HOLDEN

D9.1: Ethical analysis of patient autonomy in healthcare for appropriate use of RF-sensing

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Executive Summary

The primary purpose of this deliverable is to examine and assess the potential impact of RF-Sensing on patient autonomy in healthcare settings, with a particular focus on its effects on palliative care.

In **Section 1**, we explore the importance of patient autonomy for healthcare. We also explain how and why Phenomenological Bioethics can offer unique insights regarding patient experiences with technologies. Then, we proceed to specify how our methodology, phenomenological interviews, is implemented in the project. Finally, we address how phenomenology can contribute to palliative care.

In **Section 2**, we explain some of the existing risks and opportunities associated with the general use of AI in palliative care practices. Later, we explain how phenomenology could inform RF-sensing design in a way that fosters patient autonomy.

We conclude that RF-sensing has the potential to positively affect patient autonomy.

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Abbreviations

Abbreviation	Description
AI	Artificial intelligence
HER	Electronic Health Records
HCP	Healthcare practitioners
HOLDEN	Ethical design of holography in dense wireless networks
ML	Machine Learning
RF	Radio Frequency
TWE	University of Twente
WP	Work Package

1. The role of autonomy in healthcare

Traditional discussions in bioethics predominantly focus on principle-based theories [1], which advocate for the existence of specific ethical principles pertinent to medical practice, such as patient autonomy, non-maleficence, beneficence, and justice. The emphasis and promotion of the principle of autonomy is particularly crucial in the context of AI in healthcare, as it aims to prevent machines from encroaching on patient autonomy, especially from legal and formal perspectives (as we will explore in section 2). The principle of patient autonomy in healthcare mandates that patients make decisions regarding medical interventions when capable of doing so, and from a legal standpoint, it protects their right to self-determination. Autonomous decisions occur when a patient is adequately informed about the nature and consequences of the intervention, possesses sufficient mental capacity to comprehend this information, exercises free choice, and remains uninfluenced by other persons or factors [1]. When these conditions are satisfied, informed consent ethically and legally legitimises medical treatment.

Although this principle-based approach to patient autonomy is relatively straightforward, the topic remains a focal point in bioethics due to the complexities surrounding the determination of a patient's ability to provide informed consent [2,3].

However, bioethical principles have limitations in safeguarding patient autonomy. While they aim to ensure the formal and legal requirements for patient autonomy, they do not necessarily guarantee the patient’s experience of making autonomous decisions. For instance, the requirement to sign extensive waivers or review lengthy documents detailing medical procedures, risks, and benefits may not always align with what a patient needs for quality healthcare. These waivers and documents can be intimidating, and effective communication between healthcare providers and patients may play a more significant role in enhancing the patient's experience of autonomy in choosing a specific medical treatment.

We believe that phenomenological bioethics can help gain a better understanding of how patient autonomy can be increased, in particular in light of the growing use of AI in healthcare. RF-sensing can become a clear example of the adequate use of AI technologies to foster patient autonomy.

2. Phenomenological bioethics

Phenomenological bioethics is a contemporary discipline that has its roots in 20th-century phenomenology, known for its emphasis on describing typical human experiences, such as pain or empathy. This discipline has evolved into an independent field of study, primarily concentrating on healthcare. It posits that certain issues in healthcare are best comprehended by examining the actual experiences of patients, rather than by applying general principles [4,5,6]. Specifically, phenomenological bioethics advocates that certain aspects of health should be understood in terms of individuals being able to identify with themselves, while recognising the influence of various social perceptions of health, which may have either a positive or negative impact on the individual.

2.1. The case of palliative care

Phenomenology has been identified as a suitable method for enhancing palliative care [7,8]. This can be achieved through qualitative interviews, commonly known as phenomenological interviews, which can be conducted with patients or healthcare providers. These interviews are typically open-ended and not constrained by a fixed structure or content, but they share a common goal of focusing on the actual experiences of patients and healthcare providers within medical and nursing contexts (more in Section 2.2 below).

In palliative care research, studies have examined how patient comfort can be better understood through interviews with patients, by identifying recurring themes in their responses to specific questions regarding their healthcare experiences. For instance, Coelho and colleagues [8] discovered that humanising care and addressing existential topics such as hope and relationships significantly enhance patient comfort. Additional factors that contribute to patient comfort, as highlighted in the study, include creating differentiated environments and managing symptoms effectively.

Phenomenology can be integrated into the healthcare process, even though it is not a type of medicine. To understand how this might be applied, one can consider the phenomenological interview [9,6]. Its critical component makes it particularly useful for identifying social biases or stigma related to certain medical conditions or treatment pathways, as it seeks to explore both personal patient experiences and societal perspectives on disease and health conditions. To them we turn now.

