Bridging the Gap - Health, Technology and Intermediaries

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Abstract. The demands for health care services are rising steadily. To meet these demands, the prevailing health care paradigm has been put under scrutiny. We have already passed the verge of a paradigm shift where patients are regarded cooperative partners who play an important role in their own care. In the core of this ongoing shift is technology that enables a new kind of service provisioning and digitalization of services. This has created a dilemma; how the patients who are not able (or willing) to use these new services can be reached? To answer this question, a fresh outlook on the roles related to health service provisioning is needed. This examination calls for identification of health technology intermediaries, mediators, who stand at the crossroad of health, care and technology. This exploratory work will look into the intermediary roles, outlining a set of skills and capabilities needed from a mediator.

Keywords: Health Care Information Systems · Health Service Provisioning · Intermediaries

1 Introduction

It is a commonly accepted view that the field of health care is changing in fundamental ways. This change is put into motion by economic and societal drivers, such as ageing societies [1], which are affecting all levels of the field, from funding to practicalities of care. Probably one of the most visible trends associated with the ongoing change is related to re-delegation of care. Instead of placing responsibilities of care into the hands of a health service provider, they are gradually shifted towards the patient (or one's relative). This re-delegation is particularly evident if we look into the patient-physician relationship, which has changed fundamentally during the last two decades. While the traditional (or paternalistic) relationship was one of the most prevalent models until the turn of the millennium, other models have gained a more foothold since then. These models, which are in general more equal in terms of decision making, and more consumer-oriented reflecting the spirit of our time, include the partnership model and the self-governing model. In the first one the actors (patient and physician) are considered equal and the patient has more responsibilities than in a traditional model [2]. In the second one, the patient is even in a more prominent position as the relationship is akin to the one between a buyer and a seller [2]. Key enablers in this change are electronic health services that alter geographical and spatial dimensions of care. In practice, these services extend reach of the health service provider, from traditional confines of care delivery to homes and hobbies, and from (doctor's) practice to everyday life.

This development trend, however, has a drawback which needs addressing before the services become the primary (if not even sole) way of conducting affairs in the health care domain, as has happened in the banking sector [3], [4]. In the core of

health care has always been a patient whose preferences have formed a corner stone in health decision making. The advance of electronic health services is rapidly challenging this arrangement as 'traditional', face-to-face, health services are being replaced with their electronic counterparts, such as interactive virtual clinics [5] that employ web-based solutions in remote service delivery. In this kind of situation where electronic health services are becoming more and more commonplace, health care decision makers must ask themselves how the patients who prefer the traditional service models, or are simply unwilling to use technology, can be reached.

Unless this question is answered, we face a very real threat of placing a group of patients into the 'fringe' of health care as they are not able, or willing, to meet the demands of modern health service provisioning. In order to estimate how many people are in a risk of falling into the 'fringe', we need to look into the current statistics provided by the OECD[1]. First of all, in the OECD countries 80 % of individuals aged 16-74 were Internet users in 2013 compared to 60 % in 2005. In Luxembourg, Switzerland and Nordic countries, more than 90 % of the adult population were Internet users in 2013. As an opposite indicator, in Greece, Italy, Mexico and Turkey less than 60 % of adult population used the Internet. These differences are wider for older generations. For example, over 75 % of 55-74 year-olds in Denmark use the Internet while less than 10 % use Internet in Mexico. All in all, nearly half of the elderly people in the OECD countries used the Internet.

If we look deeper into consumer technology infrastructures, namely into broadband communication and wired band subscriptions, the penetration rate was 27 % in 2013. At the same time, wireless broadband subscriptions reached almost 75 %. As a related, more regional indicator, access to computers from home in the European Union (EU28) was 78.41 % in 2012 and the Internet access from home was at the same time 76.1 %. Interestingly, if we look into the discussed indicators, or to others related to the use or acquisition of ICT, two generalizations can be made. One, a penetration rate of 90 % or more is not common. For example, there are 34 Member Countries in OECD and only in one[2] country household broadband access was more than 90 % (Iceland, 92.4 %). Two, the development amongst 'high-tiered' countries, such as Iceland, tends to slow down with one exception; the amount of wireless broadband subscriptions. This will continue to rise with the expansion of Internet of Things (IoT) and Machine-to-Machine (M2M) communications, and wider availability of affordable mobile devices.

