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Evaluation and Improvement of Palliative Care: A health technology to improve the quality of death and reduce hospital oncology expenses

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Abstract: Objectives: Palliative care is an approach that promotes the quality of life of patients and their families facing any life-threatening illness, regardless of diagnosis. To this end, it requires early identification, through assessment of status, performance and decision-making. In order to facilitate this process, this research aimed to develop a mobile mHealth application designed to assess prognosis and life expectancy, support decision-making about the transition to palliative care, and offer educational content on the subject. Method: A research project was conducted to develop a scientific and technological production. Through a multidisciplinary team, with periodic meetings, integrative literature reviews on the topic were initially carried out, as well as benchmarking to identify needs and establish the requirements for the design and redesign stages of the application interface. Results: An application was created that allows patient registration, completion of performance status assessment scales, monitoring of patient history, and obtaining information via a fixed platform and through interaction with a chatbot. Conclusions: The importance of a mobile application with features that are easy to use for healthcare professionals is considered, facilitating the effective monitoring of patient progress. This tool can contribute as an addition to the therapeutic process, being used by any professional category, assisting them in making decisions about the appropriate therapeutic approach for each patient in oncology.

Keywords: Palliative care, status performance, health technology, mhealth, oncology.

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ESP Evaluación y mejora de los cuidados paliativos: una tecnología sanitaria para mejorar la calidad de las muertes y reducir los gastos hospitalarios en oncología

ESP Resumen: Objetivos: los cuidados paliativos son un enfoque que promueve la calidad de vida de los pacientes y sus familias frente a cualquier enfermedad potencialmente mortal. Para ello se requiere una identificación temprana mediante la evaluación de la situación, el rendimiento y la adopción de decisiones. Para facilitar este proceso, esta investigación tuvo como objetivo desarrollar una aplicación móvil de mHealth diseñada para evaluar el pronóstico y la esperanza de vida, apoyar la toma de decisiones sobre la transición a los cuidados paliativos y ofrecer contenido educativo sobre el tema. Método: Se llevó a cabo un proyecto de investigación para desarrollar una producción científica y tecnológica. A través de un equipo multidisciplinario se realizaron inicialmente revisiones integradoras de la literatura, así como evaluaciones comparativas para identificar las necesidades y establecer los requisitos para las etapas de diseño y rediseño de la interfaz de aplicación. Resultados: Se creó una aplicación que permite el registro del paciente, la realización de las escalas de evaluación del estado de rendimiento, el seguimiento del historial del paciente y la obtención de información a través de una plataforma fija y mediante la interacción con un *chatbot*. Conclusiones: Se considera la importancia de una aplicación móvil con características que sean fáciles de usar para los profesionales de la salud, facilitando el seguimiento efectivo del progreso del paciente. Esta herramienta puede contribuir como complemento al proceso terapéutico, siendo utilizada por cualquier categoría profesional, asistiéndolos en la toma de decisiones sobre el enfoque terapéutico apropiado para cada paciente en oncología.

Palabras clave: Cuidados paliativos, status performance, health technology, mhealth, oncología.

Sumario: 1. Introduction 2. Method 3. Results and discussion 4. Conclusion 5. References

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1. Introduction

Throughout history, from the Middle Ages to the present day, the social representation of death has undergone significant transformations. In the early Middle Ages, death was understood as a natural, familial and collective event, experienced within communities and marked by public and shared rituals. Over time, however, the experience of death became progressively more individualized. Individuals began to worry more about their singular existence, and the influence of Christianity became more evident — with emphasis on the concern with the final judgment, the salvation of the soul and the destiny in the afterlife(1).

From the 18th century onwards, there was a growing appreciation of the figure of the “other”: the pain and loss of those who remained alive became central to conceptions of death. In this context, the cult of the dead gradually intensified, and cemeteries began to play increasingly important roles in the symbolic process of dying(1).

