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Pediatric hospice and palliative care: Designing a mobile app for clinical practice

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Most children who die from health-related conditions spend their brief lives encountering a wide variety of clinicians, from primary physicians and nurse practitioners to oncologists and neurologists. Many of these providers act as gate-keepers to hospice care through the referral process. One of the barriers to pediatric hospice and palliative care use is that pediatric clinicians generally lack an understanding of and experience with this service, which influences their decision to refer children to hospice.¹ In fact, most physicians have limited or no training in core end-of-life competencies,^{2,3} less than 50% of residents are taught how to hold conversations about pediatric end of life,⁴ and over 25% of pediatricians do not even know whether local hospice services even exist.⁵ Although there have been significant strides to increase formal end-of-life educational opportunities for clinicians, improved training in communications between clinicians and families about end of life, and increased understanding of clinicians' hospice referral practices, very few children access hospice and palliative care at end of life.⁶

Perhaps it is time to try something completely different. What if we provided clinicians with a technological tool to assist them in understanding and experiencing pediatric hospice care, all in the palm of their hands? Along with formal education and training, information on pediatric hospice care could be accessible 24/7 when clinicians need it, whether in the exam room with children and their families, in the office while reviewing tests, or in the clinical conference with the care team. Although the evidence is in its infancy,⁷⁻¹⁰ the cutting-edge technology associated with smart phones and tablets (e.g., iPads) may have the potential to significantly influence health care. By providing a powerful platform, mobile applications (apps) may increase awareness of pediatric hospice care, assist clinicians' discussions with

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children and families about it, and create a seamless referral to hospice that would ultimately improve access to pediatric hospice and palliative care.

Mobile App Design

Our design team, which consisted of a nurse, information systems engineer, physician, and Big Data analyst, is designing a mobile app to meet the needs of clinicians who care for children with terminal illnesses. Grounded in discovery learning theory,¹¹ the pediatric mobile app meets the fast-paced informational needs of clinicians for use with smart devices, such as iPhones/iPads and Android phones. The mobile app offers an easy-to-navigate menu of choices (Figure 1A), and with the tap of a finger, clinicians will be connected to the most current information about pediatric hospice care provided by experts in the field. From the main menu, a click on *Pediatric Hospice Care* (Figure 1B) will route clinicians to publicly available, evidence-based information about pediatric hospice care, including definitions, a description of the pediatric hospice care team, and eligibility criteria. Clinicians will be “pushed” to resources from expert organizations such as the National Hospice and Palliative Care Organization. Clinicians are now able to share information with families verbally, or with a click, they can send the information to the families’ computer or mobile device.

The *Is It Time?* button forwards clinicians to a screen where they identify their specialties and the end-of-life clinical situation they are encountering with the child and family. For example, clinicians may indicate if the child has stopped responding to treatment or the family has expressed an interest in hospice care. Clinicians are then forwarded to sample clinical protocols. Through the *Talking to Families* menu (Figure 1C), the clinician obtains evidence-based information on the topic of how to have a conversation about pediatric hospice and palliative care with a family. Additional information is pulled into the app with a link to the literature, You Tube videos, and information such as the new National Institute of Nursing Research materials on “Palliative Care: Conversations Matter.” (<https://www.ninr.nih.gov/newsandinformation/conversationsmatter#.UxD2EoWCRJE>)

The *Referral* button empowers clinicians to select hospice services needed by the child and family (Figure 2). Using administrative and geocoded data from state hospice provider databases, the app is populated with hospice providers’ services, addresses, phone numbers, and map locations. With a touch, clinicians can initiate a referral directly to the hospice provider in the child’s community. The mobile app revolutionizes the clinical practice of referring pediatric patients and their families to hospice and palliative services.

Figure 3 displays the different approaches clinicians may use to maneuver through the mobile app’s functions. These different pathways make the mobile app clinically relevant and designed around the informational needs of the end-user, the clinician.