On the basis of this analysis a hypothesis can be made. In the near future, 10 % of the population in the OECD countries will be in a risk of falling into the 'fringe' as they are not able, or willing, to use the technology needed in the modern health service provisioning. If the risk is fulfilled, it will not only degrade the function of mature health ecosystems that are turning digital; it will also prevent them from functioning in a sustainable fashion after the transformation. It follows from the nature of the problem, that the answer to the problem is not solely technological by nature as technology is a fundamental part of the problem. One possible answer is the use of a mediator ([6], p. 41), an intermediary in the crux of health, care and technology.

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[1] https://data.oecd.org/; http://www.oecd-ilibrary.org/ (Accessed: May 11, 2016).
[2] Data from South Korea was not comparable as it included mobile phone access.

2 On intermediaries and mediators

There have been intermediaries in the field of health care for a long time. Patient advocates [7] and case managers [8] are practical examples of this role. Even the role of a practical nurse in home care is inherently intermediary, as it often involves interpreting health related information to the patient, and helping one in health related decision making. Most of these intermediaries are either formal positions or a 'job within a job'. As such, they are effectively subjected to the rules and regulations of the service providers. Individuals in these kinds of roles can be characterized as provider-side intermediaries.

When it comes to more informal intermediaries, and ones working as patient-side intermediaries, the relatives often take up the task. In practical terms, this could mean that the spouse of an elderly person acts as a kind of case manager, ensuring that needs and demands of the elderly person are acknowledged. Even though these kind of informal intermediaries can become an expert in specifics of an ailment or condition (cf. [9], p. 1809-1810), they are rarely competent in making formal and long-term health related decisions ([10], p. 180) such as, outlining a care plan. In practice, the lack of competence often follows from absence of formal training and education that gives perspective to health care professionals for handling a variety of conditions and ailments.

Mediators ([6], p. 41) are a specific kind of intermediaries. They operate on the patient-side, bridging the gap between the patient and health service providers. While mediator has similar characteristics to other intermediary roles in the field of health care, technology expands and differentiates the role from the others. More specifically, the role focuses on patient-side health technology and health care information systems, and acts as 'conduit' for technology and underlying services. As such, the role is a hybrid between those of a nurse and a technical support.

A real-world example on the need for a mediator comes from electronic health records (EHR), which are considered as essential tools for increasing collaboration between health care and social service providers, and patients ([11], p.2). From the health service provider-side, these solutions contain functions relevant for daily clinical work, such as maintaining patient record and medication lists, tracking clinical tasks, and managing diagnostic tests. From patient-side, the functions are often limited to accessing patient record, and managing consent and authorizations. However, as the EU Digital Agenda states ([12], p. 29), the goal is set further than mere access to personal health information.

We are already seeing solutions which are more mature, not just in terms of technology, but also in terms of patient engagement. These solutions, such as the one used in Mayo Clinic, expand the reach of the traditional health care to everyday lives of the patients in the form of mobile health applications (cf. [13]). As these kinds of allegiances are becoming more and more common, diverse, and the traditional care becomes intertwined with aspects of well-being and fitness, a need for a mediator arises.

Today, not in some unforeseeable future, there are individuals who need someone to help them to bridge the gap between new and emerging technologies, and the new ways of providing care. In the basest form, this is realized as a need to fill in the forms that are online and not on paper anymore, or as a need to understand what the often jargon-filled health records actually stand for. Tomorrow, these same individuals may need help in conducting online medical examination in virtual clinics [5], or in uploading health-related information from their mobile health applications, which they are expected to use in managing a disease, such as diabetes.

3   Framework for mediation

Basic division into provider-side and patient-side intermediaries is often enough as it conveys the essentials of the role and responsibilities. With this kind of dichotomy it is easy to understand a) for whom the intermediary actually works for, and b) what kind of legal and organizational constrains are in effect. However, in order to delve into intricacies of the actual position of an intermediary in relation to different stakeholders, a more specific framework is needed.

