Exploring the Integration of Pal in the Dutch Healthcare System

A mobile application to support informal care providers of patients in palliative home care

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A mobile application to support informal care providers of patients in palliative home care

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Date

January, 2025

Type project

Research report

Version

1.0

Content

1 Introduction

This report presents the outcomes of an explorative study on the integration in the Dutch healthcare system of a mobile application, Pal, to support informal care providers of patients in palliative home care. This study is conducted by The Hague University of Applied Sciences for the Municipality of The Hague (Technologie voor Thuis programma).

1.1 Pal

Pal is designed as an application to equip informal caregivers with tools for care planning, symptom tracking, and accessing practical information. By addressing various aspects of caregiving, Pal aims to empower families to navigate the challenges that arise in home-based care. The application contains:
1. A shared care planner: informal caregivers can share and communicate on care with other informal caretakers.
2. Symptom tracking: informal caregivers can keep track of symptoms and share these with other informal caretakers.
3. A resource library: informal caregivers have access to a tailored library to help them navigate caregiving and palliative care.

The project was driven by a growing demand for innovative solutions in Dutch healthcare, where challenges such as a critical shortage of skilled professionals and an aging population create a need for new approaches. Recognizing this potential, Pal was awarded the title of most promising start-up in The Hague's social domain during the CareTech Network Program finale in December 2023. As part of this award, Pal partnered with The Hague University of Applied Sciences to conduct further research on the application's implementation.

In addition, a grant application was submitted to ZonMw to further evaluate the implementation of Pal. Unfortunately, the application was not approved, but we remain vigilant for other opportunities to continue the study and support the app's further development.

1.2 Aims of the study

This study sought to identify how Pal could best be integrated into the Dutch healthcare system. The two primary aims included:
1. **Exploring implementation routes for Pal.** This involved identifying the potential care providers and/or organizations involved in palliative care through which Pal could be implemented.
2. **Identifying key factors for successful implementation.** This objective centered on understanding the factors that influence the adoption and long-term sustainability of Pal, and the essential (localized) content required for effective use.

2 Methodology

2.1 Method and partners

This study employed a qualitative exploratory research design, using semi-structured interviews as the primary method of data collection. Healthcare professionals with a connection to palliative care were identified as the target participants for this study, and their selection was determined in collaboration with the founders of Pal and the Vereniging Transmurale Zorg (VTZ) in The Hague. Recruitment was carried out through the networks of VTZ, Hadoks and Stichting Haagse Gezondheidscentra (SHG).

2.2 Participants

Eight interviews were conducted with professionals from diverse roles within the healthcare system, namely:
1. Nurse practitioner
2. Manager of specialist care
3. Community nurse
4. Manager of a palliative care organization
5. Policy advisor at a care organization
6. Care manager
7. General Practitioner
8. Program manager for elderly care

2.3 Interview guide

The eight interviews were conducted either in person or digitally, covering the following topics: current practices and policies, perceptions of Pal, (challenges related to) implementation of Pal, stakeholder engagement and collaboration, and considerations and recommendations for the (content of) Pal. Within each theme, probing questions were asked based on participants' responses and what they deemed relevant.

2.4 Data analysis

The interview transcriptions were systematically analyzed by two researchers (R. van der Vaart & E.F. van Herwijnen). A thematic coding approach was used to identify key patterns and insights relevant to the study objectives.

3 Results

3.1 Potential implementation routes

The implementation of Pal in the Dutch healthcare system depends heavily on the specific care pathways of individual patients, which can vary significantly. Interviews with healthcare professionals revealed that there is no single standard route for implementation due to these differences. Below, the potential implementation routes are discussed.

3.1.1 Healthcare professionals

Healthcare professionals, such as general practitioners (GPs), could play a key role in introducing Pal to informal caregivers. GPs often serve as central figures in the care of palliative patients, but their approaches can vary across practices. As one professional stated, *"We [Hadoks] have 160 GP practices connected to us, and they all probably do things slightly differently."*

An appropriate moment to introduce Pal could be at a common "marker point" of GPs, which indicates when a patient is expected to pass away within 12 months. This marker often prompts conversations with the patient and their relatives. A respondent noted, *"GPs use the marker point as a guideline to start an advanced care planning or proactive care discussion."* This moment provides an opportunity to introduce Pal as a tool for informal caregivers.

Other key moments mentioned in the interviews for introducing Pal include:

- When a patient is discharged from specialist care and referred back to the GP.
- When the burden on informal caregivers increases significantly.
- When the patient begins to lose autonomy and becomes more dependent on their caregivers.

In these situations, GPs can recommend Pal to help caregivers manage tasks and access information. As one respondent explained, *"When you notice the caregiver is taking on more and more, you could say: 'Hey, you have a lot coming at you right now. Did you know there is an app that can help you organize and find information?"*

Practice nurses (POHs in Dutch) could also introduce Pal, as they maintain accessible contact with both patients and informal caregivers. Similarly, oncology nurses, community nurses, dementia case managers, and eldercare consultants are other professionals mentioned in the interviews who could play a role in recommending Pal. This collaborative approach highlights the shared responsibility of the palliative care network.