With the advent of modernity, especially from the 19th century onwards, a profound change occurred in this representation: death began to be silenced, treated as a taboo, and dying was progressively displaced from the public to the private and institutional sphere, becoming an object of social and cultural prohibition. Top of the form In contemporary Western society, death is often avoided in everyday discourses — it is neither spoken about nor thought about; it is often denied or repelled, which reinforces its forbidden nature(1-2).

Bottom of the form

This change in perspective has also led to a shift in the place where death occurs. While, previously, the end of life was experienced naturally, at home and surrounded by family, today, the predominant search is for hospitals and health institutions, where technical advances and the presence of specialized professionals attempt to postpone the dying process as much as possible, assuming responsibility for the patient(1). This phenomenon is intensified by the increase in the prevalence of chronic diseases, such as cancer, which require continuous and complex care. To illustrate this change, in the 19th century, approximately 90% of people died at home; currently, approximately 70% of deaths occur in hospitals(3).

This institutionalization of death significantly impacts the experience of dying, especially for the three main actors involved in the process: patient, family and healthcare team. The patient, often removed from the home environment, may become isolated, in an impersonal space, far from emotional bonds, dying amid institutional rules and surrounded by strangers. The family, in turn, often does not accept the proximity of death and nurtures the expectation of a possible cure, even in the face of an irreversible prognosis. This denial makes the farewell process difficult and reinforces the decision to keep the patient hospitalized, preventing the experience of rituals that could give meaning to the loss(4-5).

In this context, health professionals — whose academic training is largely guided by the ideal of preserving life at all costs — often face difficulties in dealing with human finitude. Death, in this scenario, is often perceived as a sign of impotence, failure or even professional shame. Consequently, the available biotechnological resources are used not only as therapeutic instruments, but also as ways of postponing the inevitable, avoiding facing death, contact with the patient's feelings and open dialogue with family members(4, 6–8). Death, therefore, is denied, establishing a true pact of silence between the team, patient and family(9–10).

One of the most obvious consequences of this denial is the practice of dysthanasia — a term that is still little used outside of academia, but is widely used in Brazilian hospital routines. Dysthanasia, also known as therapeutic obstinacy or medical futility, consists of adopting disproportionate clinical interventions with the aim of artificially prolonging the lives of patients with no possibility of cure. It is, therefore, the extension of the dying process, which often leads to additional and unnecessary suffering for the patient and their loved ones(5, 11-14).

This scenario contributes to the construction of a negative social representation of cancer. The fear associated with the disease is not limited to the prospect of death, but is also related to the way in which one dies: dying from cancer is often imagined as a painful, prolonged process marked by physical and emotional suffering. Thus, the fear of suffering sometimes becomes greater than the fear of death itself.

In addition to the emotional and ethical impacts, dysthanasia entails considerable financial costs. A Brazilian study conducted with cancer patients showed that those undergoing this type of intervention generated, on average, expenses of R$2,316.92 for exams and procedures in the last 30 days of life — more than double the costs related to palliative care, a less invasive approach that is more focused on the patient 's dignity and comfort(14).

In contrast to therapeutic obstinacy, palliative care emerges as an ethical and humane alternative . The World Health Organization (WHO) defines Palliative Care as an approach that aims to improve the quality of life of patients and their families facing any disease that threatens the continuity of life, regardless of the diagnosis. To this end, it requires early identification, evaluation and impeccable treatment of pain and other distressing situations of a physical, psychosocial and/or spiritual nature. Palliative care must be present from the moment of diagnosis, extending until terminality, and can be applied in four different phases: early, complementary, predominant or exclusive. Its fundamental pillars are: (1) comprehensive and humanized care of the patient, through an interprofessional team, (2) effective communication between patient-family-professionals, and (3) the search for quality of life and death for the patient(14-18).

