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Mobile health technology and home hospice care: promise and pitfalls

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Abstract

With the increasing use of mobile devices (e.g., smart phones, tablets) in our everyday lives, people have the ability to communicate and share information faster than ever before. This has led to the development of promising applications aimed at improving health and healthcare delivery for those with limited access. Hospice care, which is commonly provided at home, may particularly benefit from the use of this technology platform. This commentary outlines several potential benefits and pitfalls of incorporating mobile health (mHealth) applications into existing home hospice care while highlighting some of the relevant telemedicine work being done in the palliative and End-of-Life care fields.

Keywords

Mobile health; Hospice; Telemedicine; End of life

Introduction

The use of mobile devices (i.e., smartphones, tablets) has become infused into our everyday life, with over 75% of Americans owning a smartphone.¹ On average, Americans spend 5 hours on their phones each day, leading to a cultural shift in how individuals communicate and share information.¹ Leveraging the use of mobile devices and other mobile health (mHealth) technologies into healthcare systems has substantial potential to improve research, healthcare delivery and patient outcomes. As mHealth technologies become more prevalent in the healthcare field, their use in End-of-Life (EoL) care, particularly care delivered by hospice organizations, requires in-depth study to effectively understand how to best harness these tools to improve care for terminally ill patients and their caregivers.

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Ethics approval None

While there is no standardized definition of mHealth, the World Health Organization describes the term as the “medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices.”² Increasingly, mobile devices are being used to access applications that allow for various forms of communication, information sharing, movement/location tracking, and measurement of health-related data (e.g., heart rate, sleep) through sensor-based technology.³ Some of these applications aim to improve care by delivering an automated or standardized intervention/treatment that is patient directed, while others incorporate live interactions with healthcare professionals.^{4–6}

To better understand how mHealth technology can be used to improve hospice care, one needs to understand the structure of hospice delivery in America. Hospice provides comprehensive medical, psychosocial, and spiritual care and support to terminally ill patients and their families.⁷ Approximately 60% to 70% of patients receive hospice care at home.^{7,8} While care delivered at home consists of visits from hospice providers (e.g., physicians, nurses, social workers, spiritual care counselors, volunteers), informal caregivers (e.g., spouses, children, relatives, friends) play an essential role in providing day-to-day care for home hospice patients.^{9–12} Because caregivers and hospice providers serve as critical and complimentary components of the care delivery process – both groups are needed to help deliver quality care to hospice patients. An effective partnership can help relieve troubling symptoms and caregiving concerns that often arise during the course of EoL care, thus avoiding poor patient/caregiver outcomes and inappropriate care transitions. Given the promise of mHealth technology to shape how care is delivered and facilitate connections between patients/caregivers and providers, its implementation in the home hospice setting has the potential to measurably improve care.

As research examining the use of this technology in various palliative care and EoL settings continues to expand, understanding efficacy and applying subsequent best practices are critically important. This commentary describes the potential benefits and pitfalls of using mHealth technology in the delivery of home hospice care and proposes a research agenda to advance knowledge regarding the role of these devices.

Potential benefits of mHealth technology

Virtual visits

Delivering effective home-based hospice care relies on visits from hospice providers to reduce patient suffering by addressing medical, psychosocial, and spiritual issues which are not uncommon in both patients and caregivers. Yet, home hospice visits may not occur as often as needed or in a timely manner that meets patient and caregiver needs. This is especially challenging for patients living in remote areas or whenever an acute change requires immediate attention.^{13,14} Research utilizing Medicare data shows that hospice nurses visit patients twice a week on average, and over 30% of patients did not have any contact with a hospice provider during the last week on hospice care.^{15,16} Given these statistics, mHealth technology designed to complement existing hospice visits has the potential to address some of these concerns. One can imagine that virtual visits (e.g., video chat, text messaging) using a mobile device could complement existing home visits,

enhancing the ability to communicate and relay information both verbally and visually. Patient symptoms, caregiver distress/burden, and other EoL issues could be shared with hospice providers, and this could lead to earlier interventions to enhance care for both patients and caregivers.