One way to categorize mediation is to look into activities of an intermediary; what is one's role in terms of mediated activities. In relation to the development and appropriation of new technologies, Stewart and Hyysalo [14] use a three-tiered approach that originates from Stewart's previous work [15] on the roles of cybercafés in the 1990s. In their work, they identify three distinct categories: a) facilitating, b) configuring, and c) brokering.

Summarizing their work very briefly, facilitating can be described as providing opportunities to others. As such, it encompasses aspects of education, gathering and distributing resources, influencing regulations and setting local rules. Configuring, as the name suggests, refers to configuring technology but often only in a minor way as it also has a symbolic meaning. Configuring also refers to creation of space that facilitates appropriation (such as a cybercafé), influencing individual's goals and perceptions. [14]

Lastly, brokering refers to a role intermediaries take when they set themselves up to support appropriation process. This includes negotiating on behalf of the represented individuals and institutions, for example when a new supplier is introduced to a project, or when requirements for a new product are discussed. Of the three categories, brokering can be seen as the most direct way of interaction between a user and a supplier. [14]

The three-tiered approach devised by the authors [14] is befitting to the field of health care as it can be used for investigating activities of intermediaries already working in the field, and for analysing the missing ones. For example, work of a case manager in the field [8] is often related to brokering. This kind of an intermediary acts on behalf of a patient brokering services for the actual beneficiary. As material side of things is often present as well in the form of medical aids, medication or nursing supplies, facilitating is also an integral element in the work of an intermediary. Another aspect of facilitating that is commonly present in the role of an intermediary is education. For example, when a patient is discharged from a hospital to home care, patient education in the form of care instructions is often provided.

However, there is one particular area of facilitation that has not received sufficient attention; configuring. When it comes to electronic health care services, different health apps, or 'gadgets', users (patients) are often on their own. Or, if they need advice, users are expected to turn to online tutorials and support forums which themselves require a degree of technology literacy from the user. This kind of lack of configuring is not limited only to 'gadgetry' as it applies to a grander scheme of things.

As digitalization and concurrent service reform is changing the field of health care from the perspective of a user into a 'health space' [16] where information and services converge, a more profound need for configuring emerges. As the 'space' shifts and changes according the user's expectations and needs, configuring is needed to enable new uses (and users) of health-related information. As symbolic configuring touches upon issues such as rules and regulations on the use of health-related information, a specific area of conflict emerges.

It is commonly known that the health care domain is heavily regulated from the provider-side. However, on the user-side 'anarchy' reigns as the users tend to use technology according to their personal preferences, even moods. In this kind of contested landscape, born from personal control and self-service society, mediating a middle-ground between opposite views can be a challenge for any intermediary.

Another aspect related to intermediaries depicted by Stewart and Hyysalo [14] is related to the niche of a particular intermediary. While in the field of development and appropriation of new technologies, intermediaries may operate with a different focus. For example, if an intermediary operates solely on the design-side with a specific technology or product, the focus can be characterized as 'short and thing'. On the other hand, an intermediary who operates with a broad range of technologies or products with multiple actors (suppliers, end users, etc.) the focus can be characterized as 'long and fat'.

In the field of health care, formal intermediaries such as case managers [10] operate primarily on the provider-side, coordinating services on behalf of the actual beneficiary. What services are coordinated depends on the professional role of the intermediary, and on the prevailing health care system. For example, a case manager may operate solely on the field of mental health, and health service coverage varies from country to country [17]. This makes the reach of a formal intermediary a 'short' one, but the overall focus varies from 'thin' to 'fat' depending on the health care system.

Informal intermediaries, such as relatives who provide non-medical custodial care and assist the beneficiary in their everyday lives, often have a short reach as well. Reasons for this are often deeply embedded in the national legislation where managing affairs for someone else may be subject to legal or regulatory controls (cf. [18]). Another deeply embedded factor that effectively limits the reach of an intermediary is power imbalance present in the patient-physician relationship [19].