To increase access, dissemination and adherence to these care measures, the use of mobile communication technologies — such as smartphones and tablets — is strategic, especially through the development of health-focused applications. Mobile health (mHealth), as defined by the WHO(19), is the medical and public health practice supported by mobile devices, including smartphones, health monitors and wireless technologies in general. This technological modality aims to expand the reach of services, strengthen health information systems and improve the quality of care programs. Furthermore, mHealth offers important advantages: saving time, agility in the exchange and secure storage of data, reduction of information loss and the possibility of collecting data in the patient's own environment, without the need for travel.

In this context, the present study aimed to develop a mobile mHealth application designed to assess prognosis and life expectancy, support decision-making regarding the transition to palliative care, and offer educational content on the subject. The idea arose from the identification of two complementary movements in today's society. On the one hand, the difficulty faced by health professionals in recognizing the prognosis and life expectancy of patients, as well as in carrying out the appropriate therapeutic transition to palliative care. On the other hand, the limitation of patients and family members in understanding what palliative care is and in recognizing its value. At the same time, there is the widespread dissemination of mobile devices, the increase in digital connectivity, and the growing technological accessibility in all social classes.

In this sense, it is understood that, through new technologies, it is possible to create complementary alternatives and innovative communication and intervention strategies, capable of reaching diverse audiences more effectively. The proposal includes the development of a digital tool that encourages active and conscious user participation, enabling self-assessments in a playful, interactive and accessible way, thus promoting health education and empowerment in the care and decision-making process.

2. Method

This study is characterized as an applied research of a technological nature, aimed at developing a digital solution in the health field: a mobile mHealth application designed to support prognostic assessment, therapeutic decision-making and education in palliative care. The project was carried out using a method based on user-centered design and collaborative engineering principles, which ensured that the tool was built based on evidence, real needs in the health field and digital accessibility guidelines. To this end, a multidisciplinary team, composed of researchers from the areas of health, technology and communication, conducted four main stages.

A. Needs Assessment (Benchmarking)

An exploratory review was conducted between December 2018 and January 2019 on the Google Play (Android) and App Store (iOS) platforms, using pre-established descriptors, inclusion and exclusion criteria. Applications on the topic were selected and analyzed regarding their functionalities, target audience, accessibility and limitations. This stage allowed mapping gaps to be filled by the new technology and served as a basis for outlining the application requirements.

B. Defining Requirements and Functionalities

Based on market analysis and theoretical references on palliative care and mHealth , the functional objectives of the application were defined. In regular meetings, the interdisciplinary team discussed and organized the main functionalities.

C. Design and Prototyping

Prototypes were developed in two phases:

- Low fidelity: Interfaces designed on paper, which made it possible to explore ideas and test navigation flows quickly and economically.
- High fidelity: Digital interfaces with layout, color palette, typography and graphic elements close to the final version.

D. Functional Prototype Development and Usability Testing

Based on the defined requirements, an initial functional prototype was developed on the Android platform. A usability test was then conducted with 10 healthcare professionals. Participants interacted with the application in a simulated scenario, performing different tasks.

After completing the tasks, the professionals answered an evaluation questionnaire, highlighting strengths, flaws and suggestions for improvement. The information obtained supported the adjustment of the final version of the application.

3. Results and discussion

Benchmarking for identifying needs and establishing requirements

Initially, a Benchmarking review was carried out to identify applications on the subject available for smartphones. To this end, a selection of applications was made in the months of December/2018 and January/2019, on “Google Play” on the Android system and on the “App Store” on the iOS system, using the descriptors “Palliative Care”; OR “Symptom Management” AND “Orthothanasia”; OR “Palliative Care”; OR “Symptomas Management” AND “Orthothanasia”.

In the first search, free of filters, using the chosen descriptors, 51 applications were identified. 26 applications were found with the descriptors in Portuguese: “Cuidados Paliativos” (n = 6), “Manejo de Sintomas” (n = 10) and “Ortotanásia” (n = 10). And 25 applications were found with the descriptors in English: “Palliative Care” (n = 5), “Symptoms Management” (n = 10) and “Orthothanasia” (n = 10).

