

# Digitisation of patient preferences in palliative care: mobile app prototype

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Received 27 July 2023  
Accepted 1 August 2023



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**To cite:** Ferreira J, Ferreira M, Fernandes CS, et al. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2023-004516

## ABSTRACT

**Background** Engaging in advance care planning can be emotionally challenging, but gamification and technology are suggested as a potential solution.

**Objective** Present the development stages of a mobile app prototype to improve quality of life for patients in palliative care.

**Design** The study started with a comprehensive literature review to establish a foundation. Subsequently, interviews were conducted to validate the proposed features of the mobile application. Following the development phase, usability tests were conducted to evaluate the overall usability of the mobile application. Furthermore, an oral questionnaire was administered to understand user satisfaction about the implemented features.

**Results** A three-phase testing approach was employed based on the chosen user-centred design methodology to obtain the results. Three iterations were conducted, with improvements being made based on feedback and tested in subsequent phases. Despite the added complexity arising from the health status of patients in palliative care, the usability tests and implemented features received positive feedback from both patients and healthcare providers.

**Conclusion** The research findings have demonstrated the potential of digitisation in enhancing the quality of life for patients in palliative care. This was achieved through the implementation of patient-centred design, personalised care, the inclusion of social chatrooms and facilitating end-of-life discussions.

## INTRODUCTION

Palliative care focuses on improving the quality of life for patients dealing with serious or life-threatening illnesses.<sup>1</sup> However, there are several obstacles that hinder optimal palliative care, including lack of awareness about what palliative care really is, limited access, cultural and religious beliefs, and communication barriers.<sup>1–5</sup>

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Social interaction reduces loneliness and enhances the quality of time for patients and advance care planning games encourage discussions about end of life.

## WHAT THIS STUDY ADDS

⇒ Features such as personal preferences, end-of-life preferences and social interaction on a mobile app had positive feedback from patients and healthcare providers.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Digitisation has the potential to improve the quality of life of patients in palliative care.

Engaging in advance care planning can be emotionally challenging, but gamification and technology are suggested as a potential solution. It can make the process more interactive and less daunting.<sup>2 6 7</sup>

Digitisation in medicine is a growing trend,<sup>8 9</sup> offering numerous benefits such as telemedicine, electronic health records, improved accessibility and organisation, reduced errors, increased collaboration and integration of multiple features into a single application.<sup>10 11</sup>

The outcomes of the literature review revealed the importance of healthcare digitisation in palliative care to improve the quality of life for patients. The key focuses include symptom tracking,<sup>11 12</sup> educational videos,<sup>13 14</sup> social interaction<sup>3 5</sup> and preferences games.<sup>5 7</sup> The limitations identified in the literature review encompassed challenges such as evaluating performance quantitatively,<sup>2 13</sup> small or biased study populations,<sup>4 6 9–11</sup> heterogeneity in study designs and instruments used,<sup>6 10 11 13</sup> and considerations regarding accessibility, security, usability and legal aspects of digital palliative care tools.

There is a lack of mHealth apps targeting the social convoy members.<sup>14</sup>

The main objective of the study is to develop a mobile app with features such as patient profiles, personal preference, conversation sections for private or group chats, a game section introducing advance care planning concepts and healthcare provider login for accessing patient preferences.

User-centred design is a design process that prioritises the needs, goals and overall satisfaction of users throughout the product's design and development.<sup>15</sup> This updated standard complements existing design methodologies and emphasises a user-focused perspective that can be integrated into various development processes.

The proposed study aims to present the development stages of a mobile app prototype to improve quality of life for patients in palliative care. The results are expected to contribute to new knowledge and have a positive impact on the field.

## METHODS

### Study design

In the process of developing a mobile app prototype to improve quality of life for patients in palliative care, a comprehensive approach was taken. This involved conducting a literature review and interviews with healthcare providers to gather insights and validate the findings. The prototype was developed using a user-centred design methodology, incorporating iterative stages of prototyping and testing. User feedback was collected and used to refine the prototype, ensuring it aligned with user needs and preferences. That is, the following steps were followed: research, definition of requirements, iterative prototyping, tests and evaluations. The study received ethical approval, participants were informed about the objectives and purpose of the study, data anonymity and confidentiality were guaranteed. The research step is not explored in this context because it awaits publication in another article.

### Participants and analyses

For the definition of requirements, we made some interviews with health professionals specialise in palliative care. In this step, five health professionals were included, through a convenience sample. The data were treated using content analysis.

In the process of developing a mobile application, testing and validation are crucial to ensure its functionality, usability and user satisfaction. The testing process involved three moments and included both patients and healthcare providers. Each moment brought new insights and led to improvements in the app's design and features. In total, nine patients and three healthcare providers participated in this step, through a convenience sample.

