

Creating a toolkit with stakeholders for leveraging tablet computers to support person-centred dementia care in hospitals

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Abstract

Introduction: People with dementia may refuse care because they feel overwhelmed by an unfamiliar environment. Everyday technology such as tablets have the potential to support person-centred dementia care in hospitals.

Aims: We aimed to identify barriers and enabling factors in order to develop a toolkit to support the use of tablets in engaging individual and group activities, especially to play family videos, for hospitalized older people with dementia.

Methods: A participatory action research approach was employed. We facilitated staff focus groups and conducted interviews with stakeholders. A toolkit was developed based on participants' perspectives on how to support successful adoption.

Results: Our analysis identified two enabling factors: users' engagement in developing a toolkit for support and adapting implementation to meet local needs. Barriers included staff and family inexperience, mechanical instability of hardware, issues around privacy and data access, technology use and personalization of messages. The toolkit includes short videos, a brochure for family caregivers, and a pocket card for staff.

Discussion and implications: Staff, family and patients start with varying levels of experience with the use of tablets, making education and support vitally important to implementation. Health organizations should involve staff, patients, and families to find practical solutions.

Keywords

Dementia, tablets, technology, hospital, co-production

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Introduction

Dementia is a clinical syndrome characterized by progressive cognitive decline in cognitive function. People living with dementia experience symptoms that include memory loss, agitation, depression, and language and mobility issues. Dementia is a leading cause of disability in older people, affecting those who have dementia as well as their family and caregivers. While interventions are available, symptoms are difficult to manage and can lead to caregiver burnout. Non-pharmacological management should be prioritized before medication due to the adverse effects of

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pharmaceuticals and lack of evidence for improvement in cognitive outcomes, especially in those with mild cognitive impairment.^{2,3}

Staying in an unfamiliar hospital ward can be overwhelming for people with dementia. Hospitals in general are unequipped to address the unique needs of patients with cognitive impairment since they find it difficult to conform to standard procedures set by the hospital. Separation from family and friends can exacerbate this emotional distress in people with dementia. Anxiety in family caregivers of hospitalized people with dementia is high.

Person-centred care has been widely recognized as best practice in dementia care, but robust evidence is limited to demonstrate what works based on defined outcomes and how to realize person-centred care in hospitals. Person-centred care involves holistic care, paying attention to psychosocial needs, respecting patients as individuals and enabling their abilities. Overlooking personhood in a task-focused culture can trigger responsive behaviours, which are an expression of unmet needs through disruptive verbal or physical actions. Strategies for transitions in care have been developed to promote person-centred care; key elements include education and communication among the care team, family and patient. 10–12

One study attempting to implement psychosocial interventions tailored to the individual, including intensive counselling, found no long-term improvement in patients with mild dementia. The authors hypothesized that this was due to a lack of reinforcement of the interventions. Yet, others have identified benefits in such approaches when performed in more severe cases of dementia or for longer durations. Technology-based interventions that improve communication are showing promise to enable person-centred care, particularly when staff are well trained to use them such as internet connectivity and device power supply are optimized. 14-16

In our recent review of the use of touchscreen tablets in care settings, three benefits were found for patients living with dementia: an increase in engagement in care activities,² a decrease in responsive behaviours and³ a positive effect on quality of life. ¹⁷ A study investigating the use of Skype on tablets with older residents in a long-term care setting reported positively about residents being able to talk with family. 18 Other scholars have explored and identified benefits in using tablets for reminiscence through visual images and music, and cognitively stimulating applications and games. 19,20 In our tablet study, we found practical feasibility and acceptance of using the tablet to deliver family video messages to reassure patients with early to late stages of dementia in a Canadian hospital. 14 In this paper, we report the knowledge translation process - how we support clinical teams to implement the technology by using a co-produced toolkit, disseminating information and providing the means to act on research demonstrating the tablet's benefits. The toolkit consists of short videos, a brochure for family caregivers, and a pocket card for staff. We are a transdisciplinary team, comprising a medical student, physicians, nurses, patient and family partners. Our investigation identified two key enabling factors: users' engagement in developing a toolkit for support and adapting implementation to meet local needs. We also found five key barriers: staff and family inexperience with tablet use, mechanical instability of hardware, issues around privacy and access to data, technology use and personalization of messages.