Based on this survey, the following initial inclusion criteria were defined: applications that had a theme related to the objective of the study and made it possible to answer the predefined guiding question. The following initial exclusion criteria were defined: repeated applications. After using these inclusion and exclusion criteria, the selection was reduced to 6 applications in Portuguese and 6 in English .

To complete this stage, the functionalities of the available applications and market demands were verified. From this data, useful functionalities and gaps to be filled were identified and, consequently, the requirements that should be met in the new mobile application were outlined (see Table 1).

Table 1. Application requirements

Code	Requirement
R1	The system is aimed at any health professional and must contain a registration form
R2	Still in the registration phase, ask the user to accept the terms of use of the tool (if the user does not accept, the system will not be accessed)
R3	The system must request a login and password to access the information areas
R4	Recover personal data of the system access user
R5	Provide information about the origin, version and purpose of the system
R6	Present performance status assessment scales in Checklist format
R7	Present assessment results with scales in graphical form and with a timeline history
R8	Obtain basic information about the scales used and about the main concepts
R8	(Chatbot) Answer questions asked in natural language (text) about palliative care, covering topics such as concepts, doubts and implementation of the SPIKES protocol

Subsequently, meetings were held through the alliance of multidisciplinary efforts of Psychology, Computer Science and Engineering, Medicine, Audiovisual and New Media. In these meetings, the functionalities of the application were constructed. Through a long process, carried out through successive discussions among the team, with a focus on the usability of the application, to decide on the functionalities, nomenclature of the application and functionalities, and the format of the information for users.

The application, initially aimed at the *Android platform*, is aimed at any health professional and has three functionalities: 1) Patient Assessment, where the patient assessment scales are located, adapted to the Brazilian reality - Palliative Performance Scale (PPS), ECOG Scale and Edmonton Symptom Assessment System (ESAS-r), 2) Textual psychoeducation and 3) *quiz*.

Design and redesign

This activity consisted of proposing how Information and Communication Technologies (ICTs) could satisfy the requirements identified in the previous activity. First, a low-fidelity interface prototype was designed, where only the concept and initial idea of the technology were shown (see Figure 1)[5]. Low-fidelity prototypes use materials that are different from the final version, such as paper and cardboard. They are useful due to their simplicity, low cost, and rapid production and modification, which enables support for the exploration of alternative *designs* and ideas(20).

