

# Digital information systems in outpatient palliative care and their effect on caregivers' latitude and quality of care - A qualitative study

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## Abstract

**Background:** Patient information systems are gaining importance in the health care sector and have the potential to improve its structure. However, there is a research gap regarding the impact of these systems on the quality of life and care, especially in the setting of palliative care.

**Aim:** The ADAPTIVE study aims at identifying ethical and qualitative impacts of the implementation and use of the digital information system palliative care in everyday palliative care. A particular focus is placed on the latitude for caregivers as well as the quality of care.

**Design:** A manual for qualitative interviews was developed and piloted. Data was collected during the qualitative interviews and analyzed based on qualitative content analysis by Kuckartz.

**Setting:** In total, 26 qualitative interviews with German physicians, palliative care nurses, and pharmacists were conducted and analyzed.

**Results:** The analysis of the qualitative data identified three main themes: (1) the software supports the collaboration within the team; (2) stakeholders have independent access to all information and therefore can act independently; (3) the quality of care can be indirectly improved by using the software.

**Conclusions:** The software itself supplements the existing palliative care structure and therefore has potential to increase quality of care, given the implementation and use of the software is purposeful. For effective realization and application, users should work with the full range of functions of the software to integrate it into their work in a sustainable way. If the integration is successful, healthcare providers and patients can benefit from it.

## Key statements

*What is already known about the topic?*

- The implementation of new communication and information technologies in the health sector is gaining more and more relevance since they hold the potential to improve the structure of medical settings.
- The state of global research on digital assistants mainly refers on the use in geriatric care settings and rarely in the palliative care setting.

*What this paper adds*

- The study shows that the quality of palliative care can be improved indirectly by the software but only if all providers have independent access and sufficient knowledge of the use of the software.
- The software itself is to be seen as a supplement to the existing care structure and therefore has to be implemented as such in order to serve as a support for healthcare providers.

*Implications for practice, theory, or policy*

- If implemented successfully and if users of the software felt familiar with the full range of functions, the software was able to support daily work processes in a sustainable way.

## Background

The implementation of new communication and information technologies is gaining importance in the health sector worldwide and has the potential to fundamentally transform and improve the structure of medical settings, such as palliative care. One hope associated with this development is to increase the quality of life of patients through more individualised and needs-oriented care. The use of communication and information technologies should enable greater involvement in the patients' living environment and thereby increase their self-determination. The communication and latitude of multiprofessional teams could be improved as well [1].

The state of global research on digital assistants in particular in palliative care is very limited. Existing studies mainly refer to one user or user group and focus on digital assistants that are used in geriatric

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**Keywords:** palliative Care, palliative medicine, quality of health care, information technology, qualitative research, interview

**Received:** May 17, 2023; **Accepted:** May 29, 2023; **Published:** June 05, 2023

care settings (e.g., assisted safety technologies) [2,3]. In addition, the empirical data currently available is mostly based on studies of model projects that have not been implemented and evaluated under everyday conditions [4,5]. Although these studies also address aspects relevant to our project, such as quality of life and quality of care, they rarely examine them from a genuinely medical perspective. Regarding the implementation of digital technologies in the health and social sector, there is some preliminary work on the impact on organisational processes and hierarchies [6,7]. However, the available preliminary works do not cover palliative care, particularly outpatient palliative care as a specific medical setting, nor do they provide information about possibly changed communications between physicians, nurses, patients, and other actors.

Subsequently, there is a clear research gap regarding the impact of patient information systems on the quality of life and care, especially in the setting of palliative care. Palliative care in Germany is provided in both outpatient and inpatient settings. In both settings, patient data is documented mainly on paper but increasingly also digitally shared with other providers.

In our explorative-qualitative study, we aimed at identifying the ethical and qualitative impact of the implementation and use of the digital "information system palliative care" (ISPC) in everyday clinical practice in outpatient palliative care. A particular focus is on the latitude for caregivers as well as the quality of care.

## Methods

The methodological approach of the ADAPTIVE (Impact of digital assist devices on palliative care) study is divided into two parts: work package one consisted of a literature review, work package two included a semi-structured interview study. After the approval of the Research Ethics Committee of the Medical Faculty of the Ruhr University Bochum (Reg. No. 20-6948, approval June 19, 2020), 26 qualitative interviews with physicians, palliative care nurses and pharmacists working in outpatient and inpatient settings were conducted. Study participants are only medical professionals who were not associated with or involved in the development of the software.