Methods

Aim

This study aimed to achieve two objectives:

- a. To identify the key barriers and enabling factors for effective implementation of the tablet intervention using pre-recorded family videos
- b. To develop a toolkit to support users (families and staff) to apply the tablet intervention in practice to support person-centred care in hospitals

The tablet intervention and study design

A family member of each patient participant was asked to use their phone or other digital device to self-record a one-minute video. The video was then emailed or texted to the last author. The last author uploaded the video to the tablet for use in the hospital. The pre-recorded video included a reassuring, comforting and supporting message to help the patient feel safe and allow staff to assist with a specific care task, such as taking medication or getting dressed or washed.¹⁴

We facilitated staff focus groups, conducted stakeholder interviews, and held regular monthly research meetings for a year. We developed a toolkit based on participants' perspectives on what needs to be in place to support successful adoption. A participatory action research approach was employed to co-inquire about the barriers and enabling factors for implementation, as well as to take action (i.e., making a toolkit) for cultural change in care approaches.²¹ Two core underpinnings of coproduction, positive collaboration and reflexive practice, guided our research process. We also used the five strategies, ASK ME outlined by Mann and Hung (2018):

A- Avoid assumption, by team reflection to examine our assumptions

- S- Support each person to do their best, by focusing on strengths and possibilities
- K- Knowledge to be put into action, by creating the toolkit together
- M- Meet early and regularly, engaging stakeholders throughout
- E- Ethical sensitivity and responsibility, pay attention to values (i.e., trust needed for relationship building)

Setting

The research was conducted in an older adult mental health unit and two medicals units in two large urban hospitals in Canada. The older adult mental health unit (19-bed) provides assessment and treatment related to neurocognitive disorders and mental health illnesses, including dementia and/or mood disorders for older adults with the length of stay of 2–6 months. The two medical units (20 beds each) provide acute medical assessment and treatment of older adults and the length of stay is 1–4 weeks.

Sampling procedures and participants' characteristics

The sample included 10 patients, 10 family members, 40 staff members (n = 60). Patient participants were purposively recruited. To maximize variation, we selected patients with diversity in types of dementia, behaviours of concern, socio-cultural backgrounds, gender, age,etc. We invited one family member of each selected patient participants to participate in producing the video. The family members were four daughters, four sons, and two spouses. Patient participants' inclusion criteria were (a) have a diagnosis of dementia, (b) able to see and hear the video played on the tablet, and (c) have showed responsive (aggressive) behaviours during the time of recruitment. See Table 1 for the patient participants' characteristics. For staff, a convenience sampling method was used. The only inclusion criteria for staff participants was that they must work on the unit in frontline positions. Our staff participants included 20 nurses, 15 care staff, two unit clerks, two rehabilitation assistants and one recreation assistant.

Data collection

We facilitated staff focus groups (n=3), conducted stakeholder interviews (n=3), and held monthly research meetings throughout 2019. The research team included patient partners, family partners,

Table 1. Patient participants' characteristics.

Characteristic	N (%)
Age (years)	
60–75	I (I0)
76–85	6 (60)
Older than 85	3 (30)
Gender	
Male	5 (50)
Female	5 (50)
Stages	
Early	2 (20)
Middle	7 (70)
Late	I (I0)
Ethnicity	
Caucasian	5 (50)
South Asian	4 (40)
Black	I (I0)

physicians, university students and a nurse researcher. All three focus groups were conducted in a staff room of the unit; each lasted 30–45 minutes. In the focus group, we asked open-ended questions, including: "What is your experience of using the tablet to deliver family videos for patient care?", "What are the barriers?", and "What resources and support do you need to apply the tablet intervention in everyday practice?". A total of 10–14 staff members attended each focus group. The stakeholder interviews included a nurse leader, a patient partner and a family partner. We asked: What is your perspective of using the tablet to deliver family videos for patient care? Focus group interactions and stakeholder interviews were recorded and transcribed verbatim.

Data analysis

Thematic analysis²² of the transcripts for the focus groups and stakeholder interviews was performed to identify key enabling factors for effective implementation of the tablet intervention using family videos. The data analysis process involved six phases:¹ Familiarizing ourselves with the data, Generating initial codes,³ Searching for themes,⁴ Reviewing themes,⁵ Defining and naming themes, Producing the results. In Phase 1, the text and video data in the transcriptions were read and viewed in the research meetings to gain a sense of the overall issues and concepts. For Phases 2 and 3, two authors (XX, XX) individually coded data and identified potential themes. Then, in Phases 4 and 5, the whole research team checked and validated if the themes worked in relation to the coded extracts and the entire data set. Based on the themes of barriers and strategies, we proceeded to produce the toolkit.