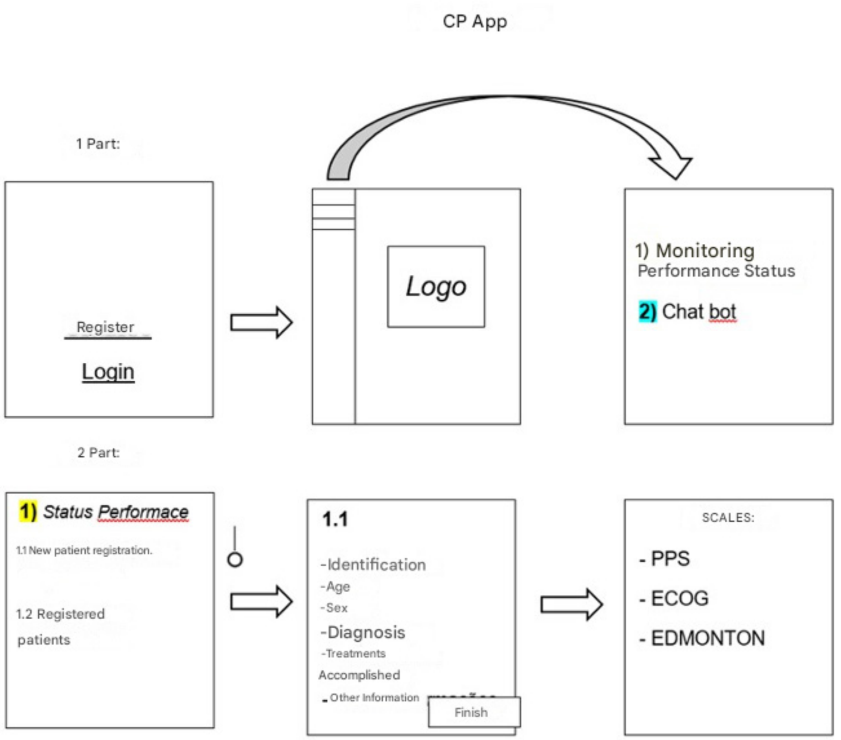

Figure 1. First version of the interfaces, low fidelity

Next, high-fidelity interfaces were prototyped, with an appearance as close as possible to the final product (see Figure 2). These interface prototypes include the color palette, typography, iconography and even content examples(20).

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[5] The application texts, originally in Portuguese, have been translated into English.

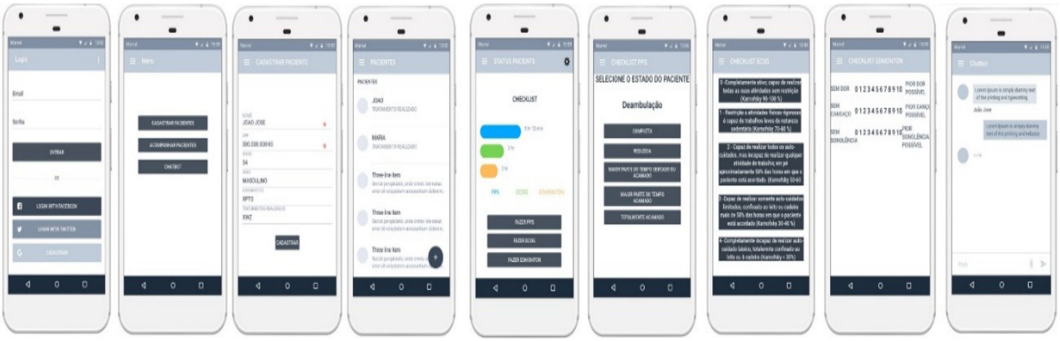
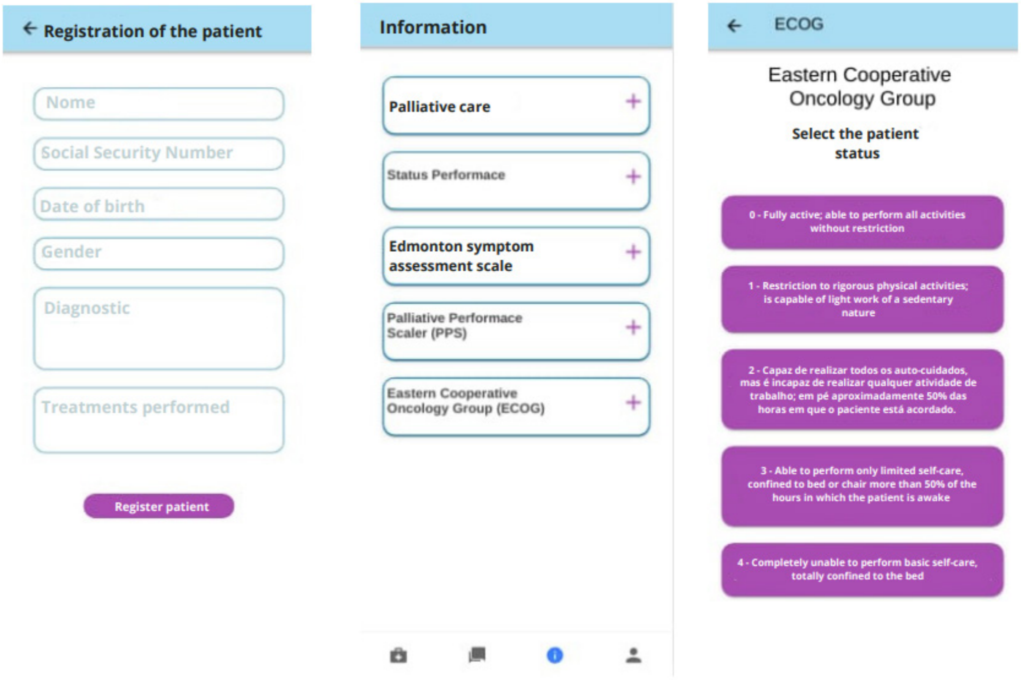


