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Person-Centred Technology-Supported Interventions

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Reflective questions

1. How can technology uplift today's healthcare services?
2. Are technology-supported innovations person-centred?
3. How can technology enhance personhood?

Introducing technology-based healthcare services

Krijgsman and Klein Wolterink (2012) make a distinction between technology-supported healthcare interventions (eHealth) along three dimensions: the care process (in which the technology becomes embedded), the user, and the technology. Along the line of the care process, technology can be used to support or improve health and healthcare. In terms of the user, the authors refer to the end user for whom the technology-supported intervention is developed, i.e. the service user, the health professional or others. In terms of technology, different interventions can be identified, varying from web-applications to home automation/smart home solutions. What the latter interventions have in common is that they all use new information and communication technology (ICT), in particular internet technology, to support and enhance health and healthcare. An additional and relevant categorisation of ICT-supported interventions can be made by incorporating their specific function or aim; an intervention can be developed to support the care process (e.g. electronic medical records or an app for making an appointment with a doctor), to reach the public (e.g. through internet-based education, prevention and campaigns) or to complement or replace traditional healthcare interventions (e.g. psychotherapy online or telemonitoring). By combining these functions with the characteristics of the pursued end-users, Krijgsman and Klein Wolterink were able to categorise all possible interventions.

In view of the current paradigm shift towards person-centred healthcare in general and person-centred technology-supported care in particular, there is, however, a need to also weigh new technology-supported interventions in terms of the level of person-centredness. In other words, an answer should be sought to the question as to what extent different technology-supported interventions support and integrate the individual's healthcare needs, preferences and values. This chapter therefore aims to provide input for this additional dimension by presenting and evaluating three technology-supported interventions in different stages of development (finished, ongoing and

being set up) along the lines of person-centredness. This input is meant to turn the functional descriptive categorisation by Krijgsman and Klein Wolterink (2012) into a living model that may serve to capture and monitor the fast expanding world of technology-supported interventions. Such an expanded model may provide a clear overview of the types of technology-supported interventions that have already evolved into a set of real person-centred technology-supported interventions and for which category more effort is needed to get there.

Technology-supported interventions: examples from three studies

The interventions presented here are just three of many examples of technology-supported interventions that are being developed as part of the technologisation of today's healthcare. The examples include: an evidence-based therapy for people with long-term conditions provided in an innovative way, a safety service for vulnerable people and their caregivers, and a support tool for empowering service users who face difficult healthcare decisions.

Web-based, self-management enhancing interventions for patients with long-term conditions

Three web-based interventions were developed and tested for people living with long-term conditions based on cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT) principles. These interventions aimed at increasing persons' self-management skills and quality of life (Oerlemans et al., 2011; Kristjánsdóttir et al., 2011, 2013a, 2013b; Nes et al., 2012, 2013, 2014). When developing the interventions, the Medical Research Council framework for complex interventions was used involving four separate stages (Craig et al., 2008): development, feasibility and piloting, evaluation, and implementation. The feasibility and efficacy of these interventions were investigated for people with irritable bowel syndrome (in a randomised controlled trial), chronic widespread pain (randomised controlled trial) and type 2 diabetes (feasibility study) with 76, 140 and 15 persons, respectively. In each study the intervention group participants completed e-diaries during several weeks on a PDA (personal digital assistant) or smartphone and received personalised, situational feedback based on their input on the same day. In the e-diaries, the participants registered activities, emotions and pain cognitions three times daily using the mobile device by choosing between predefined options and scales. A therapist had immediate access to this information through a secured website and used the situational information to formulate and send a personalised message to the participant with the aim of stimulating effective self-management in coping with the current situation. The web-based interventions appeared feasible, acceptable and supportive. In the short and medium term, the interventions also appeared to promote self-management.