There are promising interventions being tested here and abroad in various palliative care settings. ResolutionCare is a remote palliative care service provided to patients via videoconferencing technology and is funded through partnerships with public and private health plans.¹⁷ Demiris et al. found that delivering a problem-solving therapy to informal hospice caregivers via a videophone was non-inferior to a face-to-face encounter.¹⁸ In the UK, there is ongoing work to develop a virtual hospice involving the input of major stakeholder groups.¹⁹

Tracking relevant information

Another way in which mHealth technology could potentially help improve hospice care is through the collection and tracking of data in real time. Gathering and monitoring salient information such as symptoms (e.g., pain, shortness of breath, nausea) that are commonly experienced by patients at the EoL, and relaying the information to hospice providers could lead to more rapid adjustments in a patient's medication regimen to reduce suffering. In addition, many caregivers experience significant burden caring for a loved one at the EoL.^{20–26} Tracking relevant information about caregiver wellbeing, using validated assessment tools, could help hospices identify caregivers who need more visits or support services (e.g., home health aide, respite care). By closely monitoring clinically relevant issues, mHealth technology could provide hospice providers with a complementary method of evaluating the needs of both patients and caregivers, allowing them to better prioritize those in need of a phone call, inperson appointment, or virtual visit. Furthermore, data collected through app-based programs could be aggregated and merged with existing medical records, using big data analytics to study and identify those at high risk for poor outcomes.

Work done in this area has been expanding. For example, the feasibility of using mobile phones to monitor patient symptoms remotely via the Advanced Symptom Management System in Palliative Care (ASyMSp) has been established.¹⁸ Basch et al. studied patient-reported outcomes and found that in cancer patients, reporting symptoms via a web-based platform that triggered an email alert to a nurse was associated with an increase in median overall survival compared to those receiving usual care.³ Furthermore, one promising, ongoing study is looking at the development of smartwatch technology to monitor symptoms in patients with advanced illnesses.²⁷

Education for patients and caregivers

In addition to interacting with providers and tracking pertinent information, mHealth technology could offer an easier way for patients and caregivers to receive education about hospice and EoL care. Many studies show that patients and caregivers considering hospice care are often unaware of basic information such as how it is delivered or have misperceptions about what type of care will be delivered.^{28–30} Having a centralized hub where educational materials are readily accessible via a smartphone or tablet could help

patients and caregivers better understand how to manage symptoms and common medication side effects. This approach can also help to disseminate information on common EoL issues, potentially enhancing understanding and dispelling myths.

Some of these ideas are already being implemented in various electronic formats. A systematic review of clinician focused mobile applications found that many concentrated on displaying treatment guidelines, training materials, and pharmaceutical tools.³¹ Another review of mobile applications found blog-oriented apps, aggregating pertinent articles in an easy-to-read format, could act as resources for clinicians and patients.³² Furthermore, website resources such as the US's *Caring Info*, Canada's *Virtual Hospice*, and the UK's *E-hospice* provide visitors with information about palliative, EoL, and hospice care.^{33–35} Expansion of these resources into the mobile realm can help complement existing care that patients and caregivers already receive from hospice.

Other applications

Other potential applications of mHealth technology, for use in home hospice care, include having the ability to request medications/supplies through a mobile device; incorporating wearable devices to track fluctuations in vital signs that may help signal if a death is imminent; forming virtual support groups between patients, caregivers, and/or hospice providers; and using mobile devices to assist patients/caregivers in coordinating visits of hospice providers (e.g., physicians, nurses, social workers, spiritual care counselors). Although development and testing of these applications are needed, these ideas have the potential to streamline and improve care while supporting patients and caregivers throughout their home hospice experience.

