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1.6 Engage the people – health informatics and personal health management.

Abstract:

In this chapter, we discuss the opportunities to address unmet needs among citizens, healthy individuals, patients and their families and/or significant others, using new technology solutions to support everyday health management activities. Patients and their families represent an undervalued resource, and if mobilized, would actively participate through the use of digital services, positively disrupting health care interactions and patterns of care. Future-oriented, elegant tools for citizen engagement, as illustrated in the case studies in this chapter, can help redress the traditional asymmetrical relationships in healthcare, where patients are regarded as mostly passive recipients. Digital health innovation can nurture change by offering novel opportunities to collect, complement and curate information for personal use. Then, data analytics supported by appropriate standards to avoid bias, step in and tailor service portfolios to one's personal health and wellness needs. Convenience, accessibility and active use of these digital tools generates information allowing for knowledge and wisdom that can guide how best to optimize resource consumption of public and private health services. *Trust* is paramount to drive adoption. Nurses are perfectly poised to lead this paradigm shift in healthcare, if they take on the tasks of helping people to access and understand the health data generated by their new digital solutions. Nurse informaticists

will support the nurses in learning these new skills. Nurses continue to significantly impact patients' health through multiple avenues including the new role of digital technology mediator and broker.

1. Introduction

The starting point and premise for this chapter is the significant, unmet needs within our populations and opportunity for novel digital health solutions to support everyday health management (Moen and Brennan, 2005; Zayas-Cabán, 2012; Brennan and Caspar, 2016).

Although there is broad consensus that the patient's needs should drive demand, more often other considerations take precedence including: sustainability of the health system, workforce shortage, fear of the unknown, market regulation, monetization of data or shifting of traditional role expectations (van Riel et. al, 2010). However, from the individual's perspective, several factors can influence health decisions, such as knowledge, interests and capabilities, priorities and preferences for participation (Brennan and Caspar 2014). These dynamics underlie everyday health choices that carry shorter- and longer-term consequences for an individual's health and wellness. We know that most households have an "*informal, Chief Health Officer*" (CHO) that pays attention to relevant health matters, manages important interactions around health and wellness, and keeps track of information relative to daily living, health situation, goals and preferences in the household (Moen and Brennan 2005). It is essential to equip these informal CHOs with the right digital tools to transparently collect and complement the pertinent information, employ analytics and make decisions.

CHOs are health consumers that appreciate convenience. For example, the CHOs are responsible for keeping a comprehensive overview of health and illness of family members, for identifying price estimates and flexible payment options, and for electronically scheduling appointments available in most health systems. However, health care systems often fall short in meeting such expectations and that is to the detriment of safeguarding the health of the

population. All too often, individuals experience limited access to their own information, which is dispersed across diverse actors in health and care. As it stands today, coordinating content from multiple sources and health facilities is stressing and time demanding for the CHO, since the information support offered by traditional health systems is quite limited. Systematic activation, along with opportunities for engagement, prevention, and early intervention can encourage participation and self-management for an individual to maintain functional abilities, dignity and to thrive (Østensen et. al., 2016).

Despite some efforts and achievements to improve access to personal, health-related information, opportunities to actively use this information to navigate the health system and fully comprehend/ understand implications of one's data represents a challenge for almost everyone. One limiting factor is the uniform and consistent adoption of interoperability standards allowing for the seamless exchange, harmonization and use of data. Data can be exchanged instantly for many other daily uses, such as the electronic exchange of money. Deposits, withdrawals and purchases can all be made by electronically exchanging money, which is data. This is possible because the financial industry agreed on their standards when building their systems for electronic transactions. Standards provide the framework for semantic interoperability, i.e., agreed upon understanding of what the data represents, and structural interoperability, i.e., agreed upon format for how the data is exchanged.

