

Exploring Perceptions, Opinions, and Needs of Adult and Pediatric Cancer Patients, Caregivers, and Healthcare Professionals Towards Low-Fidelity Versions of the MyPal Project's Applications: Findings from 12 Pre-Pilot Focus Groups in 4 European Countries of an ePRO Intervention for Palliative Cancer Care

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Abstract

Background: Palliative care is crucial for patients with life-threatening and serious diseases like cancer, addressing their physical, psychosocial, and spiritual needs. Haematological Malignancies (HMs) significantly contribute to global cancer cases, impacting both older adults and children. To meet the increasing demand for palliative care, electronic patient-reported outcome (ePRO) interventions have emerged, offering valuable insights into patient monitoring and treatment decision-making.

Objective: This study aims to explore the perceptions, opinions, and needs of adult and pediatric cancer patients, caregivers, and healthcare professionals towards low-fidelity versions of the MyPal Project's applications, which are designed to improve palliative cancer care.

Methods: Twelve pre-pilot focus groups were conducted across four European countries, involving a diverse sample of participants. Thematic analysis was utilized to identify and extract themes and subthemes from the focus group discussions.

Results: Three main themes emerged from the focus group discussions. The first theme, "Improved Care," highlighted MyPal's potential to enhance healthcare through patient-reported measures, improving symptom monitoring, decision-making, and doctor-patient communication. The second theme, "Digital Communication Framework," addressed concerns about data privacy and the need for clearer guidelines regarding app-based reporting and phone calls. The third theme, "Applicability for Use in Healthcare," emphasized the importance of the system's ease of use, while concerns about intrusiveness and burden were raised.

Conclusions: This study provides valuable insights into the perspectives of adult and pediatric cancer patients, caregivers, and healthcare professionals towards the MyPal Project's low-fidelity applications. Understanding end-users' perceptions and needs is vital for developing patient-centered eHealth interventions that can enhance the quality of life and care for cancer patients of all ages. These findings have implications for optimizing app design and implementation, ultimately promoting the successful integration of eHealth technologies into routine palliative care practice.

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Original Manuscript



Original Paper

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Keywords: Palliative care; eHealth systems; adult cancer patients; healthcare professionals; focus groups discussions.

Introduction

Palliative care plays a vital role in the holistic treatment of patients with life-threatening and serious diseases, such as cancer. The European Association of Palliative Care (EAPC) defines palliative care as "comprehensive care that addresses physical, psychosocial, and spiritual needs, including pain management, for patients and their families" [1]. Additionally, the World Health Organization (WHO) emphasizes the importance of providing support systems to help patients lead active lives until the end [2]. To meet the needs of the aging population and the increasing prevalence of cancer and other progressive conditions, innovative interventions are essential [3] [4].

Haematological Malignancies (HMs) contribute significantly to global cancer cases [5], and account for 6.5% of all cancers around the world [6], primarily affecting older individuals with a median age of diagnosis around 70 years [7,8]. Evidence suggests that HM patients have poorer Quality of Life (QoL) compared with the general population [9], which renders them in great need for palliative care. Moreover, it is crucial to consider the impact of HMs on children and their caregivers. While childhood cancer is relatively less prevalent, it profoundly affects the lives of young patients and their families [10]. Thus, pediatric palliative care is essential to manage symptoms and enhance the QoL of young patients throughout their disease trajectory [11–13].

Given the growing demand for palliative care and the limited number of specialized healthcare professionals (HCPs) available, it becomes critical to identify methods to optimally utilize available resources. Electronic patient-reported outcomes (ePROs) have been used in various palliative care interventions for patient monitoring, providing reliable data and improving the quality of care delivered to cancer patients [14],[15]. Given the scalability of tools and interventions based on information technologies, there is substantial evidence that there is a high potential for eHealth tools and applications in palliative care [16]. The integration of ePRO assessments into standard healthcare settings presents opportunities to address the challenges of delivering care to older adults [17] with relatively fewer HCPs available to provide the required level of service [18].

However, the increased demand for palliative care, and the limitations of eHealth, discrepancies between care needs and care arrangements must be noted and rectified [19]. Namely, the question of how to engage older adults in eHealth interventions remains an issue [20], since if the interventions are not used in the manner they were meant to, their potential benefits cannot be fulfilled. Also, understanding disease-specific factors to determine how various populations may benefit from eHealth seems important in increasing their usage and, subsequently, their efficacy [21]. These characteristics could negatively impact the effective use of eHealth interventions in this patient group [22].

Participatory design holds great promise in bridging this gap, as demonstrated by a growing body of research in the development of novel healthcare services [23,24]. In the context of palliative care, participatory design is especially relevant. Actively involving patients in the design or development of eHealth tools [25], resources [26,27] or systems [28] for palliative care can provide a unique perspective on user acceptability, system usability as well as insight into the feasibility of the overall effort [29]. User perceptions are also an important determinant of the successfulness of participatory design and in extend the use of eHealth.