Challenges and Opportunities

In a world where “there is an app for that,” implementing a pediatric hospice and palliative care mobile app for clinicians offers challenges and opportunities. The first challenge is making the mobile app known to clinicians. To ensure awareness of the mobile app, we are

proactively developing a technology marketing plan with the assistance of our College of Business Administration. Faculty in the graduate marketing course are developing a marketing plan for each stage in the lifecycle of the mobile app. In the product development stage, we are creating a buzz around the mobile app by issuing upcoming product launch notices through hospice and palliative care social media outlets. For product introduction, we are issuing press releases and focusing on burst marketing efforts such as getting into the App Store “new and noteworthy” section. In addition, our app launch is planned around key events such as the American Society of Pediatric Hematology Oncology Annual Meeting. We are working with our partners in the pediatric end-of-life community, including the advocacy groups, to identify and reach pediatric clinicians with targeted marketing information. During the product growth phase, we will use Google Analytics to track our app usage and identify areas for improvements in marketing. Our goal is to ensure clinician awareness of the mobile app and its use as a resource when caring for children at the end of life.

The second challenge is ensuring the clinical audience uses the mobile app rather than getting lost in the sea of apps on a clinician's mobile device. We have developed a “keeping it fresh” plan that includes updating the content with new evidence-based information. With the assistance of our library health care liaison, we are identifying information from publication databases, professional associations, and public notices and including it in a DropBox for a monthly review and upload to the app. The app user can subscribe to alerts that signal content changes, such as new evidence and new hospice service providers. As the user-base grows, we will add research tools, such as online surveys, to collect and share data on practices. Future improvements include building an online community that draws on user-generated, dynamic, and relevant content. Clinicians could use the mobile app to find out what is trending such as referral patterns in their area.

The third implementation challenge is managing the volume of Big Data generated from the mobile app. Traditional research in pediatric hospice and palliative care has been limited to small-scale, isolated data points, which inhibits the development of new insights. Our pediatric mobile app could generate a tremendous amount of real-time, high-frequency data and provide unprecedented opportunities for new discoveries in this field. By tracking and analyzing the clickstreams and geotags used, we can better understand clinicians' interests, informational needs, interactions, and information-seeking behaviors. Such analysis will provide critical support for developing effective information channels for their decision-making needs. Being prepared for the influx of Big Data ensures high quality data for improving the mobile app and conducting future research, the data management plan must include data integrity, quality control, storage, protection, retrieval, and data mining.

Impact on Clinical Practice

Our pediatric hospice and palliative care mobile app, which is currently in the development phase, has the potential to broadly impact children's access to these services. Although we developed the mobile app with a pediatric hospice focus, it is easily adaptable for other pediatric health care services, such as dental care, developmental disabilities services, public health services, and immunization. Using an inexpensive and user-friendly technology, our

mobile app allows pediatricians and nurse practitioners to make evidence-based and informed decisions about referrals. This app empowers clinicians with information and has the potential to be an important tool in improving health care service delivery for children.

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Key Points

- Assemble an interdisciplinary team to design the mobile app to meet the needs of clinical users.
- Plan for marketing, “keeping it fresh,” and large data volumes when implementing a mobile app.
- See beyond the current application and vision future uses for your mobile app.

