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Person-centred Health Care Resting on Digitization and Systematic Processes

A position paper

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***Abstract*—This position paper argues for further research within person-centered healthcare using digitization and systematic process within the fields of information systems and quality management. The included state of art shows the existence of both digital applications and innovation, whereas there is lack of knowledge on how to engage users, especially when it comes to older citizens. Besides the digital application, we should focus on developing related systematic processes to increase both organizational value and patient value. Understanding user-design and development are necessary prerequisites to engage in digitalization and is also key to transformation in health care.**

Keywords-e-health; person-centred healthcare;quality management; information systems; position paper.

I. INTRODUCTION

The world-wide paradigm shift to a Person-Centered model of health Care (PCC) is stimulating innovation in the organization, delivery, and management of services and changing the relationship between patient and healthcare worker by increasing collaboration [1], [2]. As healthcare workers work more closely with patients to ensure PCC, the assembly line disease-oriented model of care is replaced. In PCC, the importance of involving the patient and their family is emphasized while planning and delivering care.

As part of the Swedish national vision, "In 2025, Sweden will be the best in the world at using opportunities offered by digitalization and e-health to make it easier for people to achieve good and equal health and welfare." [3]. Through technology, innovations can emerge to bridge the gap between the pragmatic and the value-based and help to engage patients more autonomously in their own care, as well as provide greater possibilities to meet their needs. The key areas of innovation relate to communication, operational support, and access to services, with an emphasis on tailored-made solutions to the individual, reinforcing the shift to a more patient-centered approach to health care.

While it is recognized in Sweden that welfare technology holds promise to transform the health care system to a PCC model, existing challenges are also acknowledged [4]. Among them are questions of personal integrity, data management, work processes and routines that enhance both the healthcare workers' procedures [5] and foster collaboration with patients to strike a balance between technological solutions and social interaction. Ahlin et al. [6] argue that digitalization is complex and often technological challenges become barriers to human connection. In their study, they found a need to develop social presence to achieve a complete transformation and quality in health care through welfare technology.

The World Health Organization (WHO) [7] suggests the need for a categorical framework for examining and developing e-health based on two categories: Digital Health Interventions and Digital Applications. Within the framework, six primary areas of development are identified including: client-to-provider telemedicine, provider-to-provider telemedicine, targeted client communication, health worker decision support, digital tracking of patient status, provision of educational training. While this model is helpful in making visible the complexities underlying the system of health care, it also invites critical reflection about how research can be designed to examine the interconnectedness of the components to achieve greater understanding about designing PCC. Much of the research to date focuses on single dimensions in the application and use of digital solutions in health care. Fewer focus on the interconnectedness of the elements to arrive at understanding how health care systems can achieve a balance between the pragmatic and the value co-creation [8].

In the field of information systems, studies in human communication online reinforce the complexity of participation in a digitally supported environment [9]. Use of digital technologies requires knowledge and competence to achieve the intended high quality of collaboration [10], [11]. In the field of quality management, innovations are taking place through service design and value co-creation, which involve the end-user in the needs assessment and design of services.

We suggest that an interdisciplinary approach, combining perspectives from Information Systems and Quality Management will contribute valuable new insights about how health care systems can transform to a PCC designed to

balance the pragmatic and the social value-based. Therefore, the aim of this position paper is to highlight central elements from both theoretical perspectives to contribute with insights about how welfare technology can be used as a driving force to transform and innovate health care system. The foundation for our argumentation will come from two research fields, quality management and information systems.

We base our position paper on interventions and innovations within home-care for older persons. In Sweden, Home Health Care is provided within a system of care, in which collaboration among all actors is central [3]. The health care plans serve as the bridge to enable participation and collaboration of all parties in the planning and follow-up of individual plans for a patient. This provides an important context in which to study how digital solutions can innovate to foster collaboration and co-creation. The population of older persons is selected based on studies showing persons in the older generation require a different kind of support when using technology, and also have different kinds of expectations about being actively engaged in their health services. Statistics reports that almost 50% of respondents in a study experience they lack competencies for using digital tools and services. A second motivation to focus on older populations is stimulated by the current pandemic in which digital solutions may help to combat challenges in providing care to persons in high-risk groups [12].

We present state of the art in Section II and conclusion in Section III.