Ethical considerations

The research was approved by the university research ethics board (2018s0221) and the hospital research institute (V2018s0221). Participation was voluntary and all participants provided informed consent. Patients and their families who expressed interest in participating after receiving study information from a nurse met with the first author who explained the study purpose and procedures and answered questions. If the patient was not capable, his/her family was asked to consent on his/her behalf and the patient was then asked for assent to participate. This consent process was ongoing to ensure that the patient's right to refuse at any time was upheld.

Results

Our analysis identified two main enabling factors: users' engagement in developing a toolkit for support and adapting implementation to meet local needs. The five key barriers are: staff and family inexperience, mechanical instability, issues with privacy and access to personal data, lack of person-centred care, and technical problems.

Enabling factors

In the focus groups, many staff voiced the need of support for the use of tablets. A nurse remarked, "I use a different phone, so how does this iPad work? We need to know how to find the family video, what is the password, what do we say to the family about this to get their help." Another care worker added, "yes, we need education and some things that we can use to help". A nurse leader went ahead and developed clear instructions about how to operate the tablet for the staff to use. Patient and family partners in the research team further developed videos, pocket cards and family brochure to support staff to adopt and adapt the intervention.

Successful tablet use also required staff to know the patients' interests and involve family for collateral information. In the focus groups, staff members underscored the salience of personalizing the use of tablets for meaningful engagement by working with families. In an interview, a nurse leader recalled a success story, "I had a patient who was so lonely and bored. She does not speak English, so it makes the communication difficult. The daughter told me she likes Chinese Opera, so we worked together to set the opera shows for the patient to watch. It made a big difference." Reduced social isolation, decreased responsive behaviours as well as the ability to personalize messages and care interaction were widely reported by nursing staff as a

result of tailoring the tablet to the patient, exemplifying the benefit of adjusting tablet use to meet local needs.

In another example from the focus groups, a patient who was initially reported by a nurse as "aggressive" became more relaxed when the tablet was provided with videos to watch. A family member explained, "I have observed a simple intervention like this, using family videos really worked. The family videos work because there is always a connection between the person and family." A nurse leader said, "I see the iPad can help to reduce the use of restraints and medications, which we know ultimately don't lead to good outcomes for our patients. I think the key to our success here is we helped everyone (staff) understand the benefits, WIIFM - what's In It For Me". XX came and showed how the tablet intervention would help us care for our patients." When the tablet was found by a nurse to be too heavy for some patients, a "mechanical arm" was introduced which alleviated the weight of the tablet for both staff and patients and allowed for optimal angle adjustment. By identifying preferences and addressing local issues, the staff could enhance tablet use.

Barriers

Table 2 displays the barriers identified by the staff, family and patient participants with recommended strategies to overcome them. Based on interviews and focus groups with stakeholders, strategies were developed to overcome the barriers. The development of these strategies relied especially on the experiences of nursing staff who have personally facilitated implementation of the tablet in the care setting and already successfully attempted some of them on their own initiative. We then developed a toolkit to help staff and families using tablets to engage the hospitalized patient with dementia by playing family videos.

Several barriers were identified with the application of everyday technology in dementia care. A common issue reported by staff, patients and families was the need for training. The reasoning for this was twofold, involving both the novelty of applications for touchscreens and the challenges surrounding dementia care in general. According to a nurse from the focus groups, this applied to staff and patients who were "not familiar with electronics" or "tech savvy". Ideas such as a three-minute video on how to access the tablet, as well as a pocket card or brochure, were suggested for training purposes, highlighting the potential usefulness of the toolkit. Applications had to be readily available when needed, requiring a consistently available power supply and internet connection.

Another important barrier involved the human interaction with the tablet technology. In our investigation, patients with decreased mobility had trouble

Table 2: Barriers and recommended strategies.

Barriers

Staff and family inexperience

- All users need detailed knowledge about the process of how to implement the tablet intervention
- Support needed to build confidence in users

Mechanical instability

- Nurses were fearful about dropping the tablet while juggling medications
- Patients found the tablet is too heavy to carry and difficult to watch when lying in bed or sitting in a wheelchair