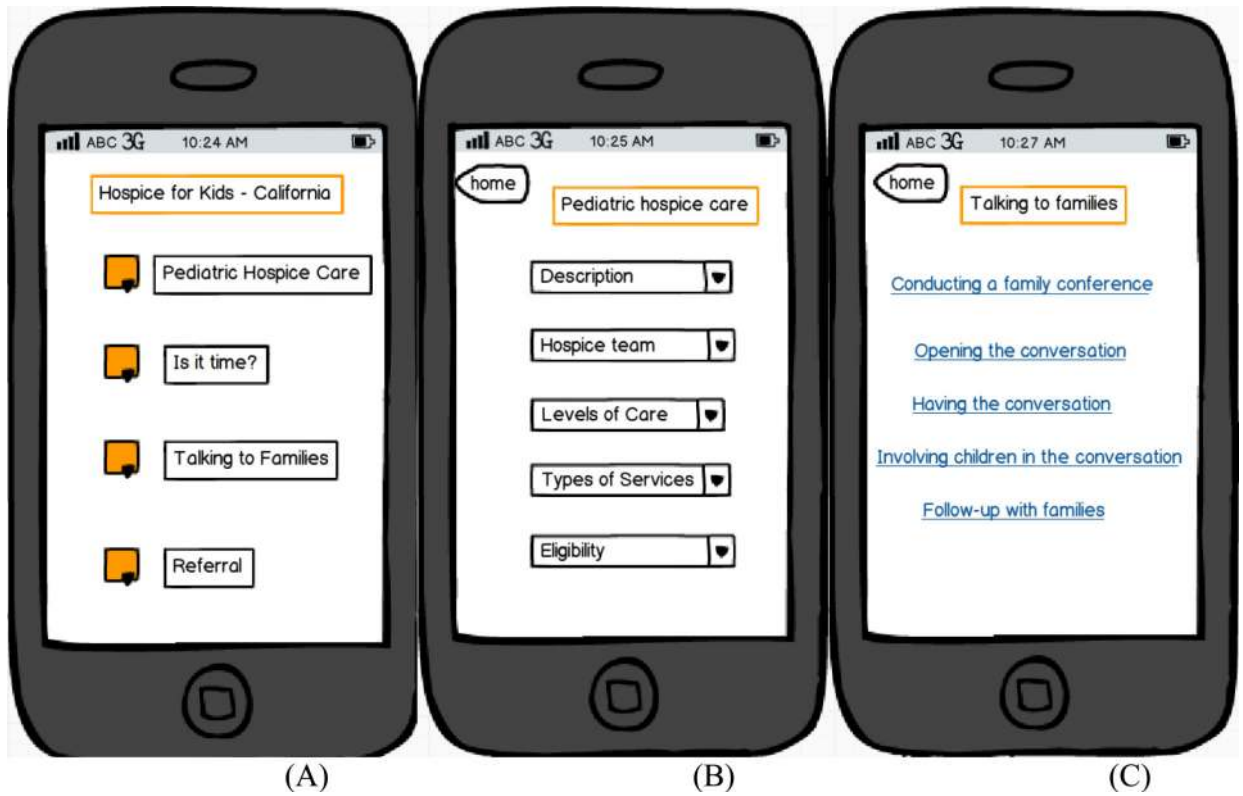


Figure 1.
Sample screenshots of the mobile app's menus. (A) Main menu, (B) Pediatric Hospice Information menu, and (C) Talking to Families menu.

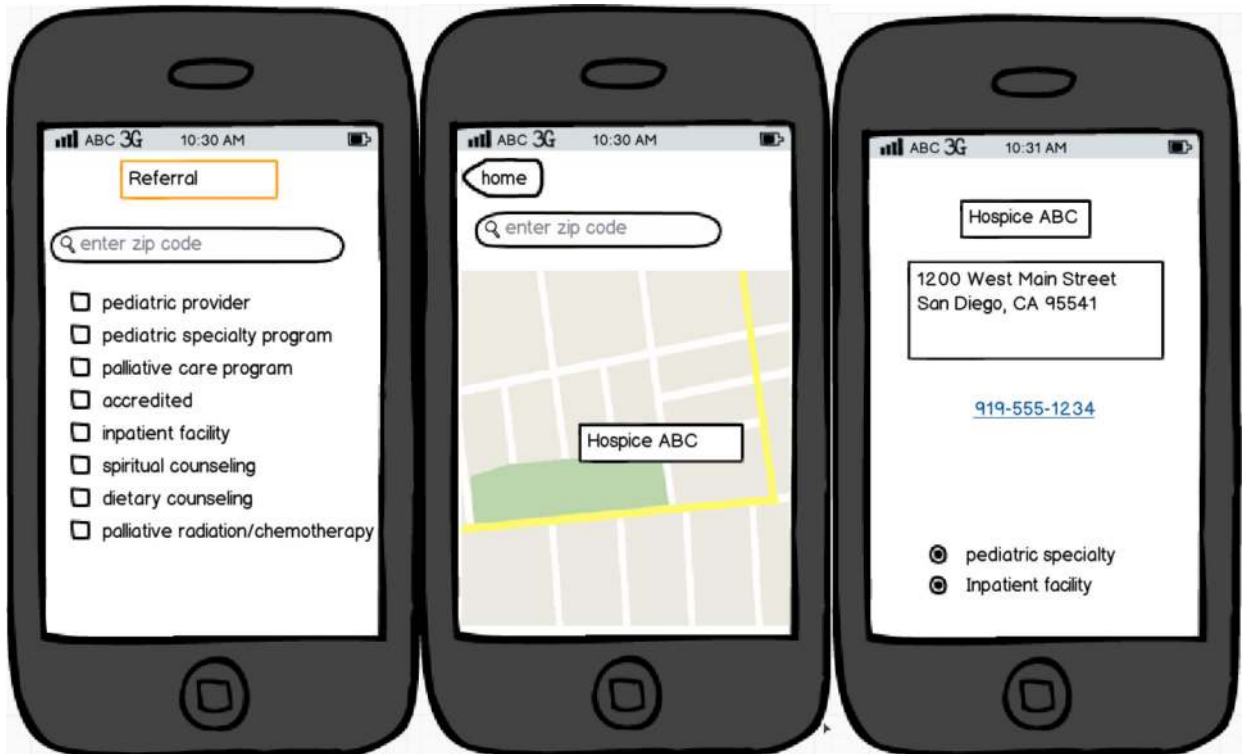


Figure 2.
Sample screenshots of the mobile app's referral menu and content.

