) guidance on goal setting for CPs to identify what is important to them (e.g., conveying resident preferences to care team), identifying strengths they bring to the conversation, and strategies and phrases to foster communication; (3) taking action by creating a plan to achieve the goal (e.g., identify date to participate in care conference); and (4) reflection of the impact of achieving the goal (e.g., confidence and competence in communicating needs or preferences leading to improved communication quality that builds relationships, informs decisions

and provides emotional support to caregivers). In these in-person sessions, CPs acknowledged talking about EOL is difficult but necessary, and conveyed that setting specific, achievable goals and taking concrete actions identified in coaching sessions was helpful (Towsley & Terrill, 2020). Despite reporting frequent communication, CPs identified gaps in their knowledge about the resident’s preferences for care, especially related to potential transitions (e.g., higher level of care) and near EOL (Towsley & Terrill, 2020).

Effective communication around preferences for now and end-of-life is recognized as a critical component of better care. A recent systematic review of provider-focused communication interventions found only “inconclusive” evidence for improving communication between health providers and “dying people and those close to them” (Ryan et al., 2022). Several systematic reviews on communication skills training interventions for informal CPs of PLWD found that these tend to be effective in increasing the CP’s communication skills, competencies, and knowledge, and in improving QOL for the PLWD (Eggenberger et al., 2013; Nguyen et al., 2019). However, all of the interventions included in these reviews were relatively resource-intensive, requiring multiple in-person/face-to-face sessions, and were conducted by a skilled therapist or similar. This makes scalability and sustainable implementation difficult. The COVID-19 pandemic compounded CP communication challenges revealing a crucial need and opportunity to improve the scalable and sustainable potential of our intervention.

Traditional intervention development has followed a top-down linear approach in which an academic expert develops, pilot tests, and efficacy tests an intervention in controlled settings prior to delivering it to the public. Unfortunately, this can lead to interventions that are efficacious in controlled settings but fall short once the intervention is moved to the community (“implementation cliff”), often because it lacks input from real-world stakeholders/end-users and is not relevant or usable by the intended population (Weisz et al., 2006; Ng & Bearman, 2014). The National Institutes of Health (NIH) Stage model for the development and evaluation of behavioral interventions offers an alternative non-linear, iterative, and mechanism-focused approach that aims to address this disconnect by promoting the development of interventions that are both maximally potent and implementable (Onken et al., 2014). Using community engagement is one way to ensure greater translation and scalability of research-based interventions to practice (Ahmed & Palermo, 2010; Lindeman et al., 2020; Wallerstein & Duran, 2010).

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Research aim/Questions

We adapted our “live” in-person coaching session intervention to a more accessible, asynchronous, and scalable tool to help caregivers have an active role in care decisions and conversations. The purpose of this study was to obtain feedback on our CONversaTion cAre Coaching Tool (CONTACT), specifically on the acceptability, appropriateness, and feasibility of the tool with a focus on content and function. This approach was used to ensure that the tool was relevant and usable to care partners and informed by the NIH stage model (Onken et al., 2014). The goal of CONTACT is to help caregivers be prepared for conversations such as communicating what matters to the resident with dementia, the resident's change in condition, the potential need for a different level of care (e.g., hospice), and treatment decisions (e.g., intubation).

METHODS

Developing CONTACT

First, we partnered with a software developer from the Therapeutic Games and Apps Lab on our campus to consider possible solutions (e.g., app or website) where CPs could engage in an interactive way so the coaching aspect was kept intact. Based on those conversations we transferred our coaching session content to REDCap and labeled the intervention CONversaTion cAre Coaching Tool (CONTACT). We asked 3 professionals with clinical/research expertise in caregiving, nursing, social work, and gerontology to review CONTACT and provide feedback on organization, features (e.g., worksheet) content, and tolerability (e.g., time to complete). One professional reviewed the tool a second time to verify the incorporation of feedback.