Information privacy and access issues

Personalization

Technical issues

- Wi-Fi connectivity
- Power demand
- Malfunctioning applications

Strategies to overcome barriers

- Create a user-friendly toolkit to support care teams and families to learn how to create videos and apply them in care activities
- Post instructions on hospital or health authority websites and bulletin boards to guide caregivers on device access when needed
- Develop user videos to provide examples of message topics
- Emphasize keeping the video message clear by recommending that one family member record one message at a time, limiting the video to one minute
- Secure the tablet with a mechanical arm on a mobile stand to prevent the device from being dropped, thereby improving convenience of use (see Figure 1)
- Patient portal applications with username and password authentication procedures in compliance with Personal Information Protection and Electronic Documents Act standards would be required for staff to access devices that hold personalized video messages, with device securely stored when not in use
- Only applications with clear privacy policies and devices supporting data encryption are recommended
- Messages should be clearly labelled and organized in albums to indicate corresponding patient for whom they were made, with patient and family always determining use of messages
- Staff should familiarize themselves with patients' life stories to understand what communication strategies work best for patients
- Staff may explore with family to find additional application activities to optimize the tablet use based on their hobbies and interests (i.e. favourite applications and games, YouTube videos and music)
- Ensure stable wireless internet connection is available throughout facility and applications are installed and tested prior to introducing them
- Nearby outlet and power cord should be secured before initiating activities using the tablet

simultaneously carrying and using the device independently, relying more on staff to alleviate the weight. Moreover, in one case a nurse found "it was hard to get to the right angle for the patient to watch [the tablet]".

With private family video messages being used, privacy was raised as a concern by staff. To ensure protection of patient and family information in our tablet project, only staff members directly involved in the care of an individual patient with dementia have local access to pre-recorded family video messages; videos are stored in a password-protected family album exclusively on the tablet used with the patient. Between individual patient uses, the tablet and its mount are disinfected

and securely stored. After the patient's discharge, the patient and the family partner determine the future use of their personalized family video messages. For instance, prior to deletion, the family video messages can be transported to a device at a long-term care home, where new care staff can more easily get to know the patient and be encouraged to practice person-centred dementia care.

The toolkit

To support clinical teams with the tablet intervention implementation, we co-produced a toolkit for leveraging the tablet in the hospital setting with patient and



Figure 1. Tablet with mechanical arm on a mobile stand.

family partners. The toolkit consists of a small collection of videos, a brochure for family caregivers, and a pocket card for nursing staff, which can be viewed at a public website https://www.vchri.ca/ipad-project.

Videos: To capture a diversity of voices, the video collection comprises 2–3 minute perspectives of three people: a person with a diagnosis of dementia, a family member caring for a spouse with dementia, and a nurse leader with first-hand, front-line knowledge of implementing the use of pre-recorded, personalized tablet video messages with patients with dementia in the hospital.

Video 1: patient partner with dementia lived hospital experience. In the first video, the patient partner (MG) briefly describes how a person with dementia can perceive the stressful nature of the hospital ward, as large teams of care providers may overwhelm people with dementia who do not recognize them or understand their intents, emphasizing the need for personcentred care. The patient partner then provides brief step-by-step instructions on how family caregivers can create a personalized tablet video message for specific care situations which the person with dementia may find distressing. These situations commonly involve intimate Activities of Daily Living (ADLs) such as taking medications, eating, toileting, dressing and

bathing, which may be perceived as a violation of privacy by people with dementia.

Video 2: family partner of patient with dementia. In the second video, the family partner (NH) continues with a brief explanation of why the pre-recorded, personalized tablet messages are simple, effective and useful from a family caregiver's perspective, clarifying how powerful video messages can be in reassuring patients as they come from the familiar voice of a friend or family member.

Video 3: nurse leader explaining tablet implementation for dementia care. In the third video, the nurse leader (CC) provides insights into the practical experiences of nursing staff who have used tablet messages to alleviate such responsive behaviours as anxiety and distress among people with dementia in the hospital. The messages help build a meaningful, personalized connection and applications are chosen using patient interests, thereby preventing social isolation and addressing the barrier of lack of person-centred care. The nurse leader also found that educating staff about the purpose, benefits, and method of operating the tablet reduced inexperience, making it important to facilitating implementation.

Family Brochure: While the family brochure is available online, a paper copy is also given to the family caregiver accompanying the person with dementia in the hospital. The immediacy of a paper brochure can more easily facilitate discussion with nursing staff regarding the kind of personalized message that is needed. The family caregiver is encouraged to take notes at the time of discussion with staff and then to write a loose script before recording a message. The trifold brochure describes the tablet intervention in greater detail, provides the rationale for its use, includes brief instructions for creating a personalized message, and contains the URL to the tablet project website, along with useful telephone numbers and links to community resources such as the Alzheimer's Society.

Pocket Card for Staff: The laminated pocket card for nursing staff can be easily attached to a lanyard, for quick reference to a short mnemonic on practical bedside guidelines during care. The lanyard also contains a QR code for nursing staff and the URL to the tablet project website.