2.2. Phenomenological interviews

Following the main idea of the phenomenological approach in philosophy, we assume that RF-sensing, as developed in HOLDEN, is not a fixed and clearly defined technology that is simply installed and used in patients' homes. Rather, it is a concept that is constructed through each patient’s interaction with the technology.

More than that, it is not only the concept itself that is important, but also how patients redefine other aspects of their lives after integrating this technology into their routine. Do they experience their autonomy and independence in the same way while using this technology? How do they change? More importantly, how do they perceive their autonomy and security when they are no longer under the constant observation of a technology designed to provide safety? How might this alter their social life? How will others in contact with them, such as caregivers, visitors, family members, nurses, doctors… perceive this intervention? And how might this affect their understanding of autonomy and independence?

To explore these questions further, we conduct semi-structured interviews in which patients are asked a series of open-ended questions.

2.2.1. Interview questions

Since the project uses phenomenological interviews to explore the ethical implications of RF-based monitoring technology in palliative care patients, the questions should aim to uncover patients' lived experiences, meanings, and emotional and ethical responses, not just their opinions or technical feedback.

Background and Contextual Understanding

1. These questions help situate the patient's experience by clarifying their familiarity with the system and its perceived function.
2. How long have you been using this technology?
3. What do you understand about how the technology works and how it relates to your condition?

Core Experience with the Technology

4. Can you describe what it's like for you to live with this monitoring system in your home?
5. How has your daily routine changed—if at all—since the technology was installed?
6. When you think about the presence of this technology, what comes to mind first?

Sense of Autonomy and Control

7. Do you feel more or less independent since the technology has been in use? In what ways?
8. Has the presence of the technology affected how you make decisions about your own care or body?
9. Can you describe a moment when you felt either more supported or more restricted because of the system?

Privacy and Intimacy

10. How do you feel about being monitored in private spaces like your bedroom or living room?
11. Have you ever felt uncomfortable or exposed because of the technology? Could you describe that moment?
12. In what ways, if any, does the technology affect your sense of privacy at home?

Trust, Care, and Relationships

13. Do you trust the system to help you in urgent situations? Why or why not?
14. Has this technology changed how you relate to your caregivers or family members?
15. Do you feel more or less connected to human care since the system was introduced?
16. In what ways, if any, does the technology make you feel safer or more cared for?

Values, Meaning, and Ethics

17. What does "good care" mean to you? Do you think this technology supports that?
18. Are there moments when you questioned whether the use of this technology was the right thing for you?
19. Do you think this kind of monitoring respects your dignity as a person? Why or why not?

Open Reflection

20. What would you want people designing this technology to know about your experience?
21. If you could change one thing about how the system works or is used, what would it be?
22. Is there anything else you'd like to share about how this technology affects your life, either positively or negatively?
23. How would you prefer your personal data to be stored or managed?

Social Life and Environment

These questions explore how the presence (or absence) of the technology affects patients' relationships, social life, and feelings about being in or out of monitored spaces.

1. How do you feel about leaving your home and going to a place where the technology cannot monitor you?
2. Has the presence of this technology affected how often you interact with friends, family, or neighbours?
3. Do you feel more isolated, more connected, or no different socially since the technology was installed?
4. Has the technology influenced your desire or willingness to receive visitors at home?
5. Do you ever feel that the technology changes how others (family, caregivers) interact with you or judge you? In what way?

2.2.2. Study design and methodology

After each interview is conducted, the transcript of the interview will be analysed using ATLAS.ti, a software specifically designed for this purpose. The general process begins by reviewing the interviews sentence by sentence and assigning relevant codes—one or more concepts—to each sentence. This constitutes the open coding phase, which will result in a comprehensive list of descriptive categories. At this stage, we will be able to understand the changes that the implementation of this technology brings about in each individual patient's lived experience.

In the second phase, known as axial coding, we examine the similarities among codes extracted from different individuals. The goal here is to identify relationships and connections between the open coding categories. Researchers explore how different categories relate to one another, forming a more structured understanding of the phenomenon. As a result, we will develop a more organised set of categories with clearly defined relationships.

The final stage, selective coding, involves integrating the identified categories into a core category that represents the central theme. At this point, we identify a central category that conceptualises the lived experience of patients and explains how they define their autonomy, independence, and other related values in the context of using this technology. This stage allows us to recognise whether and how the technology limits, violates, or even enhances their experience of these values.

From a sociological point of view, we are also interested in how this technology, if or when it becomes commercialised, might raise broader social concerns. Is it accessible and applicable to everyone? If not, and if it requires a certain level of economic or educational capacity, how might it contribute to divisions within patient communities? How might those unable to afford or access the technology feel excluded? How could widespread use of this technology transform communication between patients and healthcare providers, or between patients and their family and friends? What other potential misuses might arise when a patient is using this technology?