We first transferred content to REDCap - a consumer off-the-shelf tool typically used for creating questionnaires and other survey content (Van Bulck, Wampers, & Moons, 2018). A potential disadvantage of this approach is that the software infrastructure limits the degree of interactivity possible within the intervention. However, the advantage of REDCap is that it allowed us to prototype the coaching tool very rapidly and enabled us to commence collecting feedback from researchers, community partners, and clinical experts (Williams & Cockburn, 2003). We used the survey features to prompt users through the coaching session content, which constructed a printable worksheet outlining their individualized goal for having a conversation.

The feedback we received from our professional beta testers included the lack of human element that was lost in the transition to digital. Additionally, some users were having trouble navigating the tool or did not understand how to apply the

tool to their own situation. We saw this as a design opportunity and began producing video introductions for each section. These introductions reestablished the human element to the coaching session process and provided context and guidance for users as they navigate through the coaching tool (Williams & Cockburn, 2003). With these adaptations, we sought the next step to assess our online tool.

Survey and focus group session

To evaluate our adaptation of the coaching sessions to CONTACT, we used quantitative and qualitative approaches to engage community partners, who had experience as CPs, to complete the online coaching tool, complete a survey and provide design feedback via two focus group sessions. This approach enabled an iterative, collaborative process, to adapt our coaching sessions to a personalized, online tool to empower caregivers to be prepared for conversations. The University of Utah Institutional Review Board approved this study.

Setting and participants

All development activities and focus group sessions occurred virtually via REDCap or Zoom. Adults who identified as current or past CPs of an older adult were English-speaking, and willing and able (e.g., access to a computer) to participate and were eligible to complete the online tool and partake in the focus group session.

Procedures

Two weeks prior to the focus group sessions, we sent participants a link to complete CONTACT and a brief survey (via REDCap). GLT moderated and ALT co-moderated both focus group sessions. We reviewed the purpose of the study and session procedures for a successful discussion online. Focus groups lasted 75 minutes and were audio recorded.

Measures

The REDCap survey asked participants about their experience using the tool. Questions included 12 items rated on a Likert scale from completely disagree to completely agree about acceptability (e.g., “I like the online coaching tool”), appropriateness of the intervention (e.g., “The online coaching tool seems applicable”), feasibility (e.g., “The online coaching tool seems doable”) (Weiner et al., 2017). Participants were asked about their specific user experience; for example, how long it took them to complete the tool, whether they completed it in one sitting, and whether they talked with anyone else while completing the tool. Several open-ended questions asked participants to expand on their user experience; for example, what worked well and what did not, and what other content might

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Table 1. Demographics

	Family (n=8)
Age in years (SD)	63.75 (SD = 6.20)
Gender	
Male	1 (12.5%)
Female	7 (87.5%)
Ethnic Background	0
Not Hispanic or Latino	8 (100%)
Hispanic, Latino, or of Spanish Origin	
Race	
Non-White	0
White	8 (100%)
Education	
Some high school	0
High school graduate	0
Technical school graduate	0
Some college	2 (25%)
College graduate	3 (37.5%)
Postgrad/Professional	3 (37.5%)
Employment Status	
Full time	1 (12.5%)
Part time	3 (37.5%)
Retired	3 (37.5%)
Disability	
Other	1(12.5%)
Internet Literacy	
Navigating the internet	4.5 (1.07)
Opening and downloading files	4.38 (1.41)
Completing surveys and forms online	4.5 (1.07)
Watching videos	5 (0.00)

be helpful. Finally, participant comfort with using technology was assessed and basic demographic information was collected.