Digital night surveillance of persons with dementia

Digital surveillance technology was developed and implemented in services providing care to people living with dementia (Nilsen et al., 2016). The technology included sensors on doors and in electronic security blankets (on mattresses) used during the night, and a web-based portal to facilitate communication via traditional personal computers (PCs) as well as mobile devices like tablets and smartphones. Most of the local health services already had some welfare technology installed, such as alarm systems, and the novelty of the new systems was tied to the web-based portal into which different technological applications can be connected and administered. In this way, technology in different categories and from different producers can function together and be programmed to individual persons' needs. Initially, decisions were made regarding what type(s) of technology was suitable for the individual user, and alarm settings were customised for each person. Alterations can be made based on for instance variations in needs during the day or due to the progression of a disease. An alarm will go off when an incident happens and the technology is programmed for the

individual person. The system is programmed to send alarm messages to dedicated personnel, and they receive an alarm on the device that has been chosen by their municipality or service: a smartphone, iPad or PC, or a combination. They switch off the alarm as they check on the user. Most home care service residents are in need of night supervision. They are living with dementia and tend to get up at night and wander, which has been described as one of the behaviours that is difficult to manage (Lai and Arthur, 2003). Night surveillance in one form or another (face-to-face or technology based) is necessary to detect 'night wanderers' and guide them back to bed in order to prevent confusion and anxiety, avoid falling and injuries, and protect other residents from being disturbed and becoming frightened during the night. In the Digital Night Surveillance project, the sensors in blankets and on doors detect and send a signal when a person gets out of bed during the night and when the person leaves the room. The persons with dementia are only passively using the technology, whereas the nursing staff responsible for administrating patient data, checking equipment and receiving alarms are actively using it. The implementation requires strategies for education and training, as well as for establishment of new routines, quality assurance procedures, initial adoption and upscaling.

My hip: a web-based information and support tool for persons with hip osteoarthritis.

People confronted with hip osteoarthritis need to adapt to the consequences of their illness and to get acquainted with different ways to manage these, related to medical aspects, emotion handling and changes in life roles. Medical management includes monitoring symptoms, changing health behaviours, and working with health professionals. Emotional management concerns dealing with the emotional consequences of having a long-term condition, such as anger, guilt, despair and frustration. Role management is about coming to terms with a change in life role, i.e. from 'healthy' to 'sick', and from 'providing' to 'being cared for'. Accomplishing these challenges requires a considerable degree of informational, behavioural, emotional, and social support for the individual person (Murray, 2009). Well-designed internet interventions have promising effects on users, including enhancing knowledge, self-efficacy, perceived social support, health behaviours and clinical outcomes (Murray, 2008). Osteoarthritis of the hip is a prevalent source of pain and disability in older people and there is currently no therapy available to stop or reverse the progression of osteoarthritis. Treatment includes conservative approaches and surgical joint replacement in suitable individuals (Zhang et al., 2008). Providing persons with the information they want at the time they want it remains a challenge. Information must be tailored to individual literacy skills and meet their varying needs, as the experience and impact of osteoarthritis symptoms changes over time. In order to maximise the potential of persons to learn the required management skills and participate in decision-making, a web-based support tool will be developed based on the challenges and experiences that patients face (Brembo et al., 2016). This tool is meant to provide its users with tailored evidence-based information and to serve as a self-evaluation tool by asking service users to keep track of their experiences, values, selfmanagement strategies and symptoms over time. This track record aims to support the communication between the person and their healthcare professionals, to support self-management skills and to facilitate shared decision-making in clinical practice.

Developing technology-supported healthcare interventions in a person-centred way

Healthcare services face major challenges in the future, partly due to demographic changes, including the steady increase of the ageing population and concomitant long-term conditions. To be able to handle these challenges, there is a need to develop effective models for restructuring health and care services, for allocation of resources and quality assurance of the service as well as the level

and scope of competence. Every service user and their next of kin expects to be seen, heard and taken care of on a personalised, individual basis, regardless of the systems, levels or professionals they encounter. In a similar vein, the people working within the health and care services need a safe and efficient working environment in which they are both challenged and trusted. There is a need for both higher and broader (technological) competencies and a high degree of adaptability in order to meet future challenges.