Even thought the relationship has changed (and it still is) from that of an age-old relationship between a priest and a supplicant, there are still barriers that prevent relationship from evolving into a more balanced one. Factors such as time, continuity of care, and even the facilities themselves still uphold the traditional (or paternalistic) patient-physician relationship [19]. In this kind of a setting, it is difficult to act as an intermediary with a 'long' reach. If the aim of the ongoing health care reform is to shift responsibilities related to care from physicians to patients, these barriers must be overcome; in mediation and otherwise.

4   Skills and capabilities

It follows from the formulation of the role that in terms of relevant skills and formal training, there are two specific areas that need to be discussed when the focus is on patient-side intermediaries in the field of electronic health care services; health care and technology. In terms of health care, the mediators should possess a degree of skills relevant to the domain. These include skills in medicine and pharmaceuticals, and in particular, competence in terms of medical jargon. As the role is associated with health related decision making, a mediator should also have social acumen.

This implies that a mediator should be able give advice and answer questions related to the patient's health, and to be able to operate in emotionally charged situations with discretion. However, as the sphere of health care is expanding to adjacent fields, such as fitness, complementary therapies, and recreation, the most suitable skill set and the degree of skills, ultimately depends on the needs of the mediated person. However, regardless of these needs, the literacy skills are less subject for diversity. Of these, health literacy and eHealth literacy skills are a primary

requisite for a mediator. In literature, these literacy skills have been defined in the following manner (example).

Health literacy

"The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." [20]

eHealth Literacy

"The use of emerging information and communications technology to improve or enable health and health care." [21]

"The ability to seek, find, understand and appraise health information from electronic sources and apply knowledge gained to addressing or solving a health problem." [22]

Looking into these definitions provides a composite view to the problems associated with today's health information resources, and electronic health services. These two are of little use if the patients do not possess the sufficient skill to utilize them, and to analyse their relevance, applicability and degree of quality. As such, literacy skills are coupled with the notion of capability, and competence in them can be seen as a requisite for health care paradigm change commonly referred as empowerment.

Regardless of its vague nature (cf. [23]), the term empowerment captures well one of the current development trends in the field of health care. The term encompasses the change in the patients who are not willing to act as passive 'objects' and resign themselves to the hands of health service providers, but want to act as active 'subjects' and take matters of health and well-being into their own hands. In terms of this welcome change, mediators should be seen as enablers for the patients who consider technology as a barrier preventing them from achieving their aspirations.

5 Technology and mediators

Technology has a dual role in relation to mediators; it is a part of the problem and solution as well. As a problem, technology creates a barrier between the patient, actual beneficiary, and modern health services, therefore creating a need for a mediator. As a solution, technology can be used by a mediator in fulfilling one's role. In the following, illustrative examples of this are provided.

Technology and understanding

In terms of mediation understanding health-related information and its impact on the patient, are amongst the most important aspects of the role. This, however, does not come easily considering the state of today's health records. Even though parts of the records are structured and encoded according to the domain standards (CDA, LOINC, SNOMED, etc.), portions of the health records are in the form of free-form narrative. These portions often contain essential information in relation to patient's health and care, and as such their use in mediation is a necessity.

The portions, however, are often riddled with a) domain-specific jargon, b) abbreviations used in the service provider unit or field of specialty (for example, noradrenaline can be abbreviated as NA, NAd or norad), and c) simple spelling mistakes (cf. [24], pp. 25-41). These factors alone have a negative impact on the quality of the free-form narratives. Another factor that needs attention in terms of

language and understanding are the cross-border health care (cf. EU Directive 2011/24/EU) and health tourism, which are both increasing the number of potential health service providers.

In order to support care acquisition (especially from a foreign country), mediators should be able to understand health records regardless of a) the language they are originally written, and b) quality of the original health records. In this, natural language processing and information extraction technologies could provide a partial answer in the form of proofing and automated translation tools. These can be used in analysing the original documentation as is already done to a degree in the case of Bulgarian diabetic patients [25].

