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Designing a Mission statement Mobile app for palliative care: an innovation project utilizing design-thinking methodology

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Abstract

Background: Eliciting individual values and preferences of patients is essential to delivering high quality palliative care and ensuring patient-centered advance care planning. Despite advance care planning conserving healthcare costs by up to 36%, reducing psychological distress of patients and caregivers, and ensuring palliative care delivery in line with patient wishes, less than 33% of adults engage in it. We aimed to develop a mobile application intervention to address the challenges related to advance care planning and improve the delivery of palliative care.

Methods: Design-thinking methodology was used to develop a mobile application, in response to issues prominently identified in current palliative care literature.

Results: Issues surrounding communication of patient values from both the patient and provider side is identified as a main issue in palliative care. We designed a mobile application intervention prototype to address this.

Conclusions: Our “Mission Statement” mobile application will allow patients to create a mission statement identifying what they want their care team to know about them, as well as space to identify important values and preferences. Patients will be able to evolve their mission statement and values and preferences over the course of their palliative care journey through the application. Design-thinking methodology is an effective tool to drive healthcare innovation and bridge the gap between research findings and implementation.

Keywords: Palliative care, Advance care planning, Design-thinking, Technology, App

Background

Palliative care is a dynamic, interdisciplinary, and highly personalized process [1]. It aims to not hasten or delay death, rather, focus on pain and symptom management, improve quality of life, and emotional and spiritual care [1]. Palliative care also involves advance care planning, which includes reflection on one’s values and beliefs and then communicating them with healthcare providers and family members [2–4]. The benefits of advance care planning are well documented. Advance care planning

allows patients to receive care which is in line with their values and preferences [5, 6], allows caregivers and family members of patients to have reduced psychological distress over being a surrogate decision maker and interpreting unknown or ambiguous patient wishes [7, 8], and conserves healthcare costs by up to 36% [9, 10]. Many guidelines also report on the importance of honest and compassionate communication in end-of-life care being essential for patient-centeredness [11–13].

Despite these benefits, less than 33% of adults have engaged in advance care planning conversations or completed advance directives due to conversations around death and dying being difficult and uncomfortable [14]. Healthcare providers also face difficulty in having

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conversations around death and dying with patients, and in eliciting the values and preferences of patients [15]. Further, while patients report on communication as important for high quality care [16, 17], they also report dissatisfaction with physician communication [18]. In palliative care, where communication between patients and physicians is delicate, complex and particularly important [19], poor communication in these settings result in anxiety, depression and dissatisfaction with care amongst patients and their families [20–23].

New approaches for conversations in palliative care and with advance care planning include the use of board games in community settings which use gamification to decrease stigma around conversations around death [24, 25], and using patient-reported outcome measures (PROMs) as a communication tool [26, 27]. However, the feasibility of implementing board games in a clinical setting is currently unknown [8, 9]. Further, there is no current valid and reliable PROM found acceptable for use in palliative care [24–28].

Our team is responding to the need of improving patient communication in palliative care and advance care planning through creating a mobile application to track patient values and preferences. We are designing a mobile application which will allow patients to create a patient “mission statement”, and provide an overview of their goals, values, and wishes; which will be personalized by each patient.

A mobile application measuring patient values and creating a patient mission statement will also aid in the provision of care [29]. Through having healthcare providers conveniently, at-a-glance view the concepts most important to patients, there will be less ambiguity around patient values and preferences, which is a current problem in palliative care and advance care planning [7, 8, 30, 31]. Through having a mobile application, patients will be able to input concepts important to them and healthcare providers will be able to use it as a tool for conversation and direct care to make patients feel less burdened to repeat their information over again as well.

A mobile application tracking quality of life and values, along with a patient mission statement will also address the problem of caregiver psychological distress when making decisions around ambiguous patient values [7, 8]. Allowing patients to be in control of having their values and preferences inputted into the mobile application and displayed to caregivers and the care team will reduce ambiguity around patient values.

The aim of this paper is to provide an overview of the design-thinking methods used to drive the first phase of development of this innovation. Results from published literature documenting issues in palliative care were

leveraged to create our mission statement mobile application. Subsequent phases of development will include iterative prototyping and testing the application with stakeholders, using design-thinking methodology. Our goal is for clinicians to learn about design-thinking methodology so they can lead their own design-thinking interventions to leverage insights from literature, improving care delivery and patient outcomes.