Potential Pitfalls of Mobile Health Technology

Usability

While there are many potential benefits one can envision incorporating mHealth technology into home hospice care, understanding the potential challenges is of equal importance. Other researchers in the field have pointed out the challenge of designing technology that is user-friendly and intuitive for all parties.^{36,37} Users, which may include patients, caregivers, hospice providers, and hospice administrators, need to be considered when designing mHealth technology. It is important to note that approximately 95% of hospice patients are 65 years and older.^{7,8} Therefore, incorporating design that is feasible for use by older adults will be important to ensure its adoption. Furthermore, hospice care is delivered through a multi-disciplinary group of providers (e.g., physicians, nurses, social workers, spiritual care counselors), with each playing a specific role in delivering care. Designing an application that can be adaptable to the care receivers as well as care providers is critical, and mHealth technologies that do not take the users into consideration will likely lead to limited adoption.

Replacing live visits

A concern when implementing any type mHealth technology is replacing live face-to-face visits (i.e., home visits) with remote forms of interaction.^{36–38} Face-to-face interactions are important in establishing a relationship of trust between patient/caregivers and hospice

providers. Providers are aware that there are nuances that occur in a face-to-face visit that cannot be replicated/captured remotely. Furthermore, studies conducted with key stakeholder groups (e.g., patients, palliative care consultants, nurses, physicians) found that many see telehealth as a way to complement rather than replace existing care.^{36,38} Consequently, it is important that when designing and implementing this technology we define its limitations, effectiveness, and stakeholder preferences for care delivery.

Security

Another concern when designing mHealth technology is storing and protecting confidential user information. With information being transmitted electronically, safeguards need to be implemented to handle data and make sure it meets requirements of the Health Insurance Portability and Accountability Act (HIPAA) and any other patient privacy rules.³⁹ Information leaks can harm patients, families and hospice organizations. Therefore, protecting health information must be a critical component when implementing any mHealth technology in the care delivery process.

Identifying populations with limited access to mHealth technology

While mobile devices have been adopted by a majority of Americans and have connected people living far away from one another, there is still a subgroup who do not use or have resources to afford smartphones/wireless devices and internet service. Recent data from the Pew Research Center showed that while 80% of US adults 65 years and older own a cellphone, only 42% owned a smartphone.¹ Furthermore, minorities, people with limited resources, and less educated individuals are less likely to own a smartphone.¹ With this in mind, researchers acknowledge the need to find ways to provide access to populations that lack the resources to benefit from mHealth technologies.³⁶ While mobile devices are viewed as a way to bridge gaps in care, especially in places that are more remote, it is important to be cognizant of those that may get excluded from this type of care.

Will it impact care and how does it fit in with current practice?

The use of mHealth technology holds substantial promise and it is important that future implementation of this technology ultimately shows benefit in improving the delivery and quality of care for patients and caregivers. Therefore, studying its implementation and having explicit measurement outcomes (e.g., quality of life, caregiver burden, costs) constitute important areas to examine.

Furthermore, hospice providers should be key partners when designing, evaluating, and implementing any mHealth technologies for use in EoL care. Understanding how these tools can be applied seamlessly to their existing workloads, while not encumbering clinicians with excessive information that is unfiltered, untested, and difficult to interpret is an important aspect to consider in the implementation of any mHealth technology.³⁷ Finally, from a health systems standpoint, integration of these applications into already existing electronic medical record systems represents another challenge.³⁸ Having different systems “talk” to one another will be important for success. With thousands of EMR systems in the US alone, overcoming interoperability constitutes a significant challenge.

mHealth research agenda

While there is potential to incorporate mHealth technology to improve care in the home hospice setting, research in this field is still emerging and ongoing work is needed. Table 1 outlines a research agenda, based on the collective knowledge of the authors and a review of the literature, and represents promising starting points for translational research efforts in this area. Addressing these topics will help us to better understand how to incorporate mHealth technology so that it can have a measurable impact in this care setting.

Conclusion

mHealth constitutes a promising resource for home hospice that can potentially help to enhance care that is already being provided. However, with the potential to improve care lies multiple questions and challenges that need to be considered. As mobile devices permeate further and further into our daily lives, understanding how we can harness and adapt this technology to improve care for terminally ill patients and their caregivers is critically important.

