Editorial: Personalized Digital Health and Patient-Centric Services

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Editorial on the Research Topic

Personalized Digital Health and Patient-Centric Services

Preventing medical errors and improving patient health outcomes are challenges faced by healthcare systems worldwide. Digitalization and the development of eHealth solutions are essential to enhance the quality of care and empower patients to engage actively in managing their health, and collaboration with healthcare services. By adapting these solutions to the individual patient's needs, we can achieve personalized digital health. Digital health and eHealth are often used interchangeably, and there is no real agreement on the scope or overlap of the concepts. In this editorial, we use the concepts as synonyms. Over recent years, efforts have been made to develop digital health services that aim to improve the effectiveness and efficiency of healthcare through innovative approaches and strengthen the opportunities for self-care, self-management, and patient participation. These eHealth services are increasing as a result of the patient empowerment and patients' rights movements that campaign for easy access to medical data (Wiljer et al., 2008; Wass and Vimarlund, 2018; Bärkås et al., 2021), patient participation in their care (Riggare et al., 2019a), and in the design and improvement of the healthcare systems including eHealth services (Riggare et al., 2021).

PATIENTS' ONLINE ACCESS TO HEALTH INFORMATION

Patients use the Internet to find health-related information and learn about their specific conditions and general health (Riggare et al., 2019a). Oldenburg et al. explore how an educational website can be used to encourage patients to discuss preventative interventions with their physicians, harnessing the power of the Internet and social media to improve health. Similarly, Beaton et al. propose the design of a comprehensive educational resource for adults experiencing concussion symptoms, to help them recover and return to work.

In recent years, an international trend has emerged to give patients online access to their electronic health records (EHRs) (Essén et al., 2018; Hägglund et al., 2019). Patient Accessible EHRs (PAEHRs) describe EHRs shared with patients through an online patient portal (Wiljer et al., 2008; Moll et al., 2018; Kristiansen et al., 2019). PAEHRs can include access to clinical notes, often called open notes (Delbanco et al., 2010, 2012; Leveille et al., 2012), laboratory results and medications. In this special issue, papers cover aspects including design and acceptance of technology (Davis), implementation challenges (Cijvat et al.), and the impact that the practice of sharing clinical notes with patients may have on clinicians' documentation practices (Blease et al.). Using Normalization Process Theory (May and Finch, 2009; May et al., 2009), Davis concludes that a personal health record supporting shared decision-making makes sense and is positive to the different stakeholders participating in their study. Davis identifies more varied opinions regarding how such a tool would become used in everyday practice, where patients are more

positive and healthcare professionals more skeptical. Cijvat et al. confirm that implementation can be challenging, comparing the implementation of PAEHRs in Sweden and the Netherlands. The main barriers identified in both countries are resistance from healthcare professionals (Huvila et al., 2013; Cajander and Grünloh, 2019), and technical barriers. Facilitators vary across the two contexts, but both countries describe stakeholder engagement (including patients and healthcare professionals) and strong leadership as critical success factors.

Moreover, Blease et al. discuss how patients' access to notes can have both positive and negative effects on healthcare professionals documentation. Survey studies suggest that some healthcare professionals make an effort to write clearly and with less derogatory language (DesRoches et al., 2020), using the note as an extension of the patient visit, whereas others write fewer clinical details and even leave out important information (Petersson and Erlingsdottir, 2018; Kristiansen et al., 2019; Moll and Cajander, 2020). Poor documentation practices may lead to patient safety risks, a topic that is also addressed by Bjerkan et al. In their focus group study, Bjerkan et al. identify barriers to high-quality documentation on technical, organizational, social and individual levels. It would be interesting to explore further how patient access to their documentation could be used to encourage improved documentation practices, and act as an additional patient safety tool (Chimowitz et al., 2018).

SELF-MANAGEMENT AND ONLINE TREATMENTS

Over recent years, technologies for self-monitoring and self-tracking have emerged, allowing patients to collect a wide range of health-related data outside the clinic (Lupton, 2017; Sharon, 2017; Riggare and Hägglund, 2018; Riggare et al., 2019b). These technologies can educate patients about their health, help them manage their illness and help identify actionable insights. Despite positive outcomes, it is unclear how patient-generated data can be integrated into clinical practice (Hägglund et al., 2016). Hung et al. propose a solution for managing patient-generated data sharing with the aim of supporting collaborative self-care, allowing users with chronic and complex health management needs to have fine-grained control over sharing their patient-generated health data (PGHD) with a care team.

Self-management is important for most people with chronic health issues (Riggare and Hägglund, 2018; Riggare et al., 2019b). Issom et al. explore patients' use of a chatbot to support self-management of adults and young adults with sickle cell disease (SCD), a genetic blood disorder that causes several comorbidities that can be acute, chronic, and potentially lethal. In contrast to patients with SCD, many chronic conditions are more common in the older age groups, and in Wannheden et al.'s study 76% of the respondents are over 50 years old. Wannheden et al. explore how using a digital tool for self-monitoring and communication with healthcare satisfies or frustrates basic psychological needs. They found that individual preferences differ and that personalization of these types of tools is essential. In contrast, Lobo et al. addresses the needs of stroke family caregivers. They conclude that future research

needs to focus on improving user participation and proper understanding of the user practices and needs, as well as technical and organizational implementation.

In addition to self-management of chronic conditions, digital solutions for disease prevention and health promotion are increasingly common. The COVID-19 pandemic has caused concerns for numerous reasons, such as isolation and physical inactivity during lock-downs. Martyushev-Poklad and Yankevich review the patent landscape of automated systems for personalized health management, and conclude that few solutions exist today that support all aspects of human health. Ollier et al. designed a pandemic lifestyle care intervention and presented their study protocol in this special issue. In order to maintain physical activity, mobility and balance are essential for older adults and might impact their well-being and independence. Early identification of functional impairment may enable early risk-of-fall assessments and preventive measures and Backåberg et al. explore whether the skeleton avatar technique can predict the results of functional tests of mobility and balance. Backåberg et al. conclude that the technique can successfully predict the results of some of the functional tests and could in the future provide the means for a simple, easy, and accessible assessment of functional ability among older adults.