3.1.2 Collaboration with organisations

Collaborations with organizations such as the Vereniging Transmurale Zorg (VTZ) and the Netwerk Palliatieve Zorg (NPZ) offer other opportunities for Pal's implementation. These organizations can coordinate the promotion of Pal to their members, including GPs and other healthcare providers. While individual providers ultimately decide whether to adopt the app, VTZ can support its introduction and rollout. As one professional emphasized, *"VTZ has the most connections and can distribute it to GPs and other providers. They also have experience with rolling out palliative care projects, making them well-suited to introduce assistive tools like this."*

VTZ also offers resources such as an information guide and a palliative care pathway (transmuralezorg.nl), where Pal could be integrated as a recommended tool. The pathway outlines the stages a palliative patient and their caregivers go through, from initial diagnosis to aftercare. It includes guidance for each phase, with references to protocols, practical tools, and local care providers. By incorporating Pal into these resources, VTZ could facilitate its adoption among healthcare professionals and caregivers. One participant mentioned, *"I think it is important to connect to existing structures, such as the information guide or the care pathway of VTZ. For example, you could include a QR code with more information about the app."*

The NPZ also plays a crucial role in supporting palliative care networks. This organization aligns various providers to streamline the care journey of palliative patients. They offer training, materials, and other support for both patients and caregivers. Through the NPZ, Pal could be promoted as a tool to enhance the care experience.

3.1.3 Additional routes

Another option is to use the initiatives of municipalities as a platform to implement Pal. As one professional mentioned, *"There are initiatives like caregiver cafes or meeting points organized by municipalities."*

Additionally, platforms widely used by palliative care professionals, such as the PalliaArts app and the Palliaweb website, could include references to Pal. These platforms are trusted sources of information and could help integrate Pal into standard practices for palliative care, like one professional mentioned, *"It [PalliArts] contains practical guidelines for palliative care, such as conversion tables for medication, such as morphine, and leaflets on topics such as anxiety and sedation. [...]. It could be relevant to the development and implementation of Pal. PalliArts is often used by healthcare providers on their phones."*

3.2 Key factors for implementation

Interviews with healthcare professionals highlighted several important factors for implementing Pal in the Dutch healthcare system. These include the need for localized and general information, appropriate timing for introduction, balance in data and usage, ease of use, and data security.

3.2.1 Localized information

To better align Pal with the needs of residents in regions such as The Hague, incorporating localized information is key. This can help users quickly find relevant services and points of contact in their immediate area. Suggestions from the interviews include:

- A link to the information guide from the Vereniging Transmurale Zorg (VTZ).
- Contact details for local care providers, such as GPs, hospices, and home care organizations, making it easier for informal caregivers and healthcare providers to connect with the right professionals.
- A social map featuring initiatives and volunteer groups in the area, enabling users to identify available support options.

These additions were seen as valuable by participants, as they could improve caregivers' ability to navigate local resources effectively. One respondent noted the importance of regional

customization, saying, *"Local content would certainly be useful, especially because people are really searching sometimes. [...] Some people are just very much in their own world, especially if they are still being treated. Informal caregivers usually seek help sooner than patients. The threshold for help is simply very high, because they find it scary, do not know how, etcetera."*

3.2.2 General information

In addition to localized content, general information addressing common challenges in palliative care was identified as important. According to participants, this could include:

- An overview of common symptoms and complaints in the final stages of life, helping caregivers recognize and better understand these issues.
- Information on commonly used medications, including usage instructions and potential side effects.
- Practical guides for handling end-of-life situations, such as organizing a funeral, accessing home care, and acquiring assistive tools.
- Clear explanations of important documents, such as advance directives and other legal arrangements.

Participants emphasized that providing this information benefit caregivers by reducing uncertainty and empowering them to handle complex situations.

3.2.3 Timing of introduction

The timing of introducing Pal to caregivers was another critical factor discussed. Early introduction—for instance, while the patient is still undergoing treatment—allows caregivers to familiarize themselves with the app and its benefits. Delaying the introduction until the later stages of life may reduce its effectiveness and add emotional strain. As one respondent explained, *"You shouldn't wait until the patient is on their deathbed, as no one's head is in the right place by then."*

3.2.4 Balance in data and usage

Pal's potential to enhance the care process was recognized by some participants. By enabling caregivers to track symptoms multiple times a day, healthcare providers could gain a clearer picture of the patient's condition. One interviewee noted, *"When I now ask how the patient responded to a new medication, I often get an abstract answer, for example that things seem to be going better. But if they can keep track of the symptoms several times a day, that gives me a much better picture."*

However, concerns were also raised about the possibility of excessive data leading to an overwhelming workload for healthcare providers and more concerns for informal care providers. It was suggested that the app should strike a balance by supporting symptom tracking without encouraging an overemphasis on minor issues, as one professional emphasized, *"It is important to avoid focusing too much on every little pain instead of the patient's overall picture."*

3.2.5 Ease of use

Usability emerged as a key factor as well, particularly given that many informal caregivers are older and less digitally proficient, as one respondent stated, *"It has to be user-friendly; otherwise people will give up."* Features such as simple language, intuitive navigation, and clear buttons were highlighted as essential design elements.

Participants also stressed the importance of avoiding information overload. Regular feedback from caregivers during the app's development can help ensure that its content remains relevant and easy to navigate.

3.2.6 Security and data sharing

Furthermore, technical reliability and strong data security are key for gaining the trust of both healthcare professionals and caregivers. Respondents emphasized that users must feel confident their data is securely stored and processed. One professional stated, *"The app must be technically secure, especially given the privacy of its users. It has to be reliable."*

Lastly, clear communication is necessary to ensure caregivers understand that data entered into the app is not automatically shared with healthcare providers unless explicitly authorized. A healthcare professional mentioned, *"In addition, it must be clear to them that we, as healthcare providers, do not see their input in the app."*

4 Conclusion and closing remarks

This study provided insights into the implementation of the Pal app within the Dutch healthcare system, with a focus on its integration into various routes and the key factors contributing to successful adoption. An important conclusion is that, as palliative care does not correspond to a single diagnosis, the implementation and use of the app will require a tailored approach. There are many routes and options to be explored further, and a combination of these routes seems to be the best approach to make sure that informal caregivers get informed about Pal.