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References

1. Pew Research Center. Mobile fact sheet. Pew Res Cent 2017.
2. World Health Organization. mHealth: new horizons for health through mobile technologies. Observatory 2011;3(6):66–71.
3. Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, et al. Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. JAMA 2017; 318:E1–E2.
4. Brewer AC, Endly DC, Henley J, Amir M, Sampson BP, Moreau JF, et al. Mobile applications in dermatology. JAMA Dermatology 2013;149(11):1300–1304. [PubMed: 24067948]
5. Quinn CC, Clough SS, Minor JM, Lender D, Okafor MC, Gruber-Baldini A. WellDoc™ mobile diabetes management randomized controlled trial: change in clinical and behavioral outcomes and patient and physician satisfaction. Diabetes Technol Ther 2008;10(3):160–168. [PubMed: 18473689]
6. Plow M, Golding M. Using mHealth technology in a self-management intervention to promote physical activity among adults with chronic disabling conditions: randomized controlled trial. JMIR mHealth uHealth 2017;5(12):e185. [PubMed: 29196279]
7. NHPCO. Facts and figures: hospice care in America. Alexandria, VA: National Hospice and Palliative Care Organization; 2016.
8. NHPCO. Facts and figures: hospice care in America. Alexandria, VA: National Hospice and Palliative Care Organization; 2014.
9. Grande G, Stajduhar K, Aoun S, Toye C, Funk L, Addington-Hall J, et al. Supporting lay carers in end of life care: current gaps and future priorities. Palliat Med 2009;23(4):339–344. [PubMed: 19304804]
10. Park SM, Kim YJ, Kim S, Choi JS, Lim H- Y, Choi YS, et al. Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's work-force performance. Support Care Cancer 2010;18(6):699–706. [PubMed: 19484480]

11. Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med* 1999;341(13):956–963. [PubMed: 10498492]
12. Sheehy-Skeffington B, McLean S, Bramwell M, O’Leary N, O’Gorman A. Caregivers experiences of managing medications for palliative care patients at the end of life: a qualitative study. *Am J Hosp Palliat Med* 2014;31(2):148–154.
13. Phongtankuel V, Scherban BA, Reid MC, Finley A, Martin A, Dennis J, et al. Why do home hospice patients return to the hospital? A study of hospice provider perspectives. *J Palliat Med* 2016;19(1):51–56. [PubMed: 26702519]
14. Phongtankuel V, Paustain S, Reid M, Finley A, Martin A, Delfs J, et al. Events leading to hospitalization of home hospice patients: a study of primary caregivers’ perspectives. *Palliat Med* 2016;20:1–6.
15. Phongtankuel V, Adelman RD, Trevino K, Abramson E, Johnson P, Oromendia C, et al. Association between nursing visits and hospital-related disenrollment in the home hospice population. *Am J Hosp Palliat Med* 2017;35:316–323.
16. Gozalo PL, Teno JM, Spence C. Hospice Visit Patterns in the Last Seven Days of Life and the Service Intensity Add-On Payment. *J Palliat Med* 2017;20: 1–7.
17. ResolutionCare. [cited 2018 Feb 12]. Available from: <http://www.resolutioncare.com/>.
18. Demiris G, Parker Oliver D, Wittenberg-Lyles E, Washington K, Doorenbos A, Rue T, et al. A noninferiority trial of a problem-solving intervention for hospice caregivers: in person versus videophone. *J Palliat Med* 2012;15(6):653–660. [PubMed: 22536989]
19. Taylor A, Lennox J, Mort AJ, Heaney D, Muñoz S-A, Currie M, et al. Developing hospice care over a distance in highland scotland: a knowledge exchange process. *Chang Perspect* 2013:397–402.
20. Bee PE, Barnes P, Luker KA. A systematic review of informal caregivers’ needs in providing home-based end-of-life care to people with cancer. *J Clin Nurs* 2009;18(10):1379–1393. [PubMed: 18624779]
21. Stoltz P, Udn G, Willman A. Support for family carers who care for an elderly person at home – a systematic literature review. *Scand J Caring Sci* 2004;18(2):111–119. [PubMed: 15147473]
22. Gotze H, Braehler E, Gansera L, Schnabel A, Gottschalk-Fleischer A, Kohler N. Anxiety, depression and quality of life in family caregivers of palliative cancer patients during home care and after the patient’s death. *Eur J Cancer Care (Engl)* 2016;27(10):1–8.
23. Wahid AS, Sayma M, Jamshaid S, Kerwat D, Oyewole F, Saleh D, et al. Barriers and facilitators influencing death at home: a meta-ethnography. *Palliat Med* 2017;32:1–15.
24. Hudson PL, Aranda S, Kristjanson LJ. Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *J Palliat Med* 2004;7(1):19–25. [PubMed: 15008126]
25. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: “they don’t know what they don’t know”. *JAMA* 2004;291(4):483–491. [PubMed: 14747506]
26. Pottie CG, Burch KA, Thomas LPM, Irwin SA. Informal care-giving of hospice patients. *J Palliat Med* 2014;17(7):845–856. [PubMed: 24992371]
27. Nwosu AC, Quinn C, Samuels J, Mason S, Payne TR. Wearable smartwatch technology to monitor symptoms in advanced illness. *BMJ Support Palliat Care* 2017.
28. Friedman BT, Harwood MK, Shields M. Barriers and enablers to hospice referrals: an expert overview. *J Palliat Med* 2002;5 (1):73–84. [PubMed: 11839229]
29. Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K, Pearlman RA. How do surrogate decision makers describe hospice? Does it matter? *Am J Hosp Palliat Med* 2006;23(2):91–99.
30. Casarett D, Crowley R, Stevenson C, Xie S, Teno J. Making difficult decisions about hospice enrollment: what do patients and families want to know? *J Am Geriatr Soc* 2005;53(2): 249–254. [PubMed: 15673348]
31. Meghani SH, MacKenzie MA, Morgan B, Kang Y, Wasim A, Sayani S. Clinician-Targeted Mobile Apps in Palliative Care: A Systematic Review. *J Palliat Med* 2017;20(10):1139–1147. [PubMed: 28557549]