Access to care can be a challenge for many patients, and digitalization has proven a means to bridge that gap. Rauen et al. compare the outcome of Internet cognitive behavioral therapy (ICBT) with or without additional face-to-face outpatient psychotherapy in adult patients with moderate to severe depressive disorder. Patients who receive other face-to-face psychotherapy demonstrate slightly better outcomes after 6 months, and Rauen et al. conclude that ICBT is suitable for psychiatric treatment, although additional face-to-face outpatient psychotherapy helps stabilize long-term outcomes. Considering the increasing use of digital health in psychiatry, Blease et al. surveyed postgraduate clinical psychology students to explore their familiarity and formal exposure to topics related to artificial intelligence and machine learning during their studies, and conclude that although the students have a wide range of opinions on the topic, they receive limited formal education.

Whittaker et al. explore whether pulmonary rehabilitation can be delivered successfully online. A pilot study (26 patients and four family carers) provided pulmonary rehabilitation support via mobile phone, including exercise prescription and support. Twenty of the 30 study participants recommend the tool to others, suggesting that personal preferences play a significant role in the acceptance of technology.

TELEMEDICINE/ONLINE CONSULTATIONS

Online consultations and telemedicine with doctors and nurses are also rapidly gaining popularity but at the same time, questions are raised as to whether it is possible to provide good quality care through virtual online consultations. One can speculate about the patient experience with using these services, the contexts in which telemedicine works well, and where other forms of consultations work better.

An exciting study presented in this special issue relates to opioid use disorders and telemedicine (Cole et al.). Cole et al.

conclude that telemedicine is a viable alternative for providing care and works incredibly well in rural areas. They maintain that telemedicine can lower barriers to accessing mental healthcare such as stigma, the guilt of addiction, and anxiety surrounding an in-person meeting with a healthcare professional. Cole et al. also developed a patient satisfaction survey that serves as a measure and provides advice in evaluating patients' satisfaction regarding the quality of care provided via telemedicine.

As with many other areas in eHealth services, the pandemic has been a driver of implementation and use of self-management and online treatments. Foti et al.'s study of telemedicine induced by the pandemic for Inflammatory rheumatic disease shows positive results, and the successful implementation of telemedicine. During the lockdown, ~80% of outpatient appointments were telemedicine, and outpatient clinic face-to-face consultations were limited to urgent patients. Another exciting survey study in this special issue looks into telemedicine during the lockdown. Reicher et al. show positive experiences from patients, and the majority also state that they will continue using telemedicine in the future.

Interestingly, one-third of Reicher et al.'s respondents changed their minds about telemedicine during the lockdown. These findings are intriguing in light of telemedicine's non-use, which is addressed in another paper on this special issue (Landgren and Cajander). Landgren and Cajander show that before the pandemic in Sweden, there was a mistrust for services for political reasons, a deficiency in knowledge of available services, and a lack of perceived usefulness. Landgren and Cajander show that personal relations and continuity are more crucial than time or travel comforts. Indeed, to prevent digital exclusion, caregivers need to offer information, encouragement, or tools for the elderly and design-for-all needs to be a prerequisite in the design process.

DISCUSSION AND CONCLUSION

Digital health innovations serve society and support the sustainability of healthcare systems. Implementing these technologies is usually expensive with limited success, creating new challenges for healthcare professionals, patients, healthcare providers, and healthcare organizations (Chaudhry et al., 2006; Cajander et al., 2020; Moll and Cajander, 2020). In this special issue, we explore dimensions related to eHealth services that increase transparency, access to both care and data, and reports on how patients, family caregivers, and healthcare professionals' interactions can be impacted.

The pandemic has increased the use of eHealth services for patients, as several studies in this special topic conclude (Cole et al.; Foti et al.; Ollier et al.). Many patients and healthcare professionals who were hesitant to use eHealth services now see the need to learn, implement and adapt telemedicine and

other eHealth services to their needs. The pandemic has lowered the barrier to user adoption, and the perceived usefulness of digital e-services for patients seems to have increased significantly. Interesting future research could look into the sustainability of these changes. To what degree will telemedicine continue being used after the pandemic, in which contexts is telemedicine most valuable and what specific populations have used these digital technologies during the pandemic? Another exciting avenue of research is the effects on healthcare professionals' work environment, decision-making, and quality of care.

Despite the undeniable importance of eHealth services to many patients, some choose not to use them (Landgren and Cajander). Part of the explanation for this is that e-services for patients are still not being designed inclusively and in an accessible way. Indeed, Internet use generally (Johansson et al., 2021) and eHealth services for patients as designed today increase the digital divide in society. As we grow older, we are likely to increasingly need healthcare and potentially eHealth services. Hence, the elderly are more likely to consider eHealth services valuable and directed toward them, but research shows that the correlation between age and use of patient accessible health records is not linear (Huvila et al., 2018). Nevertheless, many experience the technology as inherently difficult to use (Huvila et al., 2021). We should not forget that at the same time as eHealth services for patients increase the digital divide; they also close it for people who are hesitant to physically attend for healthcare due to anxiety, stigma etc., as pointed out by Cole et al. and Rauen et al.

In summary, the publications in this special issue show how personalized digital health solutions can successfully be used by patients and healthcare providers to improve prevention, self-management and access to healthcare—if they are designed to meet the individual patient's needs and preferences.

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