II. STATE OF THE ART

Research and development in the transformation to a patient-centered approach to health care supported by digital solutions is broad. The research reflects an evolution beyond the mere application of digital solutions for management systems into the human dimension, under a variety of terms including e-health, mhealth, and telemedicine for example. In this state of the art, we present research on the application of digital technologies in health care as part of the paradigm shift to Patient-Centered Care. The research illustrates the need for a broader approach to developing PCC, which we suggest can be addressed by drawing on the knowledge, processes and tools from information systems and quality management. To better understand this argument, we also highlight key studies from these two fields. Among the factors identified as both promising and challenging are: accessibility, user-capacity, patient-involvement in co-creation and quality management systems that bridge internal efficiency with customer value.

A. Detailing Patient-Centred Care

Haglund [3] defines "people-centered health care as an approach to care that consciously adopts the perspectives of individuals, families, and communities, and sees them as participants as well as beneficiaries of trusted health systems that respond to their needs and preferences in humane and holistic ways" ([3], pp. 1). Shaller [13] has identified eight dimensions of patient-centered care: "1) Respect for patients' values, preferences and expressed need; 2) Coordination on and integration on of care; 3) Information, communication and education; 4) Physical comfort; 5) Emotional support and alleviation of fear and anxiety; 6) Involvement of family and friends; 7) Transition and continuity 8) Access to care". ([13], pp. V). Epstein and Street [14] argue that achieving a patient-centered approach to health care necessarily transforms the system of care from an assembly line model to a model of care, but putting people at the heart of health services. Moreover, it alters the relationship between patients and care-givers inviting the patient to be actively engaged at all levels of their own health care, shifting focus to people rather than disease [2].

Transformation to a PCC approach is supported by digital technologies, which are guided by both a pragmatic and value-based intent. Pragmatically, digital solutions aim to develop tools and services supporting reduced healthcare costs, improved diagnostic procedures, management of health, communication and collaboration between patient and caregiver, independent living [15], and access to services [1]. Value is added through the use of digital solutions to make services more accessible, to collaborate, and to provide individuals with tools and services to support independent living, thereby enhancing quality of life [14]. At the same time, [7] cautions the need to strike a balance between technological solutions and human social connections. They argue that digital solutions," should complement and enhance health system functions through mechanisms such as accelerated exchange of information...An understanding of which health system challenges can realistically be addressed by digital technologies, along with an assessment of the ecosystem's ability to absorb such digital interventions, is thus needed to inform investments in digital health." ([7], pp. iii).

The move to PCC in Sweden is supported by national and regional policy to develop PCC [3], [16]. Under the Swedish healthcare reform Nära vård ("Accessible Health Care") [16] regional governments are redesigning health care systems to provide greater accessibility to care, and stimulate patient co-involvement. Value is placed on the individual, and recognizes co-creation as an important ingredient to better understanding of the needs of the individual. Included in the reform is a recognition that health care services can and should also aim to promote greater equality and the possibility for individuals to live more independently, taking charge of their health [16]. An active agent in the new model is digitalization, under the terms e-health and "welfare technology", which reflect a comprehensive approach to e-health with the intent to both deliver equal care to all persons, as well as strengthen resources in the delivery and quality of services, and create systems to engage the individual in their own care by enhancing both independence and participation [17].

Research and development in the transformation to a patient-centered approach to health care supported by digital

solutions is broad. The research reflects an evolution beyond the mere application of digital solutions for management systems into the human dimension, under a variety of terms including e-health, mhealth, and telemedicine for example. In some countries, the term Connected Health [1] is used to reflect an overarching model that incorporates the myriad of perspectives, reflecting a "distinct balance of technology use for information sharing and connectedness together with proactive care and integrated healthcare services. Moreover, it has opened up a new vista in healthcare by digitally connecting clinicians to clinicians, patients to clinicians and patients to other patients" ([1], pp. 3). The WHO [2], cautions the need to strike a balance between technological solutions and human social connection. They state, "Digital health interventions should complement and enhance health system functions through mechanisms such as accelerated exchange of information, but will not replace the fundamental components needed by health systems such as the health workforce, financing, leadership and governance, and access to essential medicines. An understanding of which health system challenges can realistically be addressed by digital technologies, along with an assessment of the ecosystem's ability to absorb such digital interventions, is thus needed to inform investments in digital health. " ([2], pp. iii).