Used together, these tools hold the potential to enable a team-based approach to dementia care that places the person with dementia at the centre. Knowing more about the patient's life and family relationships, care routines and preferences also enable staff to spontaneously create in situ opportunities for social communication. This kind of contextual information and communication helps to transform the

generally task-driven nature of institutional care into a more person-centred care for patients with dementia.

Discussion and implications

Pre-recorded family messages are needed now more than ever—by patients with dementia, staff members, and family caregivers—especially as healthcare settings become increasingly conscious of the risk of infection transmission from in-person contact during the COVID-19 pandemic. This study examined the barriers to and enabling factors of tablet use in hospitals to support patients with dementia. While touchscreen technology has been used to facilitate assessment and screening of cognition, its use to assist with activities of daily living or provide leisure is more recent and innovative, hence raising the necessity for proper instruction and training.²³ In our study, we found education was key to achieving familiarity with tablets since staff, family members and patients start with varying levels of skill and experience. 16 Our findings are consistent with those described in another study by Loi and colleagues that user engagement is vital to success.²⁴ Moreover, studies defining patient well-being as the target outcome found it to be greatly determined by staff actions. 25,26 By demonstrating a warm, supportive demeanour and keeping a relaxed pace, staff empowered patients to become more engaged during tablet activities, thus benefiting them more.²

An important implication of our research is that users need knowledge and technical support to build confidence to use technology. Once care staff are oriented to tablet usage and understand the context of the patient's life story, they can incorporate patient preferences and are thus better equipped to provide engaging person-centred care.²⁷ Technology offers substantial potential as part of a psychosocial approach to dementia care. As nurses become more skilled in providing person-centred care by using everyday technology such as tablets, they will be better equipped to support quality of life for patients with dementia.4 The advantage of videos, brochures, and pocket cards is that they are practical and cost-effective tools. Health organizations need to invest resources on acquiring touchscreens materials and increasing human capacity; improving the staff-to-patient ratio allows for more one-to-one care support.4

Past research highlights the importance of optimizing ergonomics. Besides weight, factors that also decreased user-friendliness were the visually hindering reflectiveness of the device and finger placement freezing the screen. Staff in our interviews concurred that a mechanical stand would improve accessibility and prevent the device from being dropped. This aligns with past recommendations to keep the tablet on a

secure surface such as a table and match its height to the patient, reducing muscle stress and maximizing comfort.²³ Other related technical issues that would require resolving were Wi-Fi connectivity, battery power consumption by complex apps, and malfunctioning software.^{16,29}

Privacy was described as a concern due to the personal nature of family video messages that are individualized to the patient. The same applies to the protection of patient data during general use of mobile devices in healthcare. The important to protect private patient data from misuse by using encryption, eliminate means for information transfer and processing, and avoid human error allowing unintentional access. Because such technology is being newly integrated into hospital care practices, accompanying policy to safeguard privacy can be ambiguous. All 31-33

Conclusion

This study has explored some of the enabling factors and barriers to adopting tablet technology for dementia care in hospitals, particularly to share family messages. Our investigation identified two key enabling factors - users' engagement in developing a toolkit for support and adapting implementation to meet local needs. Based on the lessons learned, we offer practical strategies to overcome barriers associated with staff training, device use, information privacy, personalization, and technical issues. Pre-recorded, personalized family videos delivered on tablets can be a useful means of helping patients with dementia relate to and cooperate with the intimate care that nurses provide. Tablet video messages from family also enable staff to more effectively bridge communication gaps with patients with dementia, which is especially important during a pandemic when physical distancing would otherwise lead to social isolation.

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Guarantor

LH.

Contributorship

LH and JS reviewed relevant literature and conceived the study. LH developed the methodology and acquired ethical approval. LH and JS were involved in patient recruitment and data collection and analysis. As part of the toolkit, LH was involved in creating the brochure and pocket card while RO was involved in website development. JS developed the videos with CC, MG, and NH, which were edited by LH. JS, LH, and CC drafted the manuscript which was reviewed, edited, and approved by AB, MG, NH, and all the other authors.

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Supplemental material

Videos are available at:

Video 1: https://www.youtube.com/watch?v = 2uHbeAS03nw, https://www.youtube.com/watch?v = 5f8RSOz6Hok

Video 2: https://www.youtube.com/watch?v=lsEsuux9-OA

Video 3: https://www.youtube.com/watch?v=qU6OanRYbQo

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