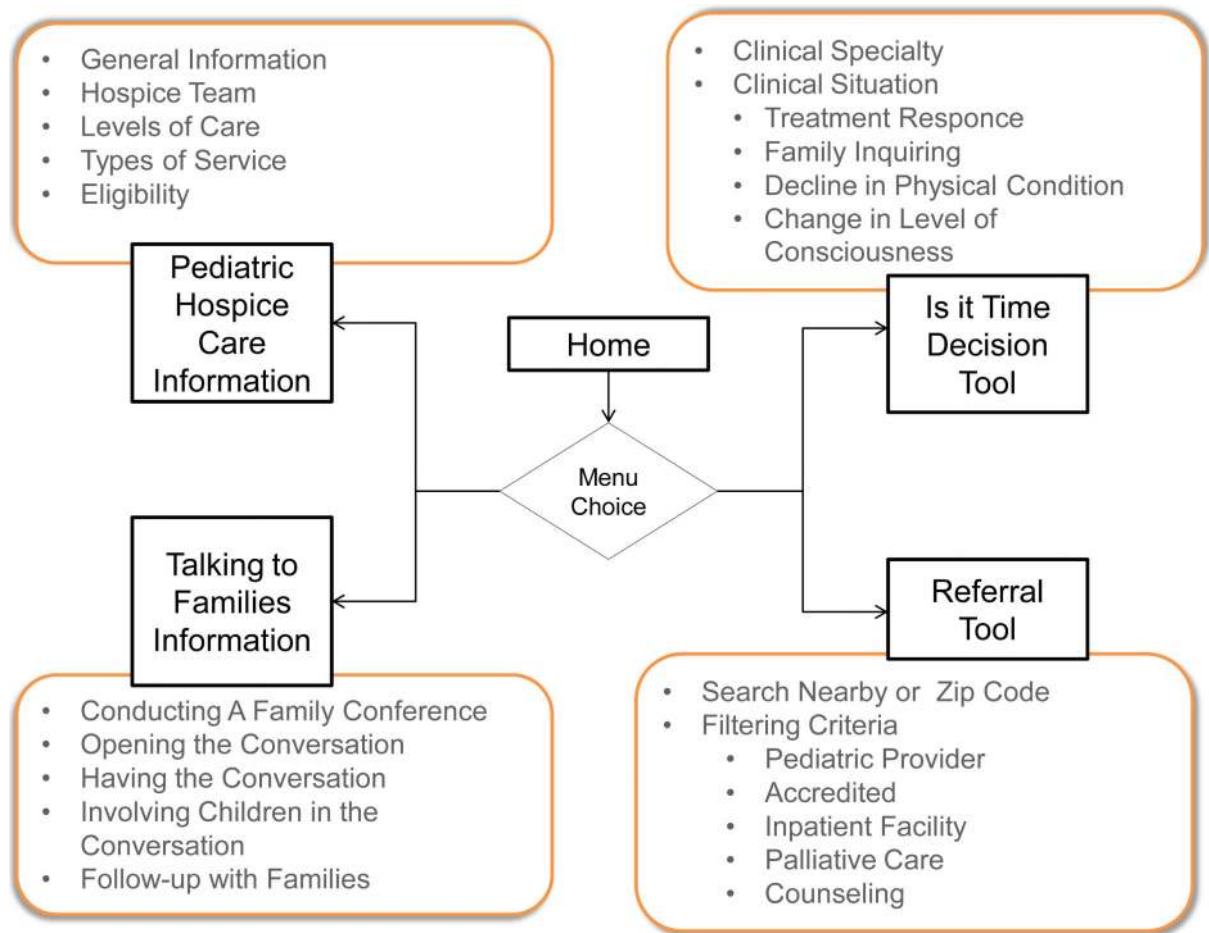


Figure 3. Design flowchart of the pediatric hospice and palliative care mobile app functions.