The aim of this study is to explore the perceptions, opinions, and needs of potential end-users, including healthcare professionals, adult cancer patients, and caregivers of pediatric cancer patients, regarding different aspects of a palliative care e-health solution, called MyPal. Specifically, we seek to gain insight into users' perceptions of system functionalities, advantages, and disadvantages, as well as their recommendations for enhancing MyPal. The MyPal project [30], is a collaborative H2020 research project, funded by the European Commission, aiming to use eHealth technologies, in order to support cancer patients and healthcare professionals. The main goal of MyPal is to develop and clinically assess new ePRO-based interventions for the palliation of cancer patients, in order to improve their Quality of Life [31]. The project targets both adults with chronic hematologic malignancies and pediatric patients with leukemia or solid tumors, along with their caregivers. MyPal has committed to both adopting a patient-centered approach and adapting technology in order to cater for fundamentally different profiles of patients of different age groups as well as levels of digital and health literacy. Therefore, during the MyPal intervention design and protocol development, the context of healthcare provision i.e. current clinical practice for cancer patients, their interaction with healthcare professionals, provision of palliative care etc., but also users' personal needs were considered.

Methods

Design

The study was cross-sectional and employed a qualitative methodology. The data was collected via focus group discussions, that took place in five clinical sites across Europe.

Sample

More specifically, twelve focus groups (FG) of four to eight participants were conducted with: a) adult patients with Chronic lymphocytic leukemia (CLL) or Myelodysplastic syndromes (MDS), b), parents and children with hematological cancers or solid tumors and c) healthcare professionals working in participating clinical sites across Europe, namely Greece, Italy, Germany, and the Czech Republic (see Table 1)

Table 1. Focus groups per country and clinical site.

| Country | Clinical Site | Adult Patients FG | Parents and children FG | HCPs FG |
|---------|--|-------------------|-------------------------|---------|
| Greece | Centre For Research and Technology Hellas (CERTH) | 2 | - | - |
| | Panepistimiako Geniko Nosokomeio Irakleiou (PAGNI) | 1 | - | 1 |

| | | | | |
|-----------------------|---|---|---|---|
| Italy | Universita Vita-Salute San Raffaele (USR) | 1 | - | - |
| Germany | Medizinische Hochschule Hannover (MHH) | - | 1 | 1 |
| | Universitat Des Saarlandes (USAAR) | - | 1 | 1 |
| Czech Republic | Fakultni Nemocnice Brno (BRNO) | 2 | 1 | - |

Materials

A series of vignettes were developed by a software engineer with expertise in eHealth and participatory design techniques and a health psychologist. These vignettes presented one or more imaginary end-users (called personas) of the system and targeted each participant group: Adult Patients, HCPs and pediatric patients along with their carers respectively (see Error: Reference source not found). In each vignette, a persona was introduced and then illustrated how the it interacted with the MyPal app and all its components from enrollment to the clinical trial up until its end (see Figure 1).

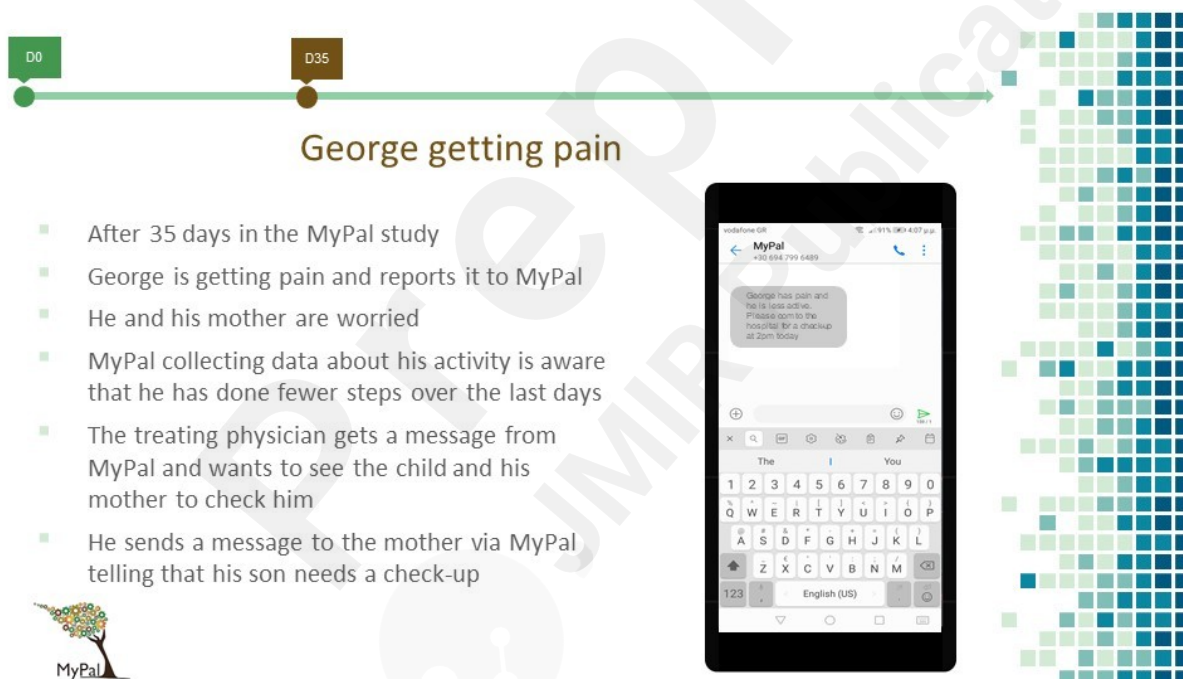


Figure 1. Vignette for Adult Patient

Based on the vignettes, **discussion guides** were created in order to assist the elicitation of participants' perceptions and judgments, in a semi-structured way (see Error: Reference source not found). The discussion guides included showing the user scenario divided into episodes, and then making relevant questions to the participants.