Nowadays, with the emergence of the HL7[®] Fast Healthcare Interoperability Resources (FHIR[®]) standard, healthcare data is moving towards a universally agreed upon interoperability standard. This standard allows for data to be electronically exchanged in real-time with both semantic and structural integrity as well as data security. HL7 FHIR[®] is rapidly being adopted by large and small tech vendors, regulatory agencies, third party payers and pharmaceutical companies, among many others (HL7, 2019). HL7 FHIR[®] powers systems that expose an interface to patients, such as Apple's Health Kit and the International

Patient Summary (IPS) that facilitate access to key health and wellness information. HL7 FHIR[®] is changing the way healthcare data can be received and reviewed. However, there are still very few tools and services that are designed or deployed to actively engage and empower citizens to be “on top of” their own health information and manage all this information in collaboration with their care provider(s) at different levels of care, health systems and organizations. Health data analytics in general do not observe data quality and interoperability standards leaving important ethical issues unresolved (Leung et. al., 2019). The “Inverse Care Law” proposed by Hart (1971) still applies in today’s digital reality. Which is to say that the availability and productive use of digital health tools varies inversely with the actual needs. Thus, our current state is one in which access to and adoption of digital tools underscores persistent disparities in health care. Patient information remains fragmented, and chains of health and care activity are most often broken, largely due to technical and structural obstacles. These include: limited or partial access to health records systems, lack of interoperability and little opportunity to actively select or use information for relevant, everyday purposes (Wibe, et. al., 2015; Hibbard and Greene, 2013). We observe that providers and health systems increasingly offer access via dedicated, secure portals as a service to their members and patients. The individual can manually enter information into specific applications of personal choice, or keep the information as paper files -- more or less organized. This situation leads to a mix of data in incompatible formats ranging from access to subsets of personal health information in digital form, image sets in digital media and digital snippets of exchanges and data in static paper documents subject to the person’s choice. This situation calls for ad-hoc, time consuming and non-scaling strategies in navigating and comprehending the plethora of disconnected information, often without quality control or reliable guidance, thereby creating confusion leading to misinformation.

Fragmented or unavailable health information can create significant risk of errors (Coiera 2011), unintended adverse events or even premature deaths (Helse- og omsorgsdepartementet, 2014). In the area of medication management, the magnitude of the challenge for the individual and society are demonstrated by World Health Organization's (WHO) reporting that more than 50% of all medicines are prescribed, dispensed, or sold inappropriately worldwide (WHO, 2002). In fact, estimates suggest that as many as 125,000 premature deaths are caused each year in the United States (US) (Martin, et. al., 2005), and around 200,000 premature deaths annually in Europe due to poor adherence to treatment (OECD, 2020). In addition to the personal cost and burden, these challenges with inappropriate medication use and adherence to treatment carry a high societal cost that puts significant burden on healthcare systems (Cutler, et. al., 2018). Even minor improvements could present great potential for personal gains and societal improvement, ensuring health and well-being for all, aligned with the United Nations SDG3 "ensure healthy lives and promote wellbeing at all ages" (United Nations, 2015). Thus, there is significant untapped potential for nursing and health informatics to mobilize and support prevention and early intervention, thereby avoiding costly treatments and improving our populations' health. All these goals remain at the core of our nursing profession, service and research.

2. Obvious paradox – opportunities for health informatics

Health information systems in use today, seek to optimize health systems operations and support health providers in making operational planning. At the same time, current health systems research focuses on resilience of health organizations and health systems employing machine learning and analytics (Ozcan, 2017). However, many health informatics solutions fall short of consumer convenience, as there are very few tools available for wider availability that facilitate active use of health information by individuals. The rapid shift to virtual communication for many care and treatment purposes has uncovered the importance

of active use of personal health information. To receive the full benefit of such applications, it becomes increasingly important for the individual to have good digital skills and appropriate health literacy for comprehension of cues, concerns and consequences (Sørensen, et. al., 2012).