## RESULTS

To facilitate the presentation of the results, the same steps presented in the methodology will be followed:

research, definition of requirements, iterative prototyping, tests and evaluations.

### Research

The state-of-the-art analysis of the digitisation of patient preferences in palliative care reveals several key insights. The key focuses include social interaction and preferences games.

### Definition of requirements

In this stage, five interviews were conducted. The participants included one male and four female professionals aged between 24 and 37 years. They represented five different professions (nurse, physiotherapist, occupational therapist, animator and a psychologist), had experience ranging from 1 to 16 years in providing palliative care.

These requisites include incorporating patients' preferences, providing healthcare providers consultation regarding those preferences, implementing a chat feature for social interactions and group support, and designing a game that helps patients organise their end-of-life preferences and introduces them to advance care planning.

### Iterative prototyping

The mobile app features a shared login and sign-up process for both patients and healthcare providers. Once logged in, patients can edit their profile, choose personal preferences, engage in conversations with healthcare providers and play a game to explore end-of-life preferences. Healthcare providers, on the other hand, can access and review patients' preferences within the same institution (figure 1A–C).

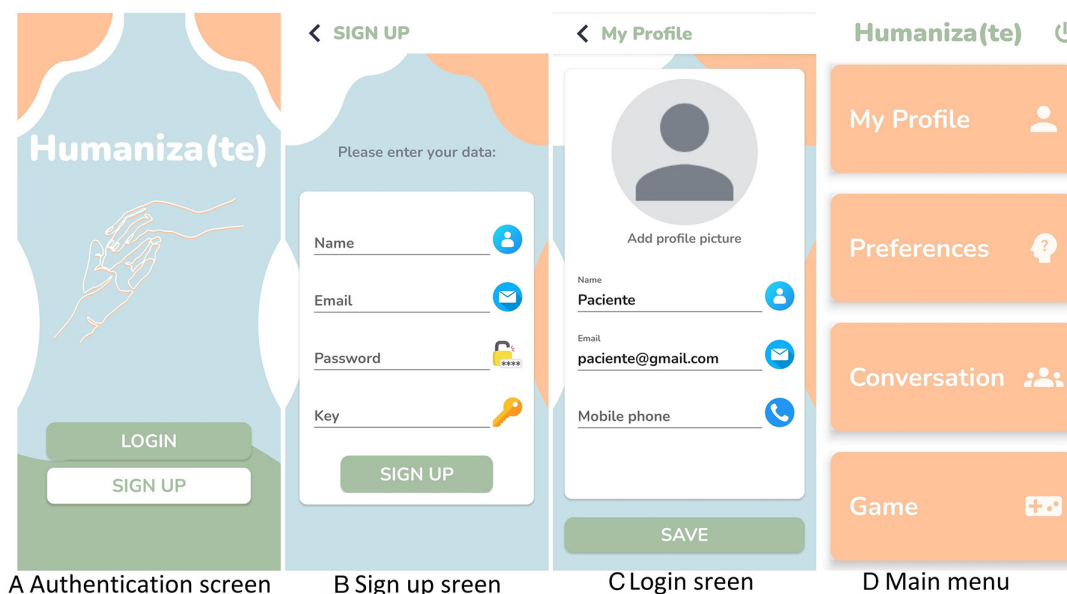
In the 'My Profile' section, patients can view and edit their profile information (figure 2A). The 'Preferences' section allows them to set their preferences through a list of options and the ability to provide personalised preferences (figure 2B). The 'Conversation' section enables patients to engage in private and group chats with other patients (figure 2C). The 'Game' section presents a game where patients can prioritise their end-of-life preferences (figure 2D).

### Iterative prototyping

The client-server architecture was adopted, with the client component being the mobile app running on the user's device and the server component handling backend operations and data management. The design of the mobile app focuses on creating visually appealing screens, intuitive navigation and seamless interactions. Data security and privacy measures are implemented, including authentication and authorisation mechanisms, data encryption in transit and at rest, and compliance with privacy regulations like General Data Protection Regulation and Consumer Privacy Act.

### Tests and evaluations

The testing phases conducted on the mobile app provided valuable feedback regarding its functionality,



**Figure 1** Authentication screen and main menu.

usability and overall user experience. The testing process involved three moments and included both patients and healthcare providers. Each moment brought new insights and led to improvements in the app's design and features. In total nine patients and three healthcare providers participated in this step.