The purposive recruitment of prospective participants took place from July to November 2020 in different setting, e.g., clinics, general practices, hospices, nursing homes and pharmacies. Due to the Covid-19 pandemic, we have faced some challenges in the recruitment process. Prospective participants were provided with an information form outlining the aims and objectives of the study and the research team. Interested participants were contacted via telephone to schedule for an interview. A total of 21 interviews were conducted by telephone and 5 interviews by face-to-face. All participants were informed about the study in writing and verbally. They provided their written consent to the data collection afterwards. The interviews lasted between 45 and 60 minutes.

Using a semistructured guide, the interviews were designed to focus on the following themes: daily work routine, implementation of the software, functionality and realisation of the software, data protection and potential for improvement.

All 26 Interviews were audiotaped. The audio files of the interviews were transferred to an external transcription office. There, the interviews were transcribed literally and pseudonymized, so that no persons or institutions could be identified. The written transcripts were analyzed by two researchers using the MAXQDA software. The researchers followed the principles of qualitative content analysis by Kuckartz [8].

All results were critically examined and discussed within our research team. Discrepancies were clarified through discussion.

## Results

A theoretical saturation regarding the research question was reached within the 26 qualitative interviews. On one hand, results were collected on the effect of the use of a software on the delegation of tasks, on the cooperation within the team [9]. On the other hand, presented results in this paper focus on the effect of the use of the software on the latitude for caregivers and how a change of this latitude can also impact the quality of care received by the patients.

In palliative care, the management of pain and other symptoms is one of the main goals [10]. The prescription and handling of medication especially medication to control pain symptoms could be challenging. Usually, the medication on demand and emergency medication is prescribed by the physicians providing care within the framework of a medication plan [11]. By using the software, this plan is now digitally integrated into the software and can be accessed at any time. Within this range, also other caregivers can operate and give medication independently. Administration and changes of medication take place in agreement with the physicians and are documented in the software afterwards. One member of the research team translated the quotes and another member back-translated them to eliminate any confusion of meaning:

PCTA-03 (*Palliative care physician*): Of course, they give medication. There is an emergency plan, which is stored in [the software], as a formula, as a document. Then we define an emergency medication, which the palliative care nurse is also allowed to give in an emergency. And if she is there in an emergency and nothing helps or more is needed or there is another problem, then she calls the background. And if the patient is not quite familiar to him, he can look in [the software], turn on his computer at three o'clock in the night, look, and then he says 'Well, then you can give it' or he says 'Well, then I'll come myself'. But the-, the nurses can of course give medication. And sometimes it is also the case that the nurses enter changes in medication, "after consultation with..."[...]?

In outpatient teams, the use of the software further enables an independent use of the information entered. Furthermore, asynchronous communication is possible through the software. This enables more independent care on bedside as well as via telephone, in contrast to caregivers in inpatient facilities. For example, medication administration is adjusted independently based on the information entered:

PCTA-02 (*Palliative care physician*): So it is certainly the case that the palliative care nurses, who are our coordinators, often have a much more independent access to the patients than they might have in a hospital, in a fixed, standardised therapy setting due to their professional profile. And of course the software enables them, also with the help of the information there, to carry out very independent counseling and care.

By using the software to document all steps of care, the latitude of action of the caregivers can be determined within the team:

PCTA-04 (*Palliative care physician*): Of course, you know, this is developed within the team [...], everyone knows their latitude which is greater than what would be legally exact, so to speak. So if we write in 'medication on demand is like this' and it is already used up, but you notice that it is already the right direction and I don't have the physician now, then they will go over the limit. [...] And then they ask afterwards, "Was that OK? I expanded it, don't we want to change it in the medi-

cation plan?', and then the doctor approves, 'Yes, then we'll change it, it has obviously proven itself'. Or he says 'No, I limited that for a good reason, if that doesn't work, we'll just have to do something else'.

