

Balancing Technology and Humanity in Palliative Care: The Limits of Digitalization

– Extended Abstract –

“Everything that can be digitized will be digitized” is a mantra of digital transformation. It has been said by Carly Fiorina (then CEO of Hewlett-Packard), Angela Merkel (then German Chancellor), and many others with slight variations. This begs the question: What can and should be digitalized, and – on the flipside – what are the limits to digitalization?

Digitalization has a bright side, but it also has barriers and limits. The use of digital technologies has brought numerous benefits to the healthcare sector, such as improved accessibility of information, quality of care, and efficiency (Agarwal et al. 2010; Kraus et al. 2021). Yet, there are also various barriers (specific obstacles that can be addressed or overcome) and limits (fundamental constraints that cannot be overcome, at least not in the short term) to the digital transformation of the healthcare sector. We set out to identify the most relevant limits to value creation through digital technologies.

Digitization is the technical process of converting analog signals into a form of calculation using discrete units (Legner et al. 2017). Obviously, physical things can be represented by a digital twin, but they cannot be fully digitized. More interestingly, digitalization refers to the manifold sociotechnical phenomena and processes of adopting and using digital technologies in broader individual, organizational, and societal contexts (Legner et al., 2017). Here, it is more interesting to explore the limits of digitalization of information, business processes, social processes, and social relationships. The extent to which digital transformation initiatives should be pursued depends on whether the use of digital technologies leads to overall value creation (Vial 2021). The importance of balancing the benefits from the use of digital technologies with contextual factors is referred to as “reasonable full automation,” that is, reaping the benefits of automation with regards to efficiency, quality, and the like, but only to the degree that is sensible (Mertens 1995, Beck et al. 2022).

Many digital transformation efforts fail or do not deliver the value they were supposed to create. We assume that one issue is not respecting the limits of digitalization and, hence, implementing digital solutions beyond the reasonable level. A limit, in this sense, does not preclude the use of digital technologies in a specific setting. Still, it is an unreasonable, ineffective use (Burton-Jones and Grange 2013), not delivering value but adverse effects. Consequently, knowing the limits of digitalization is important and more meaningful than exploring the barriers of digitization. Various research on barriers to digitalization, like missing skills, data insufficiency, high investment in implementation, conflicts of interest between the medical profession and health insurers, and data privacy, exists (Anderson and Agarwal 2011; Nohl-Deryk et al. 2018). While these factors hinder digitalization, we posit they can be overcome in principle. They are barriers, not limits. Limits are if some information or activities simply cannot be represented in a digital manner, as they are too difficult to codify. Or, a digital representation might generally be possible but not efficient due to the complexity of information or physical interaction, especially compared to human skills. Or, lacking acceptance respectively use of digital technologies may result in lacking value creation.

We focus on healthcare and specifically on the field of palliative care. We posit that some of the limits to digitalization are especially pertinent and relevant in this context, and digitalization offers ample additional potential. Still, due to these very limits, not everything can be digitalized. Palliative care is characterized by highly individualized care of patients, complex work in multi-professional teams, a lack of objective determination of quality, low tolerance for error, and a constant relevance of ethics, morals, and team cohesion in everyday work. Palliative care has a history and a self-concept of low-tech, high-touch care in deliberate contrast to intensive care and emergency medicine. Hence, palliative care has an unusually low level of digitalization – a perfect setting to explore the limits of digitalization.

For our study, we rely on ethnographic work and action design research. We have been working with a palliative care ward in Germany for years to understand their work system, the current level of digitalization, and potential improvements from further digitalization. The interdisciplinary research team members have spent multiple weeks onsite observing the ward's operations and processes. Multiple focus group workshops informed our perspective on potential further digitalization. In an iterative, immersive process, we design, prototype, and evaluate digital innovations to the palliative care work system. We test the general applicability of our findings in interviews and focus group workshops at other wards. This extended abstract sketches our current thinking regarding the limits of digitalization.

In general, limits to digitalization can be technical, economical, or social, or they can arise from a combination of these areas. Four examples from palliative care wards:

1. The ward has weekly multi-professional team meetings. The gist of the discussion and work assignments for the individual professions are typically documented in the hospital information system. To save time and increase the efficiency with regards to obligatory documentation, it would be great to automate this documentation with a microphone, a speech-to-text conversion including speaker identification, and a language model synthesizing the conversation and extracting work assignments. In principle, all these steps are possible. However, current technology does not yet deliver the quality required for documentation and subsequent work. This technological limit will likely disappear over time with technological progress.
2. Palliative care requires devotion to the patients and their relatives, personal presence, and personal care. Due to the emotionally demanding work, palliative care also requires team cohesion and care of the team members for each other. In principle, the chaplain for the last anointing could also be connected via video conference, or team members could discuss their stressful situations and decisions with a chatbot. However, this IT-mediated interaction does not provide the same level of human connection and consideration for human dignity as face-to-face interaction. This is a social limit to digitalization despite technical and economic feasibility.
3. In everyday work, some team members may use terms and descriptions for patients they do not want to be documented in this way, i.e., when referring to the documentation of others, team members need to read between the lines. The spoken language might conflict with the professional self-concept or with corporate policies. Yet, violating professional or organizational norms happens, as it helps team members vent their pent-up emotional baggage or is a short, efficient communication that supports efficient teamwork. We see such cases in spoken language. Team members would likely not utter the same via digital media, for example, for not wanting their norm violation to be potentially documented. Hence, digitally-mediated communication would change the content of communication and not fully deliver the value of in-person communication. This is another social limit to digitalization, despite its technical and economic feasibility.
4. Before a patient arrives in the hospital from pre-care, information on previous interventions is important for further treatment planning. Similarly, after a patient leaves the ward for post-care, information needs to be forwarded to the respective partner(s). Ideally, all involved organizations share their information rigorously. In this context, initiatives for data structure standardization already exist (Professional Record Standards Body 2022), set the foundation interfaces between organizations, and remove a technical limit. Using the standard requires, in palliative care, a corresponding hospital information system (HIS) incorporating the standard. Typically, HIS are complex systems, and updating them or even changing the manufacturer

(both affecting the whole hospital) is economically not reasonable if only for the reason that inter-organizational communication in palliative care would benefit, with the alternative being less, paper-based information exchange.

We feed these three areas into the multi-level framework of technology acceptance and use (Venkatesh et al. 2016) and outline these limits as individual-level and higher-level contextual factors that impact the use of digital technologies and ultimately influence value creation (cf. Figure 1). These contextual factors might change over time. Higher-level contextual factors encompass environmental attributes (such as ethical, societal, legislative considerations, or inter-organizational communication). As outline in example 4, communication with pre- or post-care providers is not standardized and requires “traditional” ways of data exchange. Organizational attributes (such as resistance/inertia, available resources, impact-effort considerations, organizational knowledge and norms, culture, and leadership) are another higher-level contextual factor. Individual-level contextual factors encompass user attributes (a person’s skills, knowledge, and perception), technology attributes (technical possibilities and efficiency; cf. example 1), and task attributes (extent of required tacit knowledge). Regarding the latter and as example 2 demonstrates, in some situations, technology must not interfere at all – regardless of whether there is any relevant input or output of that conversation, which could be provided/received by a digital system. In a similar vein, when team members share information (cf. example 3), a personal and informal interaction without traceability might be appropriate in selected situations.

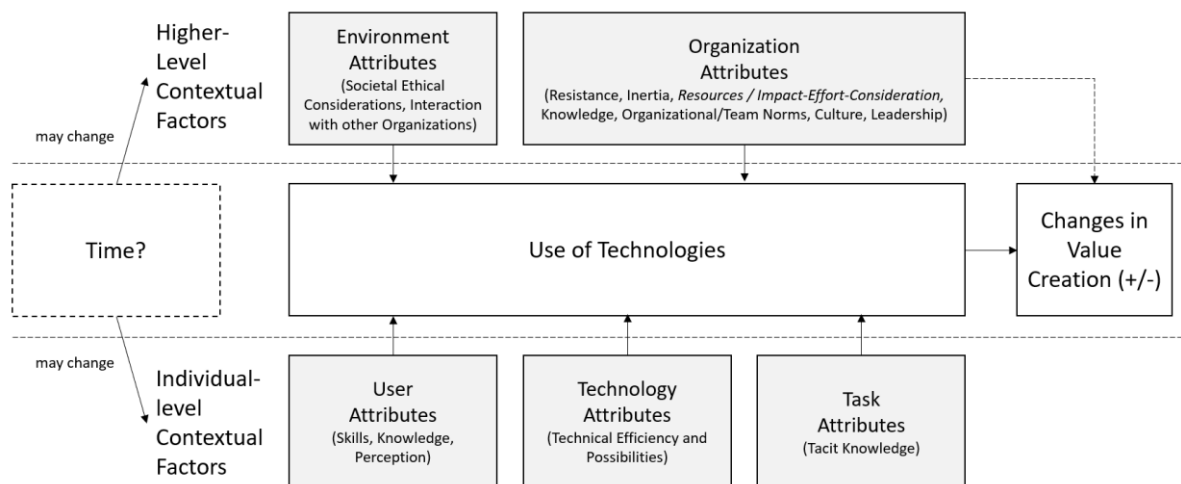


Figure 1: Contextual Factors impacting value creation through digital technologies

The findings of this study will help healthcare professionals to identify areas where the success of digital transformation initiatives could be unclear due to existing limits. Similarly, it will indicate to policy-makers and technology developers to create conditions under which existing limits are shifted in the mid- to long-term. Ultimately, this research will contribute to improving the quality of care for patients and offer practical solutions for value-creating digital transformation in healthcare.

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