Methods

Our team is using design-thinking methodology [32]. Design-thinking is human-centered methodology for creative problem solving [32]. It is outlined as prioritizing and using user empathy to guide solutions [32]. Collaboration between multidisciplinary teams to provide multiple perspectives on an issue, using ideation and applying qualitative research to generate potential solutions, iteratively testing solutions for the purpose of refining the solution, and creating and testing a prototype encompass the phases of design-thinking [32]. The cyclical process of continuously ideating, prototyping and testing solutions make it unique from linear or top-down approaches to designing health interventions [33]. Design thinking is widely used in the business and engineering sectors, with the design-thinking firm IDEO in partnership with Stanford University (now called the d.school and one of the most highly sought academic programs at Stanford) being the world’s largest design-thinking groups; designing products for Apple, GE, and other major companies [34, 35]. A recent systematic review identified twenty-four design-thinking interventions used in healthcare which all demonstrated increased satisfaction, usability and effectiveness compared to traditional interventions [33]. Asch and colleagues also report on design-thinking methodology as integral to creating high-impact innovation in healthcare. Asch calls on clinicians to employ design-thinking to create forward-thinking solutions to system issues [36].

Our team worked with the Health Leadership Academy at McMaster University on approaching the design of our intervention, using design-thinking methodology. Below we provide an overview of design-thinking methods.

The first phase of design-thinking methodology is to identify a problem [32]. Problem identification occurs through leveraging insights from stakeholders on their perspective, and synthesizing data to identify the most prominent issue [32]. Once a problem has been identified, a preliminary prototype is created as a solution, which is then refined and tested. Refining and testing occurs through the POEMS framework and qualitative analysis.

Observation of user interactions with a prototype is analyzed through the Peoples, Objects, Environment,

Messages and Services (POEMS) framework [37]. The POEMS framework is used in the field of design-thinking to analyze observational data [37]. In summary, a structured sheet consisting of the headings “Peoples”, “Objects”, “Environment”, “Messages” and “Services” are used to organize observational data of users interacting with a prototype, such as a mobile app. The “users” include all stakeholders. Data is then synthesized and combined to identify common themes regarding user interactions and the context of themes. This data is then analyzed through a bottom-up process to identify the implications of common themes and their application to refine the design of a prototype [37]. Through the process of contextual inquiry [38, 39], data results are displayed visually for the purpose of the research team to engage in peer debriefing and review the concepts as a group. Application of final themes are then applied to the prototype design. This process occurs iteratively and through each stage of development of the proposed intervention in order to refine it based on user experience.

Qualitative analysis also occurs through interviewing relevant stakeholders [32]. Semi-structured interviews are conducted to gather stakeholder perspective on a prototype [32]. Additional probing questions are asked in design-thinking methodology to elicit the way stakeholders feel and think about a prototype, in addition to their thoughts on interacting with the prototype [32]. Qualitative interviews are then transcribed verbatim and analyzed to identify common themes from across stakeholders. This data is also analyzed through a bottom-up process to identify the implication of themes to refine the prototype.

Through synthesizing observational and qualitative data, a prototype is iteratively refined in a cyclical nature.

Current status of project

This paper highlights the first phase of our project. Previously published literature, which engaged stakeholders in palliative care, was used to identify prominent issues in palliative care to design a preliminary mobile application. Current literature in palliative care identifies a prominent theme of issues with communication of patient values from both the patient and provider side [15, 30, 31]. We used this information to develop a mobile application. Details on refining and testing the prototype mobile application is the focus of the next phase of our study.

The planned intervention is our “Mission Statement” mobile application. The mobile application will allow patients to create a mission statement early in the palliative care process based upon their goals and values. The mission statement will be visible for patient family members and members of the healthcare team through patients

sharing their mission statement with healthcare providers and family, who will also have a version of the mobile application. The mission statement will be adaptable as the patient progresses through their treatment course in order to clearly identify changing patient wishes and values along the palliative care course. This intervention will create empowerment and agency in palliative care, driven and led by what the patient’s values and preferences are.

Our aims for the intervention are to reduce ambiguity in palliative care around patient goals and values and having the patient voice at the forefront rather than lost in translation.

Components of application

Currently, the mobile application is proposed to have three main components. Firstly, an open space for the patient to write a mission statement embodying the main message they would like others to know about them that may help caregivers and healthcare providers with their provision of care. Secondly, a page below for patients to respond to questions in an open-ended manner which have been identified as important for palliative care patients (e.g., what music would you want to listen to on your last day alive) [24–28]. Thirdly, a final section which will allow patients to group important values to them. Patients will be able to click and drag values such as “being in as little pain as possible”, “having my whole family with me”, and “being able to use my hands” into categories: “very important”, “a little important”, “not very important”. Each component of the app will have the flexibility for patients to write their own preferred information to maintain the app being as patient-centered and patient-focused as possible. Visuals on the final version of the application will be provided once the prototyping phase is complete.

Our proposed app will be as simple to use as possible, will act as a way to display patient values and preferences, and as a communication tool between patients, caregivers, and physicians. Stakeholder input will also be used at every step of the way in refining this prototype, following design-thinking methodology.