The growing use of digital tools currently offers little support for holistic personal health information management, as overseen by a household's self-appointed CHO (Moen, 2007). Studies of these activities demonstrate diverse, sophisticated, robust strategies to differentiate and handle the already fragmented health information for personal purposes (Moen and Brennan 2005), including:

- *Just-in-time*, i.e., information and/or artifacts are with me at most times
- *Just-at-hand*, i.e., information and/or artifacts are visible or stored in readily accessible, highly familiar locations in a household
- *Just-in-case*, i.e., information and/or artifacts, either personal health files or general health information resources, are kept away, but are easily retrievable
- *Just-because*, i.e., information and/or artifacts of temporal relevance, kept in the household until storage strategy is assigned.

These strategies illustrate appraisal of the information, anticipation of need, balancing confidentiality and privacy of the information against an interest in adding or sharing information, ensuring continuity and avoiding fragmentation of health data (Moen and Brennan 2005). The specifics of these strategies can be very personal, sophisticated and robust for self-management in the “care-between-care” periods or in guiding “inter-visit” care actions (Brennan and Casper, 2014). Therefore, understanding data management strategies are key to bridging any gaps that may happen when using both person-generated data with those of the provider(s).

Going forward we need to systematically alleviate what we think is an obvious paradox: Despite interest in and expectations for personal health management, there are few comprehensive digital solutions to support everyday activities by individuals and in collaboration with the household's CHO. What is needed is to create tools that enable us to collect, compile, curate and integrate health information from multiple institutions, services and systems. Then, we have the opportunity to share consolidated parts of this information with providers, significantly contributing to continuity in ongoing care and treatment. New digital health services that support and offer a good overview of health information with an understanding of its implications, if successfully deployed at scale will come with opportunities to engage, improve user-experience, and empower the individual (Moen, 2018). The European Union (EU) General Data Protection Regulation on Data Portability (GDPR) (European Parliament, 2016) and national laws, like the Norwegian Patient Act (Helse- og omsorgsdepartementet, 2001), state that it is every citizen's right to a digital copy of their data and that includes their health information. Similarly, the US 21st Century Cure Act includes measures to prevent and prohibit information blocking (Health Human Services, 2020). These EU and US regulations create a fertile environment for digital services that can enable and empower participation and management of personal health information for self or family members for everyday purposes, while enabling collaboration with health providers and informed decision making. In this context, HL7 FHIR[®] is the de facto standard for providing uniform and harmonized access to the disparate sources of health data.

In Europe, research and development activities have grappled with the challenges of mobility, and orientation in new contexts, especially for navigation in health and care (Chronaki, et. al., 2018). Additionally in the European context of cross-border health care services, the "*International Patient Summary*" (IPS) emerged to support patient safety and informed care provision in situations for unplanned care in another country (Heitman, 2018; Kay 2020). The

next section presents examples of solutions seeking to meet consumers' expectations for ease of access to their health information and for usefulness in managing specific health needs.

3. Case examples: Patient centered digital tools and services

Two case examples illustrate our observations on the changes coming with usable digital services for the least supported resources in healthcare: *the person*, in the role of patient or family member, or informal care giver. These examples build on data and information and point to opportunities for improvement of health care experiences. Change and responsible innovation via emerging digital services, provide convenience for the individual and support patient safety while respecting the person's preferred level of engagement.

3.1 Personal use of wearables, sensors and IoT for safety in Ambient Active Living

The pervasiveness of mobile sensors and wide-spread adoption of wearable devices) Internet of Things devices (IoT)), and growing numbers and types of implants used for treatment and care, all generate massive amounts of data that are accumulated in many formats and used for a broad set of health activities. Sensors and IoT devices provide data that can offer insights into human processes, as well as the activities in the environment, including health and wellness related activities in the home.