Another important factor that affects quality of care is time. Participants illustrated that quick and real-time access to all information enables rapid action and intervention in acute and emergency situations:

KA-03 (*Hospital physician*): We simply have quick access to a lot of data, and so we can therefore treat the patient more quickly or we know immediately, for example, if it is well filled out, which allergy or- For example, I write if something is then not recommended or if I make a home visit, I write if plan A does not work, what would be my plan B? What would be my plan C? And then, the colleagues have quick access to that, so that is of course for the patients too-, they benefit from that, for sure.

PA-01 (*Family physician*): Or communication: the more efficient and better this is, the faster we can improve the patient's situation.

Furthermore, in the software, atmospheric and other relevant (background-)information can be entered as well. This allows health care providers to avoid, for example, inappropriate or repetitive topics of conversation and, as a result, do not burden the patients additionally:

KP-02 (*Hospital nurse*): The fact that the amount of information is much more complete when every team member documents in the same system, then I think there is also this incredible double questioning of patients - we notice again and again that caregivers, doctors, and social services often ask the patients the same things. And when you see: Oh, someone has already asked clearly, a patient has told in pain that the relationship with the children has broken down, I don't have to ask again 'Oh, do you have children?' and you trigger the pain again.

From the provider's point of view, the software supports them in their daily work and communication as well as work coordination which gives them more time for the most important part of their care, to focus on their patient:

HP-01 (*Hospice nurse*): Well, I'm thinking. So to speak, benefit from it, because the better we communicate with each other and the better we are coordinated with each other and know from each other what we are doing, the better it is for the patient in the end.

PA-03 (*Family physician*): To improve the patient's quality of life, I would say indirectly at most, because I can see it quickly, I have more time available to care for the patient in the best possible way, which then leads to an increase in the quality of life in the best case.

Further, the use of the software enables caring for a larger number of palliative patients while still increasing effectiveness and safety. In Germany SAPV teams are palliative care teams that focus on the intensive and complex care of palliative patients in the context of specialized outpatient palliative care. Being able to offer outpatient palliative care services for a greater number of patients is especially important in less urban regions where these services are usually scarce:

PCTP-04 (*Palliative care nurse*): In general, many things are possible that would not be possible without the software. Especially in terms of orders, communication within the team, and so on. But to what extent does it improve the quality of life? Well, I think it enables very effective use of our SAPV team, yes. Right? Because without this software, it would not be possible for me. And of course, it also improves the quality of life of the patients. So the system would be much more complicated and we would certainly not be able to care for 500 patients a year in the area where we do it without such a communication system. And then

also quite secure etc., right? For me, that would be impossible without the system, and therefore the system clearly improves the quality of life. Because otherwise people could not be cared for at all.

In the interviews, mostly positive effects of using a software were mentioned. No statements were made about potentially negative effects or critical points that should be taken into account when using such software (such as data confidentiality issues or ethical concerns about data sovereignty).

## Discussion

### Main findings/results of the study

The qualitative findings highlight several impacts of the use of the software in everyday clinical practice in outpatient palliative care. With regards to the quality of care, our results show that several factors come into play, such as caregivers' latitude in handling medication and symptom management, number of patients that have access to outpatient palliative care services, safety, time, and patients' (background) information. Within this section we address these while discussing the three main themes that originated from the interviews:

**Software supports work within the team.** Participants emphasise the supporting function of the software for their daily work. In order to fulfill the different tasks and high demands of high-quality care, a high level of, and above all, close coordination and communication is required within the care team [12]. Patients' (background) information saved in the software was considered to be very helpful, especially in order to avoid burdening patients by asking repetitive questions or by talking about sensitive or triggering topics.

However, to ensure consistent documentation that is comprehensible to all providers involved in the care process, a common manner should be proceed. Especially since providers who are not part of the core team can also access, edit and add new information to the software, the documentation and coordination need to be transparent and targeted [11]. Another point that the participants find helpful is the rapid and location-independent access to all information. It enables them to act quickly and therefore avoid delay and save time which is essential in acute or emergency situations. Gnass et al., [11] support our findings in their study on pain management by outpatient care services. Their study calls for interprofessional procedural arrangements in medication pain therapy. These arrangements are characterised by necessary coordination processes. However, they are rarely or not at all documented in writing. A fixed written record provides the basis for working independently with the information and is therefore indispensable for the daily work in palliative care [11].