B. Digitalization and Value Co-creation in Health Care

In the area of patient-centered health care, value co-creation and service design methods have been explored to foster patient-involvement [5], [16], [18], [19], [20]. Yet as [5] found, the rhetoric still outweighs the practice. They found that patients have the ability to contribute to development of their care, but that systematic processes, methods and tools to enable patient co-creation were often lacking. [19] found similarly, that there is an awareness about the value of patient knowledge, but few practical examples exist in which patients are included in the development processes. In a more recent study, [18] identified knowledge gaps in how organisations navigate and bridge knowledge from different perspectives, suggesting the need for continued research to bridge the gap. These studies illustrate the need to better understand and develop systematic approaches that foster co-creation to enhance quality in health care toward a PCC.

Other studies of innovation health among the elderly draw similar conclusions about the lack of patient involvement. In a Swedish study, [8] provide a critical reflection on the promises and realities of digital care among the elderly, in particular in rural communities. Through an examination of innovations in the "Virtual Health Care Room", they note that digital health services are not always accessible for everyone, and that they can also lack a patient-centered perspective (ibid). They highlight the need for continued research, in particular in Sweden among the elderly, that examines health care and not just the technology. As they point out, there is little to no research on the way in which digital solutions are advancing health care among the elderly in Sweden.

In a study of digital solution to support adherence to daily medication intake among the elderly (over 65 years of age), Crawford et al. [20] found that participants were open to technology. However, factors that need to be improved upon include access, patient-specific solutions and designs. As well, gender and educational background affected patient experience. Their findings also demonstrated a positive relationship between autonomy and digital solutions. The greater the use and reliance on digital solutions the less autonomous patients felt. Among some of the respondents, technical solutions threatened self-determination and sense of self-reliance. This study indicates both the potential for continued development in the use of digital medicine, as well as the need for further research to better understand how to secure an effective and successful application among the elderly.

Other related studies, where access to services was examined, reveals complexities in the challenges that are both person specific and organizational. Wildenbos et al. [22] found that although access to technology was made available, rates of usage and adoption were low and inconsistent. Among the barriers they identified through a systematic literature review were, cognition, physical ability, perception and motivation. Suslo et al. [23] suggest that digital solutions hold promise for meeting the unique needs of the elderly, which is often complex and requires both healing and support. Yet the challenge, they suggest, is to secure digital literacy among the elderly, sufficient to benefit from the digital solutions.

A Danish study of digital service delivery among older adults [24] found that age was not a primary factor in the lack of use of e-health services, nor was accessibility. Rather, the primary reasons for "digital disengagement was lack of computer skills and lack of interest or confidence in using the internet." ([24[, pp. 48). Based on their findings, they propose that policy and programming should focus on ways to bridge the gap, targeting skills and attitudes related to technology. More significantly, they found that use of the digital technology among older populations did not necessarily result in improved communication. In fact, many respondents indicated concern that they were less understood by their caregivers. This has direct bearing on the national and international policies that aim to improve communication for patients.

In an extensive review of the research on mHealth (digital healthcare solutions) for the elderly, [25] concluded that numerous studies focus on the development of mobile applications, with particular emphasis on providing service to the end users. They suggest an exciting area of future studies exists around delivery of health care at a distance and the coordination of emergency response. Among the challenges that they highlight for future innovation are quality assurance in the use and application of mHealth, data

privacy and security, data mining and machine learning, and finally, user acceptance.

C. *Model of prerequisites for participating in the digital society*

Digital technologies like social media have fundamentally changed the way we communicate, consume, and create [26], and not least how we collaborate. Using digital technologies for collaborative purposes is simply becoming the new normal [27], [28], solving challenges with information shortages [11], but also facilitating communication [29], enabling knowledge sharing and development [30], [31], and are used for negotiating, building awareness, sense making, and learning [32]. Digital technology as a facilitator of collaboration has been theorized in, for example, the boundary object theory [11] and the distance framework [10]. In these theories, it has been illustrated how digital technology can be applied and configured for collaborative purposes, but also the importance of support of and competence in using the technology, as well as the configuration of processes supposed to be supported by technology. At the same time research on, for example, digital technologies as a boundary object has been criticized for focusing too much on the technological properties [33], [34], missing out on the "hows" and "whys" related to technology use [34]. Of course, digital technology and access to it are critical aspects of the ongoing digitalization and impact our possibilities to collaborate. But health-care workers and patients must have support to actively engage in digitalized collaboration, as is indicated above as well as by the model of different prerequisites for participation in the digital society developed by [9] (see Fig. 1). Digitalization is more than just a matter of technology.