Another field of technology, which could be of use for mediator and for the mediated patient, is decision support aids. Especially when combined with health-related information from electronic health records, and consumer-side personal health records, technologies such as decision support scripts and expert systems can help a mediator in formulation of a care plan, in performing a virtual health check, or simply in forming an opinion to be presented to the patient. Especially now when numerous health information resources, and big data of the health care domain, are coming into a wider use, expert systems can very well be the key technology for aggregating and summarizing information from the often diverse and disparate sources.

Security and privacy

In today's wired world, security and privacy are complicated issues. In order to use a specific application or service, it is possible that sensitive information must be accessed and distributed. When it comes to sensitivity, the most delicate issues are often associated with person's health, well-being or finance. In practice, this translates into person's medical record and payment history. Protecting this kind of information and enabling its safe use is not a simple matter. In addition to securing the information exchange and protecting health information sources there are other, primarily non-technical issues, such as consent and control that are of importance (cf. [26]).

Even though health and well-being are in the core of mediator's work, it does not automatically mean that a mediator should have open and all-inclusive access to patient's health, well-being or finance information. Some particulars of the information, such as current health status (such as, if the patient has diabetes), are often of the essence regardless of the mediator's sphere of operation. However, there are also certain particulars that are non-essential for mediation, or even harmful (for example, outdated medication lists or physiotherapy instructions). In order to ensure that mediators have access to the most relevant information, special attention should be put on information encapsulation (cf. [27], pp. 1329-1330; [6], p. 46).

In the context of this article, information encapsulation is an aggregate term which encompasses a subset of information management principles depicted by the Markle Foundation [17]. Of these principles a) openness and transparency, b) purpose specification, c) collection limitation and data minimization, d) use limitation, and e) individual participation and control are incorporated into the term as they effectively depict the alignment of information between the patient and the mediators. The first principle of openness and transparency [26] is all about awareness; the patients should be able to know what information is collected about them, purpose of its use, who can access it, and where the information resides.

The second principle, purpose specification [26] is more instance-specific as it addresses the issue why the information is collected in the first place, or on each occasion of change of purpose. As an associated principle, collection limitation and data minimization [26], defines boundaries to the previous principle as it depicts the

nature of information collection; information should be collected only for specific purposes and by lawful and fair means. Especially today, when unwarranted data collection by big technology companies is a common news topic, this principle has particular merit. In this, the principle of use limitation is in the same lines as it states that "personal information should not be disclosed, made available or otherwise used for purposes other than those specified" ([26], p. 4).

While the first principle of openness and transparency was about awareness, the last principle, individual participation and control, is about control. It defines [26] that the patients should be able to control access to their personal information, and review the used and stored information. Of the discussed principles, a subset of the ones presented by the Markle Foundation [26], the last principle outlines a very specific set of tools for mediation. With the control of access to the stored information, the patients are able to create specific aggregates, or subsets, of information for individual mediators to be used in their role.

It should be noticed that in particular the first and the last of the discussed principles contradict to a degree with the concept of mediation. As health related information is stored in multiform technological artefacts (such as EHRs), tools that are used for reviewing and limiting the use of information are often an integral part of the artefact. As these tools are technological by nature, they belong to the domain of a mediator. If a patient cannot operate these tools by oneself, without a mediator, how it is possible to maintain sensitivity in information encapsulation? In this, access definition and creation of information subsets on the level of existing aggregates (e.g. care record summary) or service providers (e.g. neurology polyclinic), could be of the essence.

6   How to enable mediation

Especially in the economic climate of today, enabling mediation is a challenge from the financial perspective. The public sector in most countries is struggling with the economic burden placed on them by increasing costs and decreasing income (e.g. tax revenue). It follows from this that it is difficult to justify costs of mediation, especially if they cumulate public health expenditure. Still, mediation as a function of home care is a viable option since some of the functions already overlap with mediation. For example, in the case of chronic heart failure, health promotion and teaching are often integral to the services provided at homes (cf., [28], pp. 1-2).

