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Discussion

Helping patients help themselves: Supporting the healthcare journey

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ABSTRACT

Patients often feel lost when navigating the health care system, and poor care coordination leads to negative patient outcomes, consumes resources and makes diseases more difficult to treat. Patients and citizens have become eager to take health care decision making into their own hands. To this end, solutions have been proposed which assist patients by providing them with more information and enabling them to take a more active role in their care. These include enlisting a patient navigator, consumer engagement, process mapping, decision aids, and clinical pathways. However, as the global penetration of mobile devices approaches 100%, it is timely to update and optimize health system support technologies and information dissemination pathways. There is much room for improvement and health systems are beginning to echo other industries in asking "what do consumers want?" in their applications. We believe that now is the time to address emergent gaps and supplement the irreplaceable human elements of patient navigation with a mobile or computer application. It would be able to automate parts of the process, and consolidate important information, to serve as a broad-reaching, real-time companion for healthcare consumers and their families to accompany them on their journey from diagnosis to follow up.

1. The problem

Patients describe navigating health systems as "complex", "frustrating" and "isolating" [1], and this can apply especially to those facing multiple access barriers [2]. When there is no one to oversee a patient's entire journey [3] coordinating and navigating their experience can become complex and arduous. Poor care coordination leads to negative patient outcomes and makes diseases difficult to treat by delaying vital steps [4]. It also affects service quality and can increase overutilization and test duplication. Those most often affected, the elderly and sufferers of chronic conditions, are only growing in number [1]. Those who do not speak the native language and/or are from a minority group are similarly disadvantaged [5]. There is now a global push for patient centered care, promoting a patient's active participation and decision making. It is therefore crucial to address the patient's journey to empower them and benefit the health system by achieving more efficient and effective use.

2. The patient revolution

Patients and citizens are becoming eager to make autonomous decisions and help ensure that they receive personalized, high quality care. Instead of relying solely on providers, patients also utilize advice from others who have been in similar circumstances through various platforms [6,7]. The British Medical Journal called this a "fundamental shift in the power structure in healthcare" and a "patient revolution" [8]. Providers and the system benefit from patients who are engaged in their own care, as they obtain more positive clinical outcomes, enact more adaptive behaviours and acquire new skills to effectively manage their condition. Patient engagement also improves both care quality and patient safety [9]. Thus, effort has been invested in developing and promoting solutions based on shared decision making and patient

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empowerment, providing individuals with information and enabling them to take a more active role in their care.

Consumer engagement, for example, involves groups that are interested in or affected by a particular issue [10]. It provides insight into consumer perspectives and influences recommendations and priority setting on the care providers' and policymakers' end [11,12]. Its effectiveness has been proven across time and participant groups [13,14]. Successful approaches can support medication self-monitoring and management [15], thus, providers have been encouraged to involve patients in their own care [16].

Process mapping is another approach, separating the patient's journey into a series of steps comprising the process of care [3], revealing and eliminating ineffective and unnecessary care. Commonly, this method includes interviews with patients and care providers, and/or observing the patient's journey directly. The result is a "process map", utilized to plan changes and aligning the focus of care with patient values and preferences [17]. Most process maps are provided to the clinical team or hospital/institution administration, but can be offered to patients to inform them of future steps, and to monitor that proper steps are taken [18].

Another patient support tool is the patient navigator; a nurse, outreach worker, or other professional responsible managing a patient's experience with the health system [2]. Navigators commonly deal with cost, transportation, managing a patient's feelings, and other factors [18]. Navigation can curtail spending by ensuring that resources are not spent on later stages of a disease [4]. These services can improve communication, response speed and resource utilization, thus improving the quality, continuity and efficiency of care [19]. They can also improve treatment adherence, screening rates and uptake, and diagnostic resolution likelihood [2].

Decision aids also provide users with information about their options and outcomes. They can take many forms, but share common