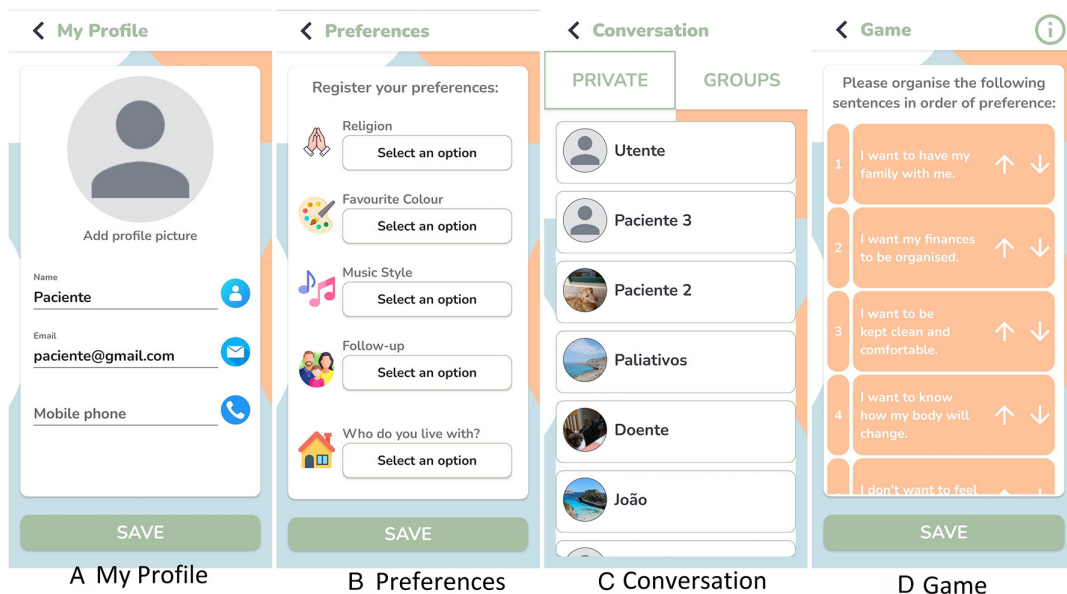
## DISCUSSION

The study successfully achieved its objective of creating a prototype aimed at enhancing the quality of life for patients in palliative care. Nowadays, palliative care is not optimally addressing the needs and preferences of the patients because of the lack of advance care planning.<sup>2 4 6</sup> It allows patients to

express their values and wishes regarding end-of-life care, even if their opinions and ideas change over time.<sup>12 13</sup>

The development process included meeting all the programmed requisites, ensuring that the prototype fulfilled the intended goals and functionalities.

The mobile app underwent three phases of testing to validate its usability and effectiveness. The testing revealed areas for improvement and changes were made based on feedback, such as adjusting label sizes, providing predefined options for preferences and enhancing the game functionality. These improvements resulted in enhanced user experiences and increased user satisfaction.



**Figure 2** Features and Patient Screen.

On the patient side, the Preferences section underwent significant improvements, allowing patients to select preferences easily using predefined options and personalised inputs. The Conversation section received positive feedback from patients who actively navigate through this section. Social interaction helps patients with good time quality as well as feeling less lonely.<sup>3</sup>

The Game section was the second most used section, with patients finding value in discussing end-of-life preferences. These game preference data are in line with other published studies.<sup>2 5 6</sup> These games have high levels of success in making people take the initiative to start talking about advance care planning.<sup>2 4 7</sup>

Healthcare providers showed enthusiasm and provided extensive feedback on the app. Accessing patients' preferences was identified as a crucial feature in delivering personalised care. The consensus among healthcare providers emphasised the importance of this feature in enhancing patient-centred care. Users found the app user-friendly and expressed satisfaction with its functionality, making it a valuable and effective tool. The study has certain limitations that should be considered when interpreting the results. The study encountered challenges in quantitatively measuring the outcomes, as the area of research is not easily quantifiable. The study was conducted with a limited number of participants, which may further restrict the applicability of the findings to a broader range of patients. A larger and more diverse sample size would enhance the study's capacity to address the specific challenges. Despite these limitations, the study serves as an important step for future development and long-term testing.

## CONCLUSION

This study successfully explored the effects of digitisation on palliative care and introduced a digitised mobile app to improve patient-centred care. The research revealed positive outcomes, including improved access to patient information for healthcare providers and positive feedback from patients regarding usability and features. However, long-term effectiveness and impacts require further research. This research fills a gap in the literature and provides valuable insights for future mobile applications developments in palliative care.

**Contributors** Conceptualisation: JF, MF, CSF, JC and MJC; methodology JF, MF, CSF and MJC; formal analysis, JF and CSF; investigation: JF, MF, CSF and MJC; writing—JF and CSF; review and editing: MF and MJC. All authors have read and agreed to the published version of the manuscript.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by EticaCodigo2023\_19ESE. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; internally peer reviewed.

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