**Independent access and action.** The enabling of independent access to all information and, as a result, allowing providers to act independently is the second main theme. The software allows independent access by using a web-based approach. Consequently, all providers with a mobile or terminal device that is equipped with the software and internet access can view, edit, and add information within the software. The requirement for this is widespread Internet access and the provision of the health care providers with appropriate devices. Internet access can still cause problems, especially in rural areas. The interviewed participants emphasise the utility of location-independent access, as it facilitates their work in a more flexible and easier way. Access to information is particularly relevant in outpatient palliative care, as different healthcare professionals are involved in the process. Location-independent access can further support the holistic care approach. It seems to be advantageous that several providers can

access the data at the same time in contrast to a paper file or a local file where data is tied to a single device.

However, the independent action can only take place within a framework set by law and by the treating physicians. Within this framework, caregivers can operate and give medication independently. In principle, caregivers are only allowed to administer medication or to carry out pain therapy measures that have been prescribed by a physician [10]. Caregivers of an outpatient care service are legally required, for example, to regularly record pain to obtain a physician's order to initiate or adjust pain treatment. Nurses may only give medication on demand if there is a written order from a physician [12]. In the interviews, the participants clarify that the latitude for action is primarily determined within the team and may sometimes exceed the usual formal and legal framework. It should nevertheless be considered to what extent a softening of these boundaries is ethically acceptable and to what extent this softening is beneficial to the care and quality of life of patients. It seems that a far greater weighting is attributed to the structure, cooperation, trust, and communication within the team.

**Improved quality of care as an outcome.** Especially in outpatient palliative care, caregivers act as a link between physicians, patients, and relatives. Their ambition is to provide the highest quality care possible [11]. The meta-review on digital health interventions by Finucane et al. describes reviews that focus, among other topics, on improving the quality of life of palliative care patients [13]. The changes in quality of life through the use of digital health interventions are mostly statistically non-significant or have positive effects. Negative effects were rarely observed. By using the software, the quality of care can be indirectly improved.

Furthermore, the software enables to care for a large number of palliative patients, as well as communication among the team. This point is particularly relevant for rural regions. For example, by using digital health technologies, communication can be done digitally so that patients and their relatives can receive better, around-the-clock care without the need for a caregiver or physician to visit the patient's home.

Overall, the findings show that the latitude is mainly reflected by independent access and independent action in daily work. Furthermore, an improved quality of care can be assumed as an outcome.

**Data security while using a software.** The results show that the interviewed health care providers mainly mention positive aspects with regard to the effects of using a software. Data security as well as ethical concerns related to data sovereignty is not discussed, although it is a relevant aspect of health care in general, but especially in even more vulnerable settings such as palliative care. The fact that the interviewed participants did not express any views on data privacy and security may be due to various reasons. It is possible that the positive effects outweigh potential risks in their everyday work and that these risks therefore slip into the background and are seen as less relevant. Other possible reason is a lack of sensitivity or awareness for the topic which would be concerning.

It is legally and ethically required that patient data should only be shared with others with the patient's permission. In addition, information shared during a clinical interaction is considered confidential and must be protected [14,15]. In one interview, it was mentioned that patients or family members must sign a privacy statement before providers are allowed to start providing palliative care. To what extent the documentation of patient data is part of this declaration was not further detailed. Controlling access to health information is important

as well, but it is not enough to protect confidentiality. As this occurs, additional security measures such as strict privacy and security policies are essential to protect patient data. Potential security measures include firewalls, antivirus software, and intrusion detection software to protect data integrity [15]. Further, the way how the data is kept after its initial use plays an important role (e.g. where is the data stored, after what time is it destroyed and how?).

The health care providers seem to feel a great relief in their daily work due to the software and have great confidence in it. This might be an additional reason for a non-thematization of data protection and other ethical aspects. Nevertheless, these are relevant issues that health care providers should be aware of.

### Strengths and limitations of the study

A limitation of the study is the focus on one specific software (ISPC). While there are other softwares used in palliative care, such as Pallidoc or Orbis, these softwares were not discussed in the interviews. However, softwares used in outpatient palliative care settings are comparable since they mostly offer the same features and options to their users. The data was collected exclusively in Germany; however, the results can also be applied to other countries. The implementation of digital information systems in palliative care can be seen worldwide, with a wide variety of digital health technologies [16]. Therefore, we assume a theoretical generalization of our findings is possible.