Figure 2. Second version of the interfaces, high fidelity

Building an interactive version (Functional Prototype)

This activity involves the use of software engineering practices and tools, aiming to facilitate development and make the technology flexible to changes. As a result, the functional prototype of the application was designed, covering all its functions, appearance and content.

Finally, a usability test was carried out, with the participation of 10 health professionals. To this end, a fictitious scenario was created with commands to be performed in the application, such as user registration, patient registration and filling out scales, analyzing the performance status history and answering questions in the chatbot. After applying the tasks, the professionals answered an evaluation questionnaire about the application's usability qualities and flaws. At the end of this process, the final version of the application was obtained (see Figure 3)[1].



← Registration of the patient

Nome

Social Security Number

Date of birth

Gender

Diagnostic

Treatments performed

Register patient

Information

Palliative care +

Status Performace +

Edmonton symptom assessment scale +

Palliative Performace Scaler (PPS) +

Eastern Cooperative Oncology Group (ECOG) +

← ECOG

Eastern Cooperative Oncology Group

Select the patient status

0 - Fully active; able to perform all activities without restriction

1 - Restriction to rigorous physical activities; is capable of light work of a sedentary nature

2 - Capaz de realizar todos os auto-cuidados, mas é incapaz de realizar qualquer atividade de trabalho; em pé aproximadamente 50% das horas em que o paciente está acordado.

3 - Able to perform only limited self-care, confined to bed or chair more than 50% of the hours in which the patient is awake

4 - Completely unable to perform basic self-care, totally confined to the bed

Figure 3. Final version of application interfaces

4. Conclusion

The scarcity of technological tools aimed at the assessment and monitoring of patients in palliative care, especially with regard to performance status, reinforces the relevance of developing accessible, intuitive and evidence-based digital solutions. In response to this demand, this study resulted in the creation of a mobile mHealth application that brings together resources such as patient registration, application of validated scales (PPS, ECOG and ESAS-r), clinical history and interaction through chatbot, integrating prognostic assessment, decision-making support and health education.

The main results demonstrate that the application addresses a significant gap in clinical practice by providing objective and continuous support for the transition process to palliative care. The positive usability reported by health professionals in the testing phase confirms its practical applicability in hospital and outpatient routines. In addition, the platform has the potential to expand access to knowledge about palliative care, both for professionals and for patients and family members, promoting health literacy and contributing to overcoming cultural barriers related to terminality and death.

From a practical perspective, the tool can be incorporated by multidisciplinary teams at different levels of healthcare, facilitating the early identification of patients with indications for palliative care and promoting more humanized and effective clinical decisions that are less focused on therapeutic obstinacy. By contributing to more ethical and patient-centered conduct, the proposed technology can also help reduce hospital costs associated with dysthanasia, which makes it socially relevant in contexts of overburdened healthcare systems.

However, like any scientific endeavor, the study has important limitations. The first refers to the small sample of professionals participating in the usability test, which restricts the generalization of the results obtained. In addition, the application has not yet been tested in real clinical contexts with patients and family members, requiring longitudinal and multicenter studies to assess its effectiveness, impact on care and acceptability in different regions and cultures.

Therefore, it is suggested that future research investigate the implementation of the application in different health services, including primary care units, general hospitals, and home care. Qualitative evaluations on user experience and quantitative studies on clinical and economic outcomes should be conducted to validate and improve the technology. Furthermore, it is proposed to adapt the application to new platforms, including iOS, and to expand its functionalities, such as integration with electronic medical records and telemonitoring resources, aiming to expand the reach and strengthen palliative care practices in Brazil and in other contexts.

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