In the western world, there is a parallel tendency to reallocate jobs and healthcare supply, from hospitals to primary and community care, from national or regional to local care services and between healthcare professions (e.g. practice nurses assuming doctors' tasks). The introduction of technology-based interventions and services and the consequent need for education, knowledge and new skills are important aspects in this on-going process. Although technology is not new to healthcare, the systematic utilisation of healthcare technology within all levels of healthcare demands a true paradigm shift in the delivery of health and care services and can thus be seen as an innovation in itself. A successful implementation of such innovations depends on the innovation itself, the health professional (individual), the organisation and the socio-political context (Fleuren et al., 2014b). To achieve the pursued use and effectiveness it is, however, crucial to take into account the needs and demands of the individual end users in every step of the development process. A theoretical framework such as Intervention Mapping (IM) (Figure 13.1) or the Measurement Instrument for Determinants of Innovations (MIDI) may guide this development towards a person-centred intervention and guarantee an acceptable product and thereby successful implementation of the developed intervention (Bartholomew et al., 2011; Fleuren et al., 2014a; Van Bruinessen et al., 2014). The IM framework systematically guides and documents the decisions through each step of the intervention development process. IM stresses the importance of developing theory and evidence-informed programmes taking an ecological approach to assessing and intervening on health problems and community participation. It incorporates theory and empirical evidence to identify determinants of behaviour, develop intervention objectives and select methods and strategies for an intervention (Bartholomew et al., 2011).

The IM framework departs from needs assessment among the intended end users. This point of departure prevents the development of interventions that do not appeal to the target group; a feature well-known in the field of technology-driven interventions. The hip osteoarthritis project, for instance, started with conducting interviews with individuals to find out what needs they had with regards to information and emotional support (Brembo et al., 2016). The interviews revealed that persons with hip osteoarthritis are in great need of information and emotional support throughout the whole hip osteoarthritis continuum. Their needs, concerns and expectations must be appropriately understood and met by health providers caring for people living with hip osteoarthritis.

[Figure 13.1]

The knowledge and model developed through this study will be used as a basis for the development of a web-based tool for people living with hip osteoarthritis, their families and involved health providers, designed to increase service user knowledge and support communication during the process of preparing individualised care plans in clinical settings. The technology used in the digital night surveillance project has been developed by small and medium-sized technological enterprises based on the needs as defined by the management and employees in the health and care services of regional municipalities. The technology has been introduced (adopted) and then further developed (fine-tuned) during the implementation, in order to work optimally within each municipality. The researchers have been studying a range of the co-creation processes that have been ongoing during the phases of development and implementation: communication processes, learning processes, stakeholder analysis, service development processes and the processes from

adoption to implementation and even continuation of the technology. The intervention developers used the MIDI as a quantitative measure of determinants relevant for healthcare professionals during the implementation process (Fleuren et al., 2014a). The MIDI survey captures four categories of determinants:

1. The innovation.
2. The potential user of the innovation.
3. The organisation where the potential user works.
4. The socio-political context.

This survey is applied at different points in time throughout the implementation process with the purpose of evaluating the development and the impact of the innovation.

Principles of person-centredness guiding the three projects

Each of the three technology-supported projects presented in this chapter has incorporated the principles of person-centredness in a different way. The web-based, self-management enhancing interventions for persons living with long-term conditions are person-centred in the sense that as part of these interventions, healthcare professionals provide personalised, situational feedback on a daily basis through smartphone or PDA, which is based on the input of the person. Service users complete online questionnaires in the form of an e-diary that reflects their current and often dysfunctional feelings, cognitions and activities. By receiving person-centred advice and suggestions, the service user's coping abilities can be strengthened and elaborated upon whereby self-management skills increase. An asset of the technology-supported interventions that furthermore strengthens the level of person-centredness is that the intervention is situational and knows no limits in terms of time and place; service users can choose their own time and manner for using the intervention. For the therapist, however, it remains a challenge to incorporate this, so far, time intensive intervention into their daily practice. The intervention seems therefore foremost person-centred for the service user, less so for the healthcare professional. The digital night surveillance of persons with dementia does seem to unburden the healthcare professional personally. Previously, the night shifts of the healthcare professional in dementia care meant being constantly alert to those residents who may wander, for example. The technology-supported preventive service takes away this demand and makes it possible to assist a resident before strong emotions and physical injury has occurred; the best of both worlds. The hip osteoarthritis project is person-centred in the way that the content of the future intervention will be guided by the input from those living with the condition as presented during the interviews at the needs assessment phase of the project. These needs guide the development and will be used as tailoring variables in the intervention, which makes the intervention more personally relevant in form and content.