If the role of a mediator is seen as a 'job within a job' for a health care professional, such as a practical nurse, it creates a demand for advanced training in the field of health and technology literature in order to meet the demands of the role. As such, one way to understand the role and its alignment with the profession is to regard mediator as a specialist nurse in similar fashion to a critical care nurse or a school nurse. There are also specific fields of informatics in nursing which already incorporate elements of technology literacy, such as nursing informatics and telenursing. So basically, the role of a mediator has an established ground in the field of nursing.

However, with this approach the original characterization of a mediator as a patient-side intermediary becomes contested. If the role is enabled as a part of home care, funded by the state or the municipality, it essentially resides on a provider-side. One minor separating factor could emerge from the funding if mediation is enabled as a service provided by the private sector. As such a service, responsibilities of a mediator, and those of a professional working for a public health service provider, could remain separate (to a degree).

Another way to consider how mediation can be enabled is to regard mediator simply as a trusted person, a relative or acquaint. This is often the case with elderly persons who trust practicalities of their health-related endeavours into the hands of a spouse or a relative, and in the field of informal care where individuals providing assistance or care reside outside the framework of organized, paid and professional work. However, this interpretation is problematic as the informal mediator does not necessarily posses the required skills or capabilities. In this kind of a setting mediation does not necessarily base on domain expertise, but on anecdotal knowledge and second-hand experiences, as is often the case in layperson's health decision making (cf. [10]).

Possibility for a halfway solution emerges from multi-mediation; use of multiple mediators. Health-related endeavours that require a specific skill-set could be assigned to professional mediators, while endeavours which are less intensive in terms of skills and capabilities could be left to the relatives, spouses or other individuals working in the field of informal care. However, it should be stated that regardless of the composition of mediators, the self-determination of the patient should not be undermined.

When evaluating overall benefits, and even meaningfulness, of mediation, it should be understood that all benefits are not economic by nature. Instead of evaluating how much money has been saved in the form of reduced hospitalization, clinical outcomes and (other) quality indicators, such as quality of life, should be taken into account as well. Furthermore, indicators that are related to the efficiency and delegation of work are of interest in order to understand the effect of multi-mediation, which can be beneficial as well as disruptive. After all, there are no guarantees that the new ways automatically fare better than the traditional ones in terms of efficiency.

7   Conclusions

Health care, or more specifically health service provisioning, of tomorrow will differ fundamentally from that of today. Issues that have been part of the core values in the field, such as delegation of responsibilities between the doctor and the patient, are changing like never before. Electronic services are the harbinger of this change, which is not solely economic or societal by nature. As global economics are changing, so are the patients who, especially in developed countries, are 'wired from birth' as depicted by Brown ([29], p. 398).

Even though electronics services, and technology in general, can be regarded as belonging to the mainstream in most areas of business, there will always be individuals who are not able or willing to use them. Especially in the future, if electronic service gain similar foothold in health care, there is a risk that these kinds of individuals will fall into the 'fringe' of health services. In other words, they will not be in equal position when compared to other patients who possess a degree of technology (incl. health and eHealth) literacy skills.

In order to prevent this kind of development from occurring in the near-future, without negating benefits that can be gained from the use of technology in health service provisioning, we need intermediaries who act as representatives for those individuals who are at risk. These intermediaries, or domain-specifically mediators, are individuals who possess a specific set of skills that help them to operate in the crux of health, care, individual and technology.

Even today there are different intermediaries, such as patient advocates (cf. [30]), who operate in the field of health care on the service-provider side. The mediators, however, are individuals who operate on the patient-side, prioritizing the needs of the mediated patient before those of other actors (such as, health service providers or

insurance companies) in relation to electronic health care services. It is the three factors of a) patient (particularly interests of one), b) health and care, and c) technology that effectively set boundaries to mediation and to the role of a mediator.

   Even though 'traditional', face-to-face services are still an option and in most cases the preferred way of providing care and associated consultation, there is a strong trend towards electronic services. In order to ensure that the health care of tomorrow is sustainable, and patients are treated equally in terms of service provisioning, we need to examine a) what kind of intermediaries are needed, b) what kind of mediation is really a viable option, and c) how different actors are positioned in the electronic 'palette' that is the future of health care.

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