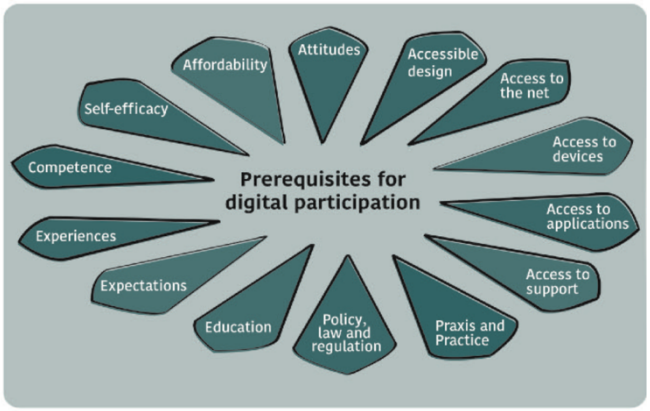

Fig. 1. Prerequisites for Digital Participation [9]

Johansson's [9] model summarizes a wide variety of prerequisites affecting individuals' possibility to participate in the digital society. For example, individuals need access to digital technology, support, and competence to use the technology. Even though the model is developed focusing on people with different disabilities or people being homeless, it can also be viewed as an illustration of the complexity of digitalization as a transformative process and aspects that must be considered to span distance with digital technologies. It illustrates that it is not enough to just make technology accessible or enact laws. There are several other prerequisites that also need to be in place for a digital transformation to take place and succeed. This complexity is what makes effective digitalization very challenging.

D. *Quality Management and Value Co-Creation*

Quality management is a systems approach to organizational, service and product development with the primary intent to meet and exceed customer needs [35], [36]. In recent years, traditional approaches to customer satisfaction have been expanded by digitalization and service design to focus on value co-creation [37]. Rather than designing services to meet the needs of customers, service design aims to engage the customer in the process of identifying needs and designing service solutions that best fit their needs [38]. Galvagno and Dalli [39] define co-creation as the "joint, collaborative, concurrent, peer-like process of producing new value, both materially and symbolically." (p. 644). Creating conditions for collaborative innovation, is according to [40] "the new imperative" emphasizing among other things value co-creation and the importance of engaging people as active collaborators.

In a recent study of digitalization and quality management, [5] argue the need for research to go beyond focus on technological innovations to the impact on business models, and organizational systems that support value co-creation. Seen within a system view, digital solutions impact both internal structures, systems and processes as well as interactions between external factors. Referring to [41] they include the following levels of interaction: process level, organizational level, business domain and societal level. Further, [5] propose an analytic framework for understanding how quality management can develop to foster value co-creation in digitalization initiatives. The framework examines value creation from a variety of roles including the customer/patient and the provider/organization, postulating the need for organizational flexibility to foster adaptability and innovation. Findings from their study recommend levels and forms of digitalization that need to be further examined and developed to achieve the balance between organizational efficiency and creating customer value.

III. Conclusion

The Resolution on Digitalization suggests the need for a comprehensive framework to better understand how to develop an effective PCC to improve health care. This position paper suggests that knowledge and practical approaches from both information systems and quality management can well serve this agenda. In particular, we

stress the importance of development knowledge and understanding about user-involvement, co-creation, and systematic processes to support involvement as necessary components to achieve the 2025 Agenda in Sweden. While a PCC is intended for all populations, there are unique challenges to applying welfare technology in Home Health Care that both advance and challenge services and user-experience. Statistics show that almost 50% of older persons experience lack of competencies for using digital tools and services. A second motivation to focus on older populations is stimulated by the current pandemic in which digital solutions may help to combat challenges in providing care to persons in high risk groups [12]. This provides an important context to study how digital solutions can innovate to foster collaboration and co-creation.

This position paper demonstrated the need for continued research into the ways in which welfare technology can be used to achieve the E-health vision 2025, and in particular with older populations. While there is good evidence of advancement and innovation in the application of digital solutions in health care, evidence also pointed to a lack of knowledge about how to engage patients in health care planning and development. Also, systematic processes need to be further developed to balance goals of organizational efficiency with patient value. Therefore, we emphasized that understanding user-design for developing PCC is key to transformation in health care.

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