A semi-structured interview was used to guide the focus group discussion. The first set of questions focused on feasibility (e.g., ability/ease to complete the tool), inviting participants to first share their overall impression of the tool, followed by asking about what worked well, what did not, and whether the tool was easy to use and intuitive to navigate. The next set of questions focused on the appropriateness of the tool including the function of CONTACT, and comprised questions about specific content that is useful or less useful, and whether there was any additional content they would deem helpful. The third set of questions focused on acceptability and asked participants to describe how they thought this tool could be useful, how this tool could make conversations easier or harder, and when and in what settings CONTACT might be used. We also asked participants to tell us about features that were essential to using the tool, and what features

that were not included might be helpful.

Data analysis

Demographics were managed in REDCap. Summary statistics were calculated. Audio recordings of focus group sessions were transcribed and verified to the recording. Using directed content analysis (Hsieh & Shannon, 2005), all members of the research team (GLT, ALT, GB) coded and categorized transcripts by feasibility, appropriateness, and acceptability. Both positive and negative codes were discussed. Discrepancies in coding were resolved in team meetings. Survey and interview findings were analyzed separately and converged at the interpretation phase (Creswell & Plano Clark, 2017).

RESULTS

Table 1 shows the demographic characteristics of the CP experts. Most were female, White, and current or recent CPs of PLWD at home or in LTC settings. All CP experts agreed or completely agreed on their ability to use the Internet for various tasks (e.g., completing surveys).

Table 2 shows the means and standard deviations and CP exemplars related to acceptability, appropriateness, and feasibility. Acceptability survey item ratings ranged from 4.13 to 4.25. Qualitatively, CPs conveyed that the tool was informative, provided direction for having a conversation, and could be useful in a variety of scenarios. They liked the definitions provided in the tool as a way to get “everyone on the same page” as well as people can choose which definitions to click. Survey item responses related to appropriateness ranged from 3.88 to 4.43. In the focus group session, CPs noted that they appreciated that instructions were provided in writing and via video and that they had the ability to customize the tool to their personal situation. Survey item ratings about feasibility ranged from 4.13 to 4.57. CPs conveyed that the tool was simple and easy to navigate, and appreciated that the icons and buttons were easy to read.

Care partner expert recommendations

Our expert CPs made a few recommendations related to the content and features of CONTACT. First, CPs recommended that we refine a few definitions to be more audience-friendly (e.g., psychosocial). Second, CPs also suggested we include a variety of conversation scenarios, such as talking with other family members. Third, CPs recommended adding additional resources related to dementia, such as different types of dementia, different levels of care, especially when having to move from one setting to another (e.g., assisted living to a nursing home), and steps to take when the person being cared for dies. Two features that CPs thought would support them in attaining their

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Table 2. Survey items and corresponding Exemplars of Acceptability, Appropriateness, and Feasibility

Survey items (Rating 1-5)	Mean	SD	Quotes
Acceptability			
The online coaching tool meets my approval.	4.13	0.83	"It was really great, it made me think a lot about these questions." S3 (FG1)
The online coaching tool is appealing to me.	4.25	0.71	"The layout was very clear and I was able to go through it very efficiently." S3 (FG2)
I like the online coaching tool.	4.25	0.89	
I welcome the online coaching tool.	4.13	0.83	"It makes [having a conversation] easier because it gives you what to ask and an organizational structure of how to do that." S3 (FG2) "I think it would be nice to have something... saying what happens if it doesn't work. Like if they are not willing to communicate or if they are scared." S2 (FG1)
Appropriateness of the Intervention			
The online coaching tool seems fitting.	4.43	1.13	"This is helpful in any situation where a caregiver is dealing with end of life. Whether it be in your own home or in a care facility, even in the hospital." S3 (FG1)
The online coaching tool) seems suitable.	4.14	1.21	
The online coaching tool seems applicable.	4.38	1.06	"This is an extremely useful tool at end of life or even not quite end of life but looking to make that change into "I'm not able to take care of myself and I need to be in an assisted living or in a nursing home environment." S1 (FG1)
The online coaching tool seems like a good match.	3.88	1.13	"Some kind of introduction that would maybe go over that... talking about the purpose and what you hope to achieve with this tool for your loved one." S3 (FG1)
Feasibility			
The online coaching tool seems implementable.	4.13	0.64	"It was really simple and I think it was at a level where everybody could understand it." S2 (FG1)
The online coaching tool seems possible.	4.57	0.79	"I liked that there were video instructions as well as written description of the instructions that it met both needs--People who can't read anymore can listen to the instructions and those who didn't want to listen could read it." S4 (FG1)
The online coaching tool seems doable.	4.43	0.53	
The online coaching tool seems easy to use.	4.50	0.53	"It followed itself and it was easy in that respect... but I would have to have someone set it up and help me with it." S2 (FG2) "What if we write this up and nothing happens? Is there a trigger or a follow up on this? Or a reminder?" S1 (FG1)