As an example, the Norwegian government prepared the whitepaper "Innovation in Care" (Helse- og omsorgsdepartementet, 2011) a decade ago, and recently launched the program "Leve Hele Livet" (A full life - all your life — A Quality Reform for Older Persons) (Helse - og omsorgsdepartementet, 2018) to accelerate uptake of "*Best Practices for Age friendly communities*" (KS, 2021). The overall goal is to stimulate improvements in areas of early intervention, prevention and cooperation through a program that focuses on nutrition, sound medication management and providing for safe physical environments and digital services. Increasingly offered as part of the community health care service, we see several types of services and digital tools emerging to enable aging-in-place, and in age-friendly and safe

environments (Helse- og omsorgsdepartementet, 2018). Therefore, several approaches have been explored in terms of feasibility, safety and attractiveness. These include:

- 1) Physical environment optimization; either in the house, e.g., new or retrofitting with good contrast, overview, light, door-video, or outdoor, e.g., rails, sturdy surface, accessibility to ensure control and safety
- 2) Sensor based surveillance which can be seen as “passive monitoring” of activities in the home environment or with the person while mobile; including GPS (global positioning system), safe home environment (“stove watch”, light sensors), personal safety (fall prevention in particular)
- 3) Engagements tools, like networking and personal enjoyment, or video-based health consultations to stimulate active contributions for prevention, early intervention or rehabilitation for a better health and life experience
- 4) Tools for mental, physical or social stimulation and recall; like social robots named Paro or Pepper, or outdoor garden (Dahlkvist, et. al., 2020) or “traveling” via “street-view” maps of a chosen, well-known surroundings
- 5) Support for informal caregivers, tools for targeted purpose- or condition specific information, sharing and preparing for special roles or responsibilities, e.g., demonstration of tools used in the home, or preparing for challenging care experiences (Janson, et. al., 2020).

GATEKEEPER (www.gatekeeper-project.eu), building on results of its predecessor project ActiveAge (Fico 2017), is an European multi centric, large-scale pilot on “*Smart Living Environments*” connecting healthcare providers, businesses, entrepreneurs, elderly citizens and their communities. The aim is to ensure healthier, independent lives for the ageing populations, improving the quality of life of citizens while demonstrating efficiency gains in health and care delivery across Europe. Development efforts focus on creating an open, trust-

based arena for matching ideas, technologies, user needs and processes. The standardization strategy is an actionable, agile part of GATEKEEPER as it aims at creating a digital health service ecosystem powered by data analytics. The HL7 FHIR[®] implementation Guide (IG) of GATEKEEPER has been created to accelerate integration of reusable IoT devices, sensor components and health analytics into services offered across Europe. Notably, mentoring is an integral part of the service redesign and consistently employs the HL7 FHIR[®] IG to align new services to the existing portfolio. In this sense, GATEKEEPER can help advance quality and consistency of health data, driving better algorithms for data analytics. Besides this purely technical perspective, one should not lose sight of bioethics, particularly in relation to data analytics and Artificial Intelligence (AI). The data used to fuel analytics should be high quality, offer no bias, and be able to explain the reason for a decision or the outcome, i.e., explainable AI (European Commission, 2021). Building trust is essential and a role that is well suited to nursing. Nurses should be proficient users of systems, such as GATEKEEPER and X-eHealth, to advice, direct, and educate patients, along the lines of “My data - My Decision - Our e-Power” (Chronaki et. al., 2017)

3.2 Personal collection, management and custodianship of personal health information

Interoperability and health informatics standards make access between disparate (individual and provider) systems possible. Privacy and security concerns, with technical, organizational and interoperability standards become important drivers for new paradigms.

Standards make data available leading to the development of curated information summaries, like the IPS. Such summary documents can include allergies, medications, problem list, and discharge summary (Chronaki, et. al., 2015). The IPS presents curated, relevant information for patient and provider mediated exchange. Therefore, should an urgent need or unplanned care episode occur, when in another country or health system, the person and their new health providers can start from a patient summary fit for the purpose of sharing critical health

information. The technical feasibility of the IPS concept has been successfully tested, and also identifying limitations of transforming clinically equivalent sections used in Europe to those used in the US (Estelrich et. al., 2015, Heitmann et al., 2018). Therefore, the EU funded X-eHealth project set out to develop the “European EHR-exchange Format” (EHRxF) that would add new guidance and detailed specifications for patient summaries, prescription, laboratory and imaging results (Bonacina et. al., 2021). After the episode of care, a person can receive a discharge summary or encounter report for future use in support of continuity of care. Privacy and security concerns, with technical, organizational and interoperability standards come as important drivers. To reap benefits, human factors and professional accountability are important for uptake and to gradually improve the summary documents. x-eHealth strives to stimulate interconnected Communities of Practice that benefit from the EHRxF.