Key learning

In this paragraph about lessons learned we look back at the three questions that guided this chapter:

1. *How can technology uplift today's healthcare services?* Clearly, technology can facilitate healthcare services in different ways. It can lighten the often-heavy burden of healthcare professionals' daily work and offer service users several facilities for use in their own time and place. As technology-supported interventions do ask for other expertise and experience, it so far remains a challenge to embed the use of these interventions within busy daily clinical practice. Besides, the use of technology-supported interventions does require specific expertise from the end user.

2. *Are technology-supported innovations person-centred?* The technology-supported interventions presented in this chapter each appear to be person-centred in their own way. This reflects the continuous evolution and broad operationalisation of the concept of person-centredness; as long as a person (being the person of the service user or the person of the healthcare professional) benefits from an intervention which is adapted to his or her own experiences, needs or characteristics, the principles of person-centredness are safeguarded. Nevertheless, attention needs to be paid to the earlier-mentioned requirements for using technology-supported interventions. For each technology-supported intervention the question should be: is the person served by technology?
3. *How can technology enhance personhood?* Before technology met healthcare, numerous technology-supported interventions were developed because there was the technology to build them, not because end users needed them. Now the different fields have started working more closely together and the development process more often starts with a thorough needs assessment. Newly developed interventions become implemented and used more often and reach a wider public.

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Editors' Commentary

There is little doubt that technology and healthcare go hand in hand and the use of technology permeates all aspects of healthcare practice. However, currently we are witnessing an unprecedented growth in the use of technology solutions for addressing health issues and practices, driven by economic and clinical effectiveness demands. Earlier in this book, Jacobs and colleagues (Chapter 5) made the case for the humanisation of ICT in healthcare and argued that 'Technology-supported healthcare can be humanising and dehumanising at the same time. When applying technology, it is important to consider and secure different aspects of person-centredness and regularly monitor end users' needs, experiences and perspectives'. Also in this book, Skovdahl and Dewing (Chapter 7) considered the ethical issues that arise when using technology in services for people living with dementia. All of these chapters make the same point explicit, i.e. that the use of technology in healthcare is not a simple solution, but brings with it a variety of complex issues that need to be thought through in order for the technology not to erode individual and collective personhood. Few of us would argue against advances that have been made in personalised medicine and robotics that have had significant impacts on tackling disease, increasing mortality rates, improving quality of life and making health services more efficient and effective. However, we have to be careful not to accept blindly technologies that can significantly erode individual autonomy, self-determination, freedom and human rights. Van Dulmen and colleagues illustrate these complexities through the three study examples presented – each one brings its own challenges in keeping personhood at the centre of decisions made and ensuring that the person does not become secondary to the 'testing' of the technology is a key challenge in each of the methodologies presented. Of course these challenges reflect the dynamic relationship that exists between person-centredness at the level of care delivery and the macro socio-political influences on this care delivery. ICT is big money and the lure of finding 'the solution' can overwhelm attention being paid to individual experience – although we are confident that the authors of this chapter are focused on the latter as a priority. The chapter does raise issues about methodologies used to test ICT solutions in healthcare and the need to ensure that these are person-centred also. Van Dulmen and colleagues illustrate the case made previously by Jacobs and colleagues (Chapter 5) that research into the testing of ICT solutions needs to adopt a mixed-methods approach incorporating innovative strategies for collaboration, participation and co-design. The language of 'end-user' continues to dominate this kind of research, so it is encouraging that van Dulmen challenges this discourse and propose ways for engaging key informants in all stages of the research. Of course, truly to advance this field of research, then it could be argued that healthcare researchers need to be much more radical and creative in their approaches and rather than merely adapting existing methodologies, they need to draw from designs outside of healthcare and particularly from the world of product design, creative industries and the arts. This is a key challenge to person-centred healthcare researchers of the future.

Figures

Figure 13.1 Modified version of the Intervention Mapping framework.