3. AI, phenomenology and healthcare

3.1. AI in palliative care: ethical challenges

Research indicates that AI holds significant potential for palliative care, with mortality prediction being one of its most widely applied uses [10]. However, palliative care is inherently holistic, requiring attentiveness to patients' needs beyond merely predicting mortality. Effective care delivery must respect patients' wishes and address their needs comprehensively. Machine learning (ML) in electronic health records (EHR) represents another prevalent AI application beneficial to patient treatment pathways. It can assist in monitoring EHRs to identify patients with less than 12 months to live, thus necessitating advanced care [11]. Additionally, remote health monitoring via AI offers frequent health assessments for palliative care patients at home, improving access to health data and facilitating personalised treatment plans.

These cases underscore the importance of designing AI systems that promote patient autonomy:

> "[...] *phenomenological approaches may help us to develop hypotheses regarding the relationship between particular styles of palliative care provision and the unique experiences of very sick people and those close to them*" [7, p. 131].

Ethical challenges associated with AI in palliative care are numerous. Concerns about privacy and informed consent are prominent, as AI applications in healthcare require access to extensive sensitive patient data:

> "[...] *there is an additional risk that such companies gain undue influence and impose their own values and incentives (eg, profit maximisation) that are not congruent with, and even run counter to, long--standing values in healthcare (eg, trust)*" [12, p. 4].

Another critical ethical challenge involves the potential loss of empathy and personal contact due to increased automation [11]. Phenomenology can mitigate this by emphasising intersubjectivity, particularly empathy and listening to patient experiences, in healthcare relations. The discussion raises the question of whether AI should completely replace or merely supplement human care for vulnerable individuals, such as palliative care patients. Given the value placed on human contact by technology users [12,8], total replacement is unfavourable. AI implementation in healthcare must avoid mirroring societal issues exacerbating vulnerable populations' challenges [13]. Kathleen Lynch's [14] warning is pertinent:

> "[...] *assistive technologies can complement personal care; however, they cannot replace it completely. Helping someone with washing or showering, with dressing, getting up, going to bed or going to the toilet is not just a matter of physical assistance, though it is that. It also involves respecting them, as well as encouraging, reassuring, supporting and explaining; how important these care dispositions are in any given day or event will vary with the person involved."* (pp. 89-90)

A phenomenological approach to health and healthcare could also enhance educational programs by connecting scientific understanding with human values [4]. As AI usage in healthcare increases, incorporating phenomenological approaches into medical and nursing education is crucial. While not a form of medicine, these approaches provide valuable insights for medical education, particularly in palliative care.

3.2. RF-sensing for palliative care

Building on previous work developed in WP6 from other consortium members, we believe that the uses of RF-sensing in palliative care are very close to those proposed by TWE and Adant in Deliverable 6.1. RF-sensing technology offers the possibility of continuous monitoring of a person, i.e., a palliative care patient, in a non-intrusive way, i.e., without the need for physical contact or wearable devices. RF-sensing has the potential to enable continuous health monitoring, including heart rate analysis, activity tracking, and mobility detection, facilitating different medical interventions if/when required. Regarding the impact of RF-sensing on patient autonomy, already reflected in the same deliverable, we abide by the importance of empowering patients by enabling health monitoring via non-invasive and passive activity monitoring.

As stated above, in healthcare, patient autonomy encompasses not only the provision of comprehensive information regarding healthcare practices but also the enhancement of patient consent and decision-making processes. Additionally, it includes the patient's experience, particularly in palliative care, of maintaining independence to the greatest extent possible and enjoying a high quality of life based on personal standards and considerations. The discretion offered by HOLDEN technology can significantly enhance the experience of patient autonomy, surpassing the capabilities of more invasive sensing technologies, such as video cameras.

Moreover, recent scholarly work on autonomy within feminist theory has underscored the significance of relationships and their constitutive role in shaping individual identity [15,16]. This perspective, known as ‘relational autonomy’, emphasises the necessity of perceiving the subject as inherently embedded in social relations, from which autonomy emerges as a capacity that must be nurtured and developed throughout one’s life. Consequently, the autonomous individual is seen to arise from the interactions and social conditions in which they are situated [17]. Within this framework, decision-making is perceived as occurring within an interdependent system involving the subject and their network of support and care, which also includes a wide array of technologies for medical purposes. Choices acknowledge the ongoing influence exerted by these individual relationships and the moral responsibilities arising from such connections.

The role of RF-sensing within this relational understanding of autonomy is that of a mediating technology that allows for a different understanding of the patient and their medical condition. RF-sensing shapes the patient’s interaction with a place that has so far been familiar to them, that is, their home, and it now becomes a place where treatment can be provided less invasively. The resignification of the house as a space where their life can be enjoyed, within the limits of their condition, far from traditional hospital settings, makes it possible for patients to live their final days in a way they have autonomously decided. Being at home allows for daily visits from loved ones, preserving a higher degree of autonomy compared to being bedbound at the hospital.