S= Subject; FG1 = Focus Group 1; FG2 = Focus Group 2

goal included improving the worksheet functionality and providing email reminders to undertake the actions specified to reach their goal.

DISCUSSION

Including CPs of residents living with dementia as part of the care team is critical. Coaching sessions that focus on encouraging conversation support the increased need to provide CPs with communication skills to navigate person-centered care and care coordination in long-term care settings (Gonella et al., 2019; RAISE, 2022; Kemp et al., 2020). Using a co-design approach, we enlisted CPs to complete CONTACT and provide feedback in a focus group session. Our CPs deemed our online

tool feasible, acceptable, and appropriate, noting that the video portions provided greater clarity and context around the coaching process, and it was easy to use. More specifically, CPs confirmed that they liked the educational content that was provided via video and in writing lending the tool to multiple forms of engagement (e.g., audio, video, text). Further, they conveyed that the structure provided to facilitate setting a goal for engaging in a conversation was helpful.

Long-term care settings are under-resourced, understaffed, and have limited access to information technology specialists for non-critical services. Any software deployed within LTC settings would

have to be readily accessible, highly stable, and easily implemented in a variety of circumstances, which REDcap offered. While the software infrastructure in some ways limited the degree of interactivity possible within the intervention, it allowed us to prototype the coaching tool very rapidly, so that we could begin to collect feedback from professional and CP experts (Williams & Cockburn, 2003). Using REDCap as the platform provided us with features that promote accessibility such as the ability to increase text size or text-to-speech translations. Using an iterative cycle of building out features, seeking feedback, and then making changes throughout the development and adaptation process improved the quality, applicability, and scalability of the tool long term (Williams & Cockburn, 2003).

Limitations and strengths

Our research is limited by the small, non-rationally and ethnically diverse sample, and only included CPs who read and write in English, limiting generalizability. This sample of CPs also had few problems using a computer, which may be one reason why they rated the tool as easy to use. However, one person was unfamiliar with computer use in general. Our work aligns with the National Institute on Aging stage model, specifically Stage I, which focuses on implementation and fostering the development of health behavior

interventions (Onken et al., 2014). By engaging CPs early in the development process, we mitigated potential pitfalls that could occur by using more traditional comments that include delivery of an intervention in a finalized state without end-use input (Onken et al., 2014; Ahmed & Palermo, 2010; Wallerstein & Duran, 2010). Our choice to use REDCap led to rapid development, iterative revisions, and a product ready for testing. Recommendations for future studies include better participant representation and a larger trial examining the feasibility, acceptability, and CP outcomes such as goal attainment or increased self-efficacy in having conversations could be examined. In the long term, our online tool is suitable for an embedded pragmatic trial.

CONCLUSIONS

Our collaboratively codesigned tool empowered CPs to advocate for important features of CONTACT, including the type and method of providing information to foster communication skills that would support them in having conversations. Ensuring that CPs, who serve as proxy decision makers for PLWD when they are no longer able to communicate, understand residents' preferences is vitally important for both the PLWD and CP's quality of life. Enhancing the communication skills of CPs via CONTACT may be a promising way to support CPs as an integral part of the care team.

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