Personal experience, capacity and digital health literacy are important to fully understand and appreciate the potential of these new digital services. Further advancement is expected as co-creation processes starting from the IPS can bring patients, health professionals, and informal care givers together. Co-creation and participatory design facilitate the usability and usefulness of a solution. This approach is especially important in designing visualizations that are understandable and actionable, information promoting, and that gain active engagement across groups with variable degrees of digital health literacy skills (Arcia et.al, 2016). To maintain trust and data integrity of the contributions from patients and providers, it is essential to clarify stewardship when sharing, interpreting, and complementing health information. With summary documents, we would argue that it are essential for continuity of care and treatment, as well as to support mobility and activities in different contexts of care. Increasingly digitally and health literate persons can contribute to stronger basis for decision

and everyday health choices. Ultimately, the key to creating an environment for responsible innovation is remembering that innovation travels at the speed of trust.

The *CAPABLE* project is another example, where the goal is a digital solution for the active, personal health information management (Hurlen and Moen, 2019). The starting point is also with areas where information elements are at the core in the IPS. *CAPABLE* comes with an explicit focus on user engagement and empowerment through a tool designed for individuals, not for the providers or health system owners. As such, *CAPABLE* seeks to balance the complex demands for functionality, comprehension and easy to use solutions with usability and usefulness. Therefore, the solution seek to be accessible with understandable content, high performance, and guarantee security, privacy, and trustworthiness (Janson et.al., 2020). Following this, a user of *CAPABLE* can copy, curate and add - *not substitute or alter* - health data from providers, and add personal observations. Importantly, the individual can choose to share their data with health providers when and for as long as they feel this is needed. Users will have the opportunity to report errors and correct information on what matters to them starting with visits, medications and their effects. The design of *CAPABLE* is driven by a commitment to equip and empower citizens with understandable and actionable health information that meets their personal needs. The system will be available as an affordable and effective service where the personal health information they wish to collect, complement and control, can be safely stored. As such, the solution provides universally designed, functional digital tools where a person can handle personal health matters, as the personal or household's CHO already does with more rudimentary, non-scaling tools.

Building from the *IPS*, *CAPABLE* and other citizen centered solutions, we will continue to create a new tool *G-Lens*, which aims to offer novel personal health information improvement for many users, particularly those who take numerous medications to control complex health conditions. *G-Lens* will introduce digital services based on a focusing

mechanism, taking components in the IPS to feed rules that will highlight information in the medicinal product information – ePI (electronic product information by EMA, 2021). The ePI can make approved information from a regulator about medication in use more accessible, increase understanding and actionability by patients and health professionals (Moen et.al, 2021). The goal is to create a more convenient health experience, where citizens are confident, active and responsive in personal health management, reduce fragmentation and encourage safe use of medicines for better health outcomes and quality of life.

4. The Expanded Nurses' Role

Nursing programs should prepare the nurses of the future to play the role of health information technology brokers (Matney, et. al., 2016). As digital health solutions penetrate our societies, nurses will continue to significantly impact their patients' health through multiple avenues and new roles as that of a digital technology mediator and broker. Trust is paramount to winning adoption of these new patient-centered, digital solutions, and nurses are perfectly poised to lead this paradigm shift in healthcare. In turn, learning how to use these new digital tools and their underlying technologies, to the extent that they are able to teach safe use to their patients, represents a steep learning curve. Nurse informaticists need to be ready to support nurses in this undertaking in all settings: classrooms, simulation labs, and in care delivery settings like hospital and home. Importantly, nurses will need to take on the tasks of helping people to manage the data generated by their new digital solutions.