While keeping in mind the importance of alternative medical services that RF-sensing could offer in the future, we deem it appropriate to ethically assess the potential impact of the technology, considering its current capabilities. Given the actual development of HOLDEN RF-sensing, we believe that position and activity tracking are the main features to be considered when assessing the potential impact of RF-sensing on patient autonomy. These two features can be easily associated in palliative care with the Palliative Performance Scale (more details in Deliverable 9.7), a diagnostic tool to assess the medical condition of patients, especially those receiving treatment at home.

4. Conclusion

We believe that RF-sensing fosters patient autonomy through a decision-making process that allows them to opt for receiving palliative care at home, a possibility that is only enabled by the adequate development and use of this technological advancement.

The proper design and development of RF-sensing to be included as part of palliative care in-home treatment rests on its adequate ethical development. For that, besides the privacy-related ethical concerns explored by TWE in WP2, the consortium will have to work closely together to ensure that HOLDEN is designed in a way that not only protects patient autonomy but also enhances it by offering palliative care patients the possibility to receive quality care at home.

References

[1] Beauchamp, T. L., & Childress, J. F. (2009). Principles of biomedical ethics (7th ed.). Oxford University Press.

[2] Boisaubin, E. V., & Dresser, R. (1987). Informed consent in emergency care: illusion and reform. Annals of emergency medicine, 16(1), 62-67.

[3] Pomerantz, A. S., & de Nesnera, A. (1991). Informed consent, competency, and the illusion of rationality. General Hospital Psychiatry, 13(2), 138-142.

[4] Svenaeus, F. (2018). Phenomenological bioethics: Medical technologies, human suffering, and the meaning of being alive. Routledge.

[5] Dierckxsens, G. (2021). Prostheses as narrative technologies, in: Wessels, R., Romele, A., & Coeckelbergh, M. (eds.), Interpreting technology: Ricoeur on questions concerning ethics and philosophy of technology (pp. 153-170). Rowman& Littlefield.

[6] Dierckxsens, G. & Baron, T. Phenomenological Interview and Gender Dysphoria: A Third Pathway for Diagnosis and Treatment, The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine, Volume 49, Issue 1, February 2024, Pages 28–42, https://doi.org/10.1093/jmp/jhad039

[7] Seymour, J., & Clark, D. (1998). Phenomenological approaches to palliative care research. Palliative Medicine, 12: 127–131.

[8] Coelho, A., Parola, V., Escobar-Bravo, M., & Apóstolo, J. (2016). Comfort experience in palliative care: A phenomenological study. BMC Palliative Care, 15(1). https://doi.org/10.1186/s12904-016-0145-0

[9] Zahavi, D., & Martiny, K.M. (2019). Phenomenology in nursing studies: New perspectives. International Journal of Nursing Studies, 93, 155-162.

[10] Oh, O., Demiris, G., & Ulrich, C. M. (2024). The ethical dimensions of utilizing Artificial Intelligence in palliative care. Nursing Ethics. https://doi.org/10.1177/09697330241296874

[11] Adegbesan, A., Akingbola, A., Ojo, O., Jessica, O. U., Alao, U. H., Shagaya, U., Adewole, O., & Abdullahi, O. (2024). Ethical Challenges in the Integration of Artificial Intelligence in Palliative Care. Journal of Medicine, Surgery, and Public Health, 4, 100158. https://doi.org/10.1016/j.glmedi.2024.100158

[12] Kraaijeveld, S. R., van Heijster, H., Bol, N., & Bevelander, K. E. (2025). The ethics of using virtual assistants to help people in vulnerable positions access care. Journal of Medical Ethics. https://doi.org/10.1136/jme-2024-110464

[13] São José, J. M. S., Amado, C. A. F., Ilinca, S., Buttigieg, S. C., & Taghizadeh Larsson, A. (2019). Ageism in Health Care: A Systematic Review of Operational Definitions and Inductive Conceptualizations. The Gerontologist, 59(2), e98–e108. https://doi.org/10.1093/geront/gnx020

[14] Lynch, K. (2022). Care and capitalism. Polity Press.

[15] Gary, M. (2023). Relational approaches in bioethics: A guide to their differences. Bioethics, 37(8), 733–740. https://doi.org/10.1111/bioe.13200

[16] Koggel, C. M., Harbin, A., & Llewellyn, J. J. (2022). Feminist relational theory. In Journal of Global Ethics (Vol. 18, Issue 1, pp. 1–14). Routledge. https://doi.org/10.1080/17449626.2022.2073702

[17] Delgado, J. (2019). Re-thinking relational autonomy: Challenging the triumph of autonomy through vulnerability. Bioethics Update, 5(1), 50–65. https://doi.org/10.1016/j.bioet.2018.12.001