32. Nwosu AC, Mason S. Palliative medicine and smartphones: an opportunity for innovation?: Table 1. *BMJ Support Palliat Care* 2012;2(1):75–77.
33. CaringInfo. [cited 2018 Feb 15]. Available from: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>.
34. eHospice. [cited 2018 Feb 14]. Available from: <http://www.ehospice.com/uk/en-gb/home.aspx>.
35. Virtual Hospice. [cited 2018 Feb 10]. Available from: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx.
36. Johnston B, Kidd L, Wengstrom Y, Kearney N. An evaluation of the use of Telehealth within palliative care settings across Scotland. *Palliat Med* 2012;26(2):152–161. [PubMed: 21378067]
36. Johnston B Palliative home-based technology from a practitioner's perspective: benefits and disadvantages. *Smart Homecare Technol TeleHealth* 2014;2:121–128.
38. Nwosu AC, Collins B, Mason S. Big Data analysis to improve care for people living with serious illness: The potential to use new emerging technology in palliative care. *Palliat Med* 2018;32(1): 164–166. [PubMed: 28805118]
39. Summary of the HIPAA Security Rule. 2013; [cited 2018 Feb 20]. Available from: <https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html>.

Table 1

mHealth research agenda in home hospice care

<ul style="list-style-type: none">• Measuring the impact of mHealth technology interventions on care outcomes (e.g., improving communication, reducing burdensome care transitions, reducing patient suffering and caregiver burden).• Designing technology that can be user friendly among hospice organizations, providers and patients/caregivers.• Collecting and relaying information that is clinically relevant to patients and providers.• Designing technology that works seamlessly with the existing home hospice workflow.• Designing technology that allows different devices to communicate with one another and exchange data.• Examining whether mHealth technology is cost effective to current care practices.• Designing technology that protects sensitive patient information.• Creating features that can useful to all members of the multi-disciplinary hospice team.• Designing tools that allow data to be easily gathered and analyzed for research or quality improvement.• Creating technology that can be accessible to all patients and caregivers receiving hospice care regardless of their economic and educational status or their cultural background.• Creating platforms that allows for big data analytics aimed at improving care delivery.