For nursing, collaboration with the patient and their family members / informal caregiver and the family's CHO, will involve introducing these new digital tools as part of their care plan. Mentoring to become expert users will strengthen their capacity for everyday self-care and self-management being competent custodians of their data. Digital Services, functionality and qualities that add convenience and control for the patient can also reduce pressure on nurses, primary care providers as well as specialized health services, and help comprehension or

sense-making of health and care situations when literarily “bombarded” with suggestions and information of different origin and quality. In this context, attention to updated information from an IPS and relevant “Observations of Daily Living” can support quite specific, but contextual and personal comprehension of cues and concerns to follow up ongoing treatment and therapies for best possible outcomes. Digital health tools create value and strengthen health information management, collaboration and service coordination, based on sharing of the information at the user’s discretion. Active engagement and collaboration in digital tools that support diverse information needs for self-care, treatment, and self-management will add to the nurse’s role that of a trusted advisor for health information technology.

5. Discussion

Overcoming the Hart’s inverse law paradox on the high interest in digital services but the reality being a lack of comprehensive digital solutions to support the person at their chosen site of activity, continues to be a challenge. Usable digital services are needed to equip the most important but least supported resources in health care – *the person*, as patient, informal care giver or family member, with opportunities to use their health information, at their discretion and convenience. If approached with respect, dignity and care for the person, such activities represent an untapped potential for value creation and improvement of health care experiences, with innovation delivered via novel, digital health services.

Delivery of digital health services where health information is available can engage, equip and empower the individual, allowing meaningful participation and shared decision making. Liberating the information and creating tools for active use of personal health information can redress the traditional asymmetrical relationships in healthcare, where patients are regarded as mostly passive recipients. Tools powered by analytics, can shift the balance and result in concrete benefits for the individual and the health system as a whole. In these information processes the goal is that the users can: 1) access, understand and apply

information, 2) complement information with personal, relevant comments (annotate/update) as they like/need, 3) collaborate with trusted partners and the health care team, and 4) preserve control over personal health information by choosing “what to share, with whom, and for how long” (Moen, 2018). These are central notions in the Digital Health Compass created by eStandards, the European initiative that developed a roadmap for standardization to support the large-scale deployment of digital health services (Chronaki, et.al., 2017).

The full benefits, experienced of convenience and value proposition, usable digital services to mobilize the least supported resources in health care; *the person themselves*, as patient or family members, represents an untapped potential for change and innovation via novel digital health services. Purposeful, specific digital solutions that responsibly balance transparency, safety, trust, security and privacy with increasing engagement, participation and empowerment can make a significant difference in the ongoing digital transformation in health care systems.

Summary

Patients and their families represent the most important participants in health care. They represent an undervalued resource that, if mobilized, could significantly change the interactions, improve the health and wellness of the individual (Leung et.al, 2019), Well designed digital solutions can deliver much needed tools with benefits for all. Engagement, active participation and empowerment can shift our societies to a wellness and prevention-oriented, healthcare systems with quality-of-life gains and significant economic benefits. To achieve the full advantage of a digitally transformed, healthcare systems, people must become digitally literate. Nursing is positioned to play the role of technology mentors and advocates to overcome the digital literacy gap and to gain trust in the applications. Literacy skills are fundamental to trust and being able to control with whom one shares their information and for how long. Digital skills, and efforts to advance health literacy to

comprehend cues or concerns, and monitor contextual and personal health issues becomes a priority. Nurses are key to this transformation.

Usable, elegant tools for citizen engagement, as illustrated in the case studies presented, can help redress the traditional asymmetrical relationships in healthcare, with patients as mostly passive recipients. Future service innovation can enable transformational change by offering novel opportunities to collect, complement and curate information for personal use.

Untapping the potential of these new digital technologies to alleviate unmet needs with nurses as digital mentors, can help people effectively handle the health and wellness challenges they face on a daily basis.

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