Future direction of project

We will be using design-thinking methodology to iteratively refine our mobile application to include patient and stakeholder input at every step of the way. We will begin by creating a low-fidelity coded prototype and collect qualitative and observational data from patient and provider groups. Using synthesized feedback, our team will refine the mobile application. Large-scale user testing will occur with our final prototype. We will administer our mobile application and pilot test it at hospitals and hospices in a large urban center, using the POEMS

framework to collect and analyze observational data. Qualitative feedback will also be collected from healthcare providers and patients through interviews which will measure their experience of how the app has impacted process of care and communication in palliative care.

Design-thinking uses qualitative research methods, including ethnographic observations, in order to gain rich information about the users for which the interventions are tailored to [40, 41]. Design-thinking has shown in some cases to have a bias towards action (i.e., implementing a final product without adequate user input) [40]. Proposed methods of protecting against this source of bias includes testing minimally viable products early in the design phase in order to learn from users and stakeholders how to improve them [40]. Through creation of our intervention, we will iteratively test our mobile application in line with its stages of development to gain user and stakeholder input at every stage. Through including users iteratively, we are also minimizing social desirability bias [42].

Discussion

Our proposed idea introduces a novel mobile application intervention to improve the quality of palliative care delivered and to improve the patient, provider, and caregiver experience around advance care planning. We will continue to use user-centered design-thinking methodology to create a mobile application measuring patient values and preferences, and creating a mission statement for use with patients undergoing palliative care. Through receiving input from patients, caregivers, and healthcare providers, our team will tailor our intervention, as outlined in design-thinking methodology [32], to ensure our intervention is created using patient and provider input. The results from our study will create an innovative intervention which will enhance patient-provider communication in palliative care and empower patients in this delicate area of care [43, 44].

A systematic review conducted by Slort and colleagues identified barriers and facilitators to end of life communication from both the patient and clinician level [15]. At the patient level, barriers to end of life communication identified were ambivalent patient attitudes about prognosis, not talking about their problems and needs, and changing ideas and preferences as their disease progresses [15]. At the clinician level, lack of time, difficulty in initiating conversation on an issue, personal obstacles (e.g., dealing with patient denial) and not taking initiative to contact patients spontaneously were barriers to communication [15]. Facilitators at the clinician level included taking initiative to talk about end of life issues, shared decision making, being open, and learning about patient preferences [15]. Slort and colleagues

recommended that clinicians need to continuously re-appraise their patient's needs and preferences and have a high level of communication skills to discuss emotional and spiritual end of life issues with patients [15].

A recent review conducted by Noordman and colleagues identified current strategies and tools in use by healthcare providers for communication in palliative care [30]. Face-to-face communication strategies include: the teach-back method where patients repeat back information communicated to them, jargon-free communication, and adopting a slow rate of speech [30]. Written and online strategies include supplemental graphs and illustrations for conversation, and using short sentences and paragraphs [30]. Tools (patient decision aids and question prompt lists) were also identified in one study to facilitate patient-provider communication [30]. A structured list of questions for healthcare providers to ask patients was found to empower patients to discuss prognosis and end of life issues, and reduce decision burden [30].

Further, a review by McCaffery identified that most patient decision aids and question prompt lists are not designed and tested with patients, rendering them inadequate [31]. Noordman and colleagues specifically recommend using emerging technologies and media with user-centered design for future research and to practice design technology-mediated innovations for patients in palliative care [31].

Our proposed initiative addresses the aforementioned barriers to end of life communication from the patient and clinician perspective such as lack of time, difficulty initiating conversation, and the need to constantly re-appraise patient needs and preferences. Our mobile application is also responding to the need of a patient decision aid in palliative care being created using user-centered design and leveraging emerging technology, and *applying* the important insights gained from previous research.

Conclusion

Through using design-thinking methodology, our mission statement mobile application is an innovation project, designed within healthcare; rather than copy and pasting a solution from another sector and applying it to healthcare. Identifying issues with communication in palliative care, covered extensively in current palliative care literature, led us to create our Mission Statement mobile application intervention. Leveraging user insights from literature findings to design creative solutions to complex problems in healthcare for the purpose of improving care delivery can be done effectively through design-thinking methodology. Our intervention highlights an example of applying literature findings and creating a solution to a problem through looking within

healthcare for a solution rather than insourcing innovation from other fields. Due to clinicians working directly with patients, they are uniquely positioned to develop innovative interventions through understanding patient experience. Design-thinking methodology is an innovation principle which clinicians can apply in healthcare to create interventions which improve patient experience and outcomes.

Abbreviations

PROM: Patient Reported Outcome Measure; POEMS: People, Objects, Environment, Messages and Services

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Authors' contributions

RK wrote the manuscript and designed the mobile app. ADC oversaw the study, designed the mobile app, and contributed to writing and editing the manuscript. All authors approved the study and manuscript.

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Competing interests

The authors declare that they have no competing interests.

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