Furthermore, the conducted interviews were limited to the providers' perspective and the targeted outcome "quality of care" was inductively derived from the analysis of the participants' experiences. Therefore, in a next step, it is essential to also gather the patients' perspective. Although the interviews did not focus specifically on caregivers' latitude or the quality of care, the participants presented these aspects as important consequences of using a digital information system. The results shown in this article are inductively derived from the analysis of the participants' experiences. Furthermore, there were challenges we faced in recruiting and conducting the study due to the pandemic. These may affect the process and the results of the study.

It should be noted that this emerged from the interviews and therefore reflects the individual opinions of the participants. No quality indicators were collected in the ADAPTIVE Study, such as e.g., van Baal et al. carried out [17].

However, a key strength of the study is that it offers important findings and insights into the use and impact of the software by providers in outpatient palliative care. So far, there is little empirical data on the topic, so the findings presented should be considered valuable.

### Conclusion

The qualitative data collection based on interviews with physicians, palliative care nurses and pharmacists shows that there is a clear impact of the implementation and use of the software. The analysis of the qualitative data identified three main themes: (1) the software supports the work within the team; (2) through the software, providers have independent access to all information and therefore can act independently; (3) the quality of care can be indirectly improved by using the software.

The results found are strongly interrelated and influencing each other. The quality of palliative care can only be improved indirectly by the software if all providers have independent access, and the teamwork already works well without the software. The software itself is to be seen as a supplement to the existing care structure and quality of care and

therefore serves for support. We recommend that users of the software get to work with the full range of functions of the software in order to implement it into their daily work processes in a sustainable way. If the integration and use of the software is successful, both the healthcare providers and the patients to be cared for can benefit from it. For healthcare providers, the software is a support and facilitation of their work process. For patients and their families, it can improve the quality of life in the remaining time of life, one of the main aims of palliative care [10].

### What this study adds

The study shows a clear positive impact of the implementation and use of the software on the working situation of healthcare providers and their patients. It assesses the software as a supportive supplement to the existing care structure.

### Declarations

#### Authors' contributions.

Study design and lead: IO; Recruitment and interview conduction: AS; Data analysis: AS, CG; Data interpretation: AS, CG, IO; Manuscript writing: AS, CG, HCV, IO, JH; Manuscript reviewing: AS, CG, HCV, IO, JH. The corresponding author attests that all authors have read and approved the manuscript. The corresponding author attests that all authors meet the ICMJE authorship criteria.

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### Funding

The authors would like to thank the FoRum program (Faculty of Medicine Research Grant) for providing financial support for personnel costs, including the design, interview conduction, data analysis and interpretation, and manuscript writing.

### Declaration of conflict of interest

The author(s) declare that there is no conflict of interest with respect to the research, authorship, and/or publication of this article. In particular, there are no financial benefits from the software manufacturer.

### Research ethics and patient consent

*Ethics approval and consent to participate.* The Ethics Committee of the Medical Faculty of the Ruhr University Bochum approved this study (20-6948, approval June 19, 2020). All methods were performed in accordance with the relevant guidelines and regulations of this Ethics Committee. All participants attended voluntarily and agreed to the publication of the results. All participants provided both verbal and written informed consent to participate in the study and to process the interviews.

**Consent for study participation and publication.** All participants consented to the data collection and publication of content-related

statements, provided that their data were pseudonymized. All quotes listed here were pseudonymized so that only the research team can attribute them to a specific person.

### Data availability

We are willing to make our data material evaluated in this study available to any researcher who wishes to retrace our findings. To do so, please contact the corresponding author.

### Trial registration

[https://www.drks.de/drks\\_web/navigate.do?navigationId=trial.HTML&TRIAL\\_ID=DRKS00021603](https://www.drks.de/drks_web/navigate.do?navigationId=trial.HTML&TRIAL_ID=DRKS00021603) (Registration: 02. July 2020).

### Acknowledgments

A special acknowledgment goes to Prof. Dr. med. Anke Reinacher-Schick, Prof. Dr. med. Dr. phil. Jochen Vollmann, Daniel Zenz, and all health care providers who participated in our interviews for supporting and enabling our research project.

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