Procedure

Aiming at maximizing consistency in the conduct of focus groups and the analysis of the data across every clinical site, INAB|CERTH developed a 2-hour **training workshop** which was delivered

virtually to all MyPal participating clinical sites and partners (see Error: Reference source not found). The workshop was recorded so that those who could not be present could view it in their own time.

The workshop was held after the completion of the first two focus groups in Greece. The aim of the workshop was to present a) the rationale behind interacting with potential users to elicit needs and preferences via focus groups discussions as well as b) the process which must be followed to ensure consistency among sites.

Workshop attendants were given a list of necessary materials (i.e. recorder) and conditions that have to be met (i.e. private room) in order to successfully conduct a focus group on the premises of their organization (i.e. hospital ward). Particular emphasis was placed on the recruitment of focus-group participants and the role of the moderator both of which were discussed at length as they can have an impact on the integrity of the methodological design. It should be highlighted that the consent form, the user scenario which is presented at the beginning of the focus group session and the discussion guide upon which the focus group discussion is based were all provided in the English language. Examples of each were presented and discussed in context. For example, certain questions from the discussion guide were phrased as open-ended questions which show no judgment etc.

Following this, managing the focus group discussion itself was discussed with the workshop attendants. Specifically, with regards to group dynamics, attendants were advised to pay attention to non-verbal language, manage 'air time' among members as well as use techniques to invite, reflect or summarize.

Finally, three examples from the focus groups conducted in Thessaloniki were presented. Attendants had the opportunity to comment upon the role of the moderator and his/her choice of intervention at each instance as well as the sequence or the manner the questions were posed. Furthermore, attendants were able to observe from a bird's eye view the stages of the process through which the group undergoes after the introduction of a new item on the agenda by the moderator; namely exploration, unison and solution. Key references on the conduct of focus groups [32] and a step by step thematic analysis guide [33] were provided as supplementary material.

After viewing the workshop and the material provided, the principal investigators from each clinical site extended invitations for participation in focus groups to i) patients with CLL or MDS, ii) HCPs who worked in palliative care units or oncology units and iii) parents of young patients (with or without their children) with solid tumors or hematological cancers, through the hospital units they were being looked after or worked in. A screening paragraph was developed to help HCPs from each participating site recruit participants in a standardized way.

“Within the context of a project called MyPal funded by the European Commission we are organizing a number of focus groups discussions. We are interested in developing a digital health system for cancer patients (or for HCPs looking after cancer patients) and we would very much appreciate your input as our design should ideally correspond to the needs of patients (or HCPs) like yourself. Let us know whether you would be interested in taking part”.

The focus groups initially featured a presentation of the appropriate vignette, followed by a specific discussion on this vignette based on the discussion guide. At the beginning of each session, the aim of the MyPal project was introduced followed by an explanation of the structure of the session. All focus group discussions lasted approximately 2 hours and were recorded.

Analysis

The qualitative data were analyzed by employing thematic analysis, which is an established method of management and analysis of qualitative data in applied health research [34] and usability for

mobile apps[35]. The analysis was conducted by a clinical psychologist with prior experience in thematic analysis. Ensuring uniformity of the focus group analysis in the different participating sites was the primary concern of the research team. Among the main reasons behind choosing this method of analysis were: a) the multi-disciplinary research teams involved b) the sample with clinical, patient and lay representations c) the complexity of the dataset which was generated via the collection of data in 5 different countries and languages d) the nature of the data which consisted of expressed multifaceted views with regards to specific features of the MyPal system e) the aim of the research study, i.e., the elicitation of participant perceptions.

According to Braun and Clarke's guidelines [36,37] [33], the steps that were followed were:

1. Familiarization with the qualitative data through listening to the focus groups discussions.
2. Inductive coding of the focus group data to generate preliminary concepts. These codes were developed at a national level. Examples of preliminary codes generated were: *"The physician has the chance to evaluate signs and symptoms of which the patient is not aware"*; *"It is easy, to the point, immediate"*.
3. Inductive codes were sent to INAB/CERTH and the final stages of analysis were performed on the aggregated data.
4. The initial codes were clustered the clinical psychologist, in overarching categories that reflected conceptual patterns across the data (subthemes and themes).
5. The external heterogeneity and internal homogeneity of the developed categories were reviewed in a multidisciplinary research team (health and clinical psychologists (CKar, DK), eHealth (CM, CKak) and usability experts (PB)) and refined until consensus was reached.

Results

Three themes and seven subthemes (see Figure 2) were developed from the focus group data. The first theme (**Improved Care**) portrays participants' perceptions and opinions regarding MyPal's potential to improve health care, by utilizing patient-reported measures and outcomes which can both enhance monitoring and decision making, improve doctor-patient communication, as well as highlight areas of intervention (e.g., psychological distress) which can easily go unnoticed in clinical practice. The second theme (**Digital Communication Framework**) highlights participants' need for more explicit clarification of the boundaries, roles and procedures regarding MyPal's digital communication framework and their concerns regarding the privacy of their personal data. The third theme (**Applicability of use in Healthcare**) describes the importance of the system's ease of use, presents participants' feedback regarding MyPal's burdensomeness and presents participants' ideas on how to enhance its acceptability for healthcare use.

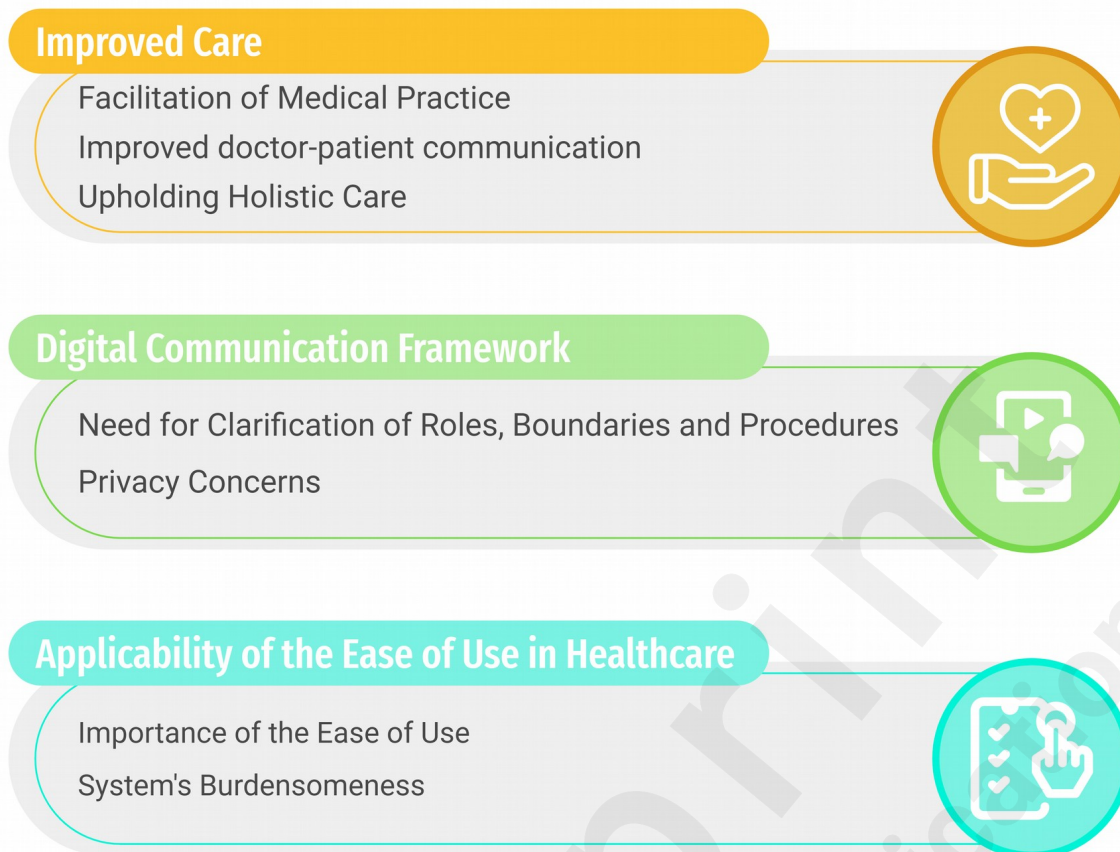


Figure 2. Main themes and subthemes identified through the thematic analysis methodology

Themes and subthemes are presented in more detail below, along with relevant quotes from the focus groups which further support and illustrate the presented concepts. The quotes' descriptions include the participant group, the clinical site, and the specific functionality of MyPal on which participants commented, i.e., Patient Reported Outcomes, Smart Bracelet, Personalization, General Judgement and Facial Recognition/Voice Recognition, Game (for the MyPal-CHILD study only)

Improved care

Facilitation of Medical Practice

Both patients, parents and HCPs reported that MyPal could promote an easier and more efficient way of symptom monitoring and reporting, especially through the patient-reported measures. Emphasis was placed on the convenience of reporting symptoms via the app, without having to visit the hospital or call the doctor.

“I think it helps, because patients don't want to visit the doctor every month, so reporting from home will be easier and less stressful” (General Judgment, HCPs, USAAR)

Patients highlighted that by self-reporting their symptoms they would become better at self-monitoring and enable their healthcare team to keep better track of their condition. Specific functionalities, such as photo-reporting and the smart bracelet, were emphasized as a means for more accurate reporting.

“The patient may not describe or may not be able to accurately describe a symptom, e.g., a rash. A

photo is far more explanatory.” (Patient Reported Outcomes, adult patients focus group, CERTH)

“It is very useful, I’ll be constantly monitored.” (Smart Bracelet, Adult Patients, USR)

HCPs pointed out the value of having immediate access to accurate patient data that can help in the documentation of patients’ states (e.g., symptoms, side effects). In addition, some mentioned that the collected data could help in more efficient decision-making in medical practice.

“This system could help with some decisions, like how often to monitor a patient.” (Smart Bracelet, HCPs PAGNI)

On the contrary, there were also HCPs who mentioned that they would be hesitant to shape decisions based on the collected data and that getting informed about patients’ symptoms through the app -and not by physically examining the patient- would make them feel uncertainty and worry regarding the symptoms’ importance.

Improved doctor-patient communication

Every group of participants highlighted the fact that MyPal could improve doctor-patient communication through the fast and direct reporting of symptoms. Of note is that both patients and HCPs among many different focus groups mentioned that MyPal could alleviate patients’ fear of burdening their physicians and enable them to report more symptoms without hesitating.

“It’s helpful for patients who hesitate to disturb their physician, because they don’t know whether their symptoms are important” (Patient reported outcomes, HCPs, CERTH)

In one focus group with HCPs, the value of MyPal questionnaires which would be used to personalize healthcare to each patient’s profile was more than emphasized. HCPs described how by getting to know each patient more through MyPal, they could tailor their communication to their specific needs.

“By using MyPal you can understand how a patient might be feeling when sometimes they become demanding in our appointments. Knowing things about them and their experiences might enable us to respond to their questions more promptly. This might address their issues, even remotely.” (Personalization, HCPs, PAGNI)

In addition, some HCPs mentioned that the discussion guide and communication training functionalities of the app could be helpful in better equipping them to respond to their patients’ needs. However, many participants noted their preference for more personal contact, via the phone or in person, and felt that communicating only through MyPal could be depersonalizing.

“I would prefer more calls and more personal contact” (General Judgment, HCPs, USAAR)

“Children have their favorite doctors and they like contacting them directly. But they do not exclude the contact with the app.” (Communication, Parents and children, BRNO)

Upholding Holistic Care

Both HCPs, patients and parents highlighted MyPal’s potential to support patients not only with regards to the physical aspects of their condition, but also to the emotional and psychological aspects. According to participants, frequent reporting through the app could mitigate the anxiety about the disease, and make patients feel secure and reassured without having to contact their doctor.

In addition, reporting data regarding patients' emotional challenges could promote holistic healthcare and improve patients' quality of life.

"It would provide important information regarding how the patient is feeling. This might help because if we know that one is not fine, next time we could spend more time with them. If we notice that one is depressed, we could refer them to a psychologist. You can't treat someone who is depressed and miserable. This isn't good, even for their medical treatment. So, when you have access to this information, you can use it as you wish" (Patient-reported outcomes, HCPs, PAGNI)

"It might be helpful in addressing aspects that would normally not be addressed without data from MyPaL" (Communication, HCPs, MHH)

Both patients, parents, and HCPs highlighted that the app could provide patients a sense that they are not alone, and that their healthcare team is there for them and takes note of their everyday struggles.

"I think that this is psychotherapeutic for the patient, at times when they have no one to talk to. It mostly helps the patient, not us." (patient reported outcomes, HCPs, PAGNI)

In addition, some patients mentioned that the personalized education functionalities of the app could be a relief and save them the stress of searching on the internet.

"It is reassuring. This app is personalized and tailored to my needs. I would be more relaxed, less anxious" (Personalization, Patients, USR)

Concerning children with hematological malignancies, their parents commented that the serious game could act as a distraction and attenuate their pain, as well as become a channel for fun and communication with peers. In addition, some parents and HCPs commented that the app might motivate children to be more active physically and empowered to better address emerging issues.

"It would help physically and psychologically, by motivating them to stay active regarding their health issue and deal with it in better ways" (General Judgement, HCPs, PAGNI)

Lastly, patients and HCPs in Greece highlighted the need for cooperation with mental health specialists in order to provide support for the psychological issues that would be reported by patients through the app.

Digital Communication Framework

Need for Clarification of Roles, Boundaries and Procedures

The description of MyPal raised several questions and concerns for participants. Patients and HCPs expressed their confusion regarding the use of telephone calls while using MyPal, i.e., in which instances could they contact their physician via phone and at which should they report their symptoms via MyPal. In addition, patients expressed the need to know who will be the HCP that receives their reported information, and how often will they be viewing the reported symptoms and reply.

"Is it possible to get a response at night hours, when something happens?" (Communication, Parents, BRNO)

Furthermore, several patients expressed the need to receive feedback from their HCPs after

submitting information to the app. Patients would like to receive immediate feedback, tailored to their unique reported symptoms, and not automatic responses. Along these lines, parents mentioned the need to be able to receive the confirmation that things are under control, when their children submit symptoms. In one focus group, patients also expressed the need for personalized medical advice:

“For instance, if you have high blood pressure use less salt, or consider walking more” (General Judgment, Patients, Greece)

On the other hand, HCPs made the point that patients should be informed explicitly that MyPal is not for emergency situations and that they should make a call, or go to the hospital in such cases. Lastly, both patients and HCPs raised concerns regarding the appropriate interpretation and clinical value of the data captured by the face recognition and the smart bracelet utilities of the app.

“If I have a fight with my husband and my facial expression is changing, this is not due to the disease.” (Facial recognition, Patients, USA)

“I would trust more seeing the patients' face myself, rather than leaving the system to estimate” (Facial Recognition, HCPs, USAAR)

“We cannot know what the measurements reflect” (Smart bracelet, HCPs, USAAR)

Privacy Concerns

Every group of participants perceived that the smart bracelet and face/voice recognition utilities would invade their privacy, along with personal questions that could potentially be included in the MyPal questionnaires for personalization purposes.

“One could feel as being constantly watched, like in George Orwell's book, a sort of Big Brother. Too much personalization could be misunderstood” (Personalization, Patients, USA)

They also expressed their concerns regarding the security of their personal data and highlighted the need for safeguarding their confidentiality. Some mentioned that the face/voice recognition could be acceptable, only under the condition that the patients could choose when to enable it.

Applicability for use in healthcare

Importance of the ease of use

Some patients and parents wondered whether CLL patients, who are generally elderly, will have the necessary technical skills to be able to use MyPal.

“The main criticism on the tool is that patients with CLL are generally elderly and they are not very familiar with this technology. If I think of my mother, who is 84 years old, I see this issue” (General Judgment, Patients, USA)

The same issue was raised for children and for people who do not have a smartphone. On the other hand, other patients viewed MyPal as an opportunity to get familiar with technology.

“Technologies are the future and it is necessary to move with the times when it comes to health.” (General Judgment, Patients, BRNO)

Lastly, patients showed appreciation of features that could facilitate the ease of use even more, like the conversational agents (e.g. Chat bot, etc.) or voice activated functionalities.

Concerns about the system's intrusiveness and burdensomeness

During many focus groups, concerns were raised regarding the intrusiveness of MyPal. Frequent notifications for the completion of pro measures were perceived as a constant reminder of CLL, which would burden patients and interfere with their everyday life, both practically and emotionally.

“They would remind the patient that he is ill even at times when he may not be conscious of it” (Personalization, Patients, CERTH)

Participants suggested that receiving notifications and having to fill PRO measures should be sparse and personalized to their preferences so as to not tire them out and make them lose their motivation to use MyPal. The intervals suggested by the participants varied. For some, weekly reporting was considered okay, while for others monthly reporting was considered more acceptable. Wearing a smart bracelet was considered a burden by some, while others believed it was completely acceptable. In addition, a few participants expressed their concern regarding addiction to the app and spending too much time on the mobile phone, especially regarding young children.

Of note were HCPs' concerns regarding the time they would have to spend using MyPal. With few exceptions, having to look at the extra information that MyPal added to clinical practice was perceived as extra workload. In addition, having to respond to patients, read the spontaneous reported messages, document their progress according to PROs and fill the patient's search engine with appropriate educational material, was perceived as highly burdensome.

“How will MyPal be added to the regular business day of physicians who already have packed schedules for example if there are incoming SMSs because of parental reports? We already have a good system, perhaps in other countries this may be helpful, but how will it be incorporated here? We ask parents to call at the ward in case of problems, how will the use of the app be integrated? It will be difficult, I don't know how it can be integrated”. (Patient Reported Outcomes, HCP, Hannover Medical School)

In addition, HCPs highlighted that they wouldn't want to feel constantly on call or get notifications during their free time.

“If I am not at work I wouldn't want to receive a notification that a patient is not well” (General Judgment, HCP, USAAR)

Along these lines, HCPs suggested the development of a **smart notification system**, which could incorporate patients' data and notify physicians only under certain conditions. Alternatively, some suggested the development of a traffic light system, which would categorize patients' reported data according to their severity. This would allow HCPs to quickly track important patients' data without having to review the whole dataset.

“If there is an alert for data (red light, green light) it could take only a few minutes” (Patient Reported Outcomes, HCPs, USAAR)

Discussion

In summary, the value of MyPal as an ehealth intervention that has the potential to improve patient monitoring and clinical outcomes, as well as uphold holistic care was appreciated by both adult and

children with cancer, as well as their caregivers and HCPs. However, several critical questions and concerns were raised, which were of great value for enhancing the digital tools of MyPal and are worth considering for the development of future interventions.

Firstly, there seemed to be a hard balance between the benefits of using the eHealth solution and the burden of use. In this direction, some main concerns were how much time and effort should one invest in MyPal or whether MyPal would be burdensome and disruptive in one's daily life or work routines. This is especially important, as the burdensomeness of use can be a factor that can greatly reduce engagement with eHealth solutions, and ultimately deprive users of the benefits of using them. Indeed, there is extensive research indicating that apps for example may be quickly discarded if notifications are perceived to be irritating or intrusive[38,39].

Finding ways to reduce the burdensomeness and assist the integration of future palliative ehealth solutions in users' daily routines would be really effective in maximizing engagement. This is critical in the design phase of an intervention, considering that the pooled estimate for dropout rates in trials of app-based interventions for chronic diseases has been found to be 43% over a variety of timelines[40].

Furthermore, participants greatly valued features that could actually improve the physician-patient relationship, while being skeptical of aspects that could result in a more depersonalized way of communication. Preserving the "real-person" contact and not substituting it with other means of indirect communication, seems to be an important element to consider in future palliative care apps. In the domain of Telehealth, for example, there are numerous mHealth consultation apps where acceptability seems to still not have reached its full potential[41]. Thus, special attention must be given to the design of those apps by incorporating the participatory design paradigm [23,24] while preserving the "real-person" contact.

Another crucial element to consider in future ehealth palliative care solutions was patients' and caregivers' wish to receive personalized feedback regarding the data they or their children submit; While ePROs augment the reporting experience, in many cases they lack the feedback element [42], thus posing miscommunication issues. Thus, the incorporation of feedback elements could optimize the user experience by constituting reporting through the app instantly relevant for patients, as they would receive an outcome based on their interaction with the app (e.g., a message that "the doctor has seen your submission and will answer through the app in 24 hours at the latest). Additionally, by adding a co-design approach, miscommunication issues are severely limited [25].

In addition to the aforementioned issues, each participant group placed emphasis on explicitly understanding the framework of using this digital solution, the impact of their interaction with the app and the role of those involved, as well as what adaptations they would have to make regarding their healthcare (e.g., when to report through the app instead of calling). The ability of end users to grasp how each element of a digital intervention is linked to their healthcare should not be taken for granted, but instead clearly explained and demonstrated, so that users can find value in using the solution to assist their healthcare and expect specific outcomes for certain interactions[43–45].

Another major aspect highlighted in this study, was that participants were unwilling to accept some monitoring features of the app, such as the facial/voice monitoring, even when the security of their personal data was guaranteed by the focus group moderators. A previous study [46] has shown that the acceptance of digital technology relies heavily on understanding patients' fears and concerns about lack of security. Many studies highlighted the importance of reducing fears or concerns regarding security among both patients and health care professionals through implementing secure computer systems and protecting personal data[47–49]. Consequently, patients and health care professionals must both be aware of the security systems that surround digital technology in health

care. Additionally, if these security systems are presented in a transparent and comprehensible way, knowledge of digital technology would increase and these concerns might decrease[23].

However, besides data security, the sense of being constantly monitored without being able to control when the monitoring starts and stops was found to be a major concern and an unacceptable feature. This is probably linked to users' perception of their private life being invaded by technology and the desire to retain control of monitoring and reporting[50].

Lastly, the importance of adjusting digital solutions to enhance the ease of use for end users of diverse age groups and other characteristics (e.g., the ability to point the finger and press a small digital button, the ability to read a small font) that may act as barriers was highlighted. This is a rather important factor since there have been various reports of older patients that struggle with locating specific buttons that younger users have no trouble with[51].

Limitations

Our sample may have consisted of participants with an interest or familiarity with digital technology and in the development of eHealth solutions, which may have introduced bias. Thus, a sample using patients with low digital literacy might show different results. Poor digital literacy can seriously impair people's interactions with health care professionals and their potential to benefit from digital health services.

Another limitation is the fact that the first coding step, i.e., inductive coding of the focus group data, was performed at a national level by different investigators. This might have introduced certain biases in the first coding phase, stemming from factors related to each individual investigator (e.g., different assumptions and values). However, since the aggregated initial codes were subsequently organized into overarching categories based on data from every participating site and participant group, these differences were smoothed over in the themes and subthemes that were ultimately developed.

One additional limitation of this study is the number of focus groups performed. Even though the goal was to hold at least 1 focus group for each user group per country, it was evident during the thematic analysis that additional focus groups could be used to elicit more diverse perceptions from the participants. Even though MyPal is a multinational project and focus groups were held in each country in order to take into consideration possible cultural disparities, a higher participation rate could probably offer additional insights that could prove highly beneficial, since more opinions could be voiced and initiate new discussions.

Also, another limitation is the validity of the FGs content. Even though the FGs content was carefully designed by experts in psychology and engineering in the consortium of the MyPal project, it was not validated with every stakeholder of the particular subsystem (i.e. it was not validated by patients and caregivers). Ensuring that the FG content is tailored according to the stakeholder's routine actions when using the proposed application could prove highly beneficial since the participants could offer more targeted perceptions.

One final limitation is the language barrier and the remoteness factor. Designing an FG for multiple countries is often accompanied by translation actions whose duration varies to a point where they delay the design phase considerable. Additionally, the remoteness factor introduces difficulties in handling cultural differences among the multilingual consortium in the design process. For instance, when two experts from different countries communicate in a non-native language to create content that will be further translated into multiple languages, the process becomes by definition complicated. As a result, the optimal preparation becomes excessively time-consuming, and simple tasks become unnecessarily complex and burdensome.

Conclusions

The purpose of this study was to investigate the perceptions of an ehealth palliative care intervention after presenting the vision of the MyPal system to all implicated stakeholders. Findings from the focus groups conducted with CLL patients offered insights into patients' requirements from and barriers in adoption an eHealth system like MyPal. It was evident that, in order to support patients and their caregivers in getting the most of MyPal, it is necessary to alleviate their concerns about the appropriate use of data and the efficiency of data analysis, while also providing reassurance with high standards of data security adopted for sensitive personal information. End users' valuable contributions were deemed very informative and contributed immensely in shaping the MyPal design and the next cycle of iteration taking place in the post-validation phase preceding the RCT for preliminary field testing. The employed participatory design approach has been very useful in that it has encouraged genuine involvement of participants, a factor which over time can empower patients and promote participants' long-term engagement.

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DK and PB: methodology, and writing—original draft. LS, MM, AS, TA and EK: methodology and implementation. CM: conceptualization and methodology, and writing. CKar: supervision, conceptualization, methodology and review. All authors contributed to the article and approved the submitted version.

Conflicts of Interest

None Declared

Abbreviations

| | | | |
|-------------|--|-----------|------|
| BRNO: | Fakultni | Nemocnice | Brno |
| CERTH: | Centre For Research and Technology | Hellas | |
| CLL: | Chronic Lymphocytic | Leukemia | |
| EAPC: | European Association of Palliative Care | | |
| FG: | Focus Groups | | |
| HCPs: | Healthcare Professionals | | |
| INAB/CERTH: | Institute of Applied Biosciences Centre for Research and Technology Hellas | | |
| MDS: | Myelodysplastic | Syndromes | |
| MHH: | Medizinische Hochschule | Hannover | |
| PAGNI: | Panepistimiako Geniko Nosokomeio Irakleiou | | |
| RCT: | randomized controlled trial | | |
| QoL: | Quality of Life | | |
| USR: | Universita Vita-Salute San Raffaele | | |
| USAAR: | Universitat Des Saarlandes | | |
| WHO: | World Health Organization | | |

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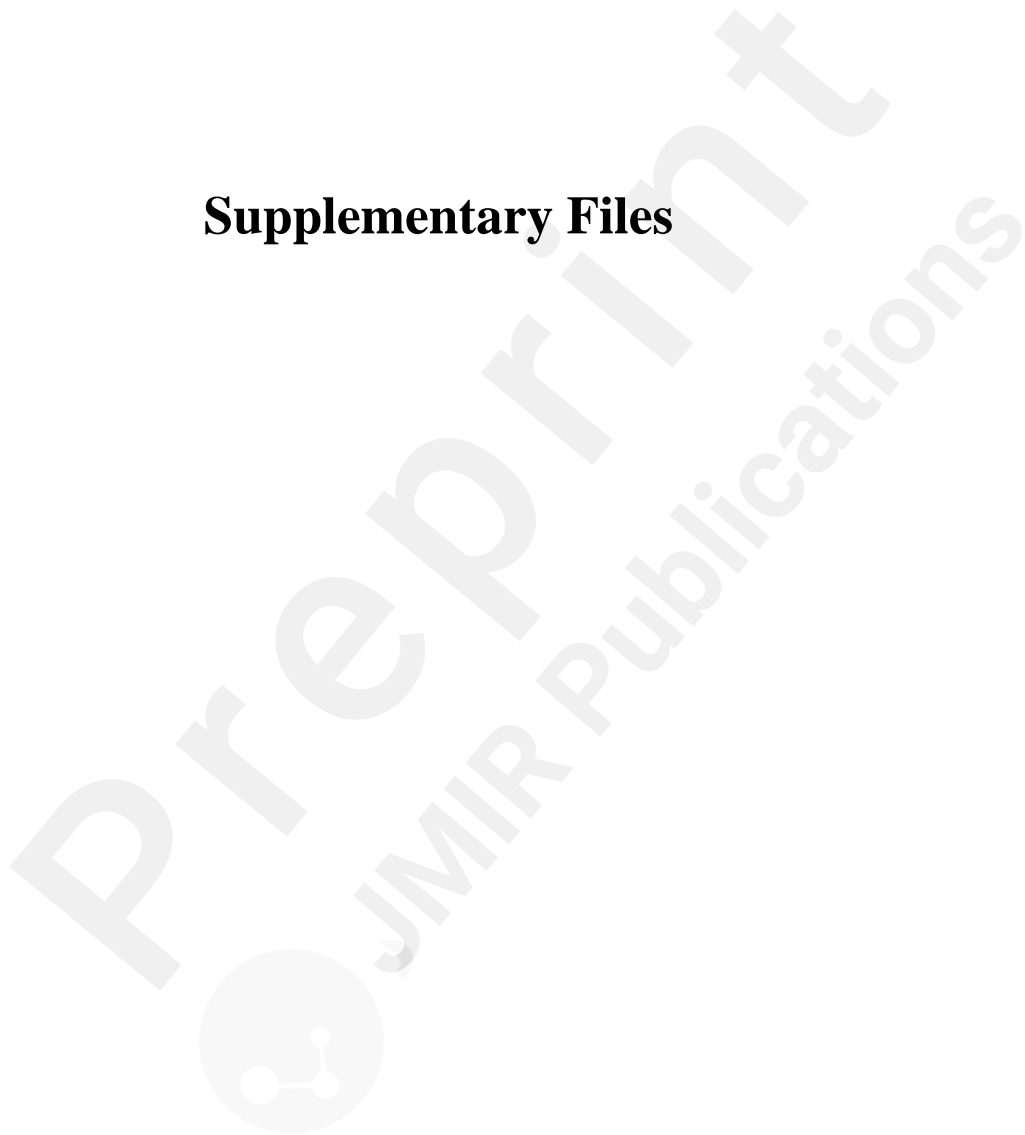
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Supplementary Files



Multimedia Appendixes

Adult Patient's Vignettes, Pediatric Patients and Parents Vignette, Sample Slides from the Focus Group Vignette of pediatric patients and their parents, Healthcare Professionals Vignette, Sample Slides from the Focus Group Vignette of HCPs.

URL: <http://asset.jmir.pub/assets/abf1c51da5b91cd9518ff261254e2c71.docx>

Discussion Guide for Focus Group of Adult Patients.

URL: <http://asset.jmir.pub/assets/856c53da12bfe3841d030af9d7815e91.docx>

Training Workshop Screenshots.

URL: <http://asset.jmir.pub/assets/9fae3632f1b77b98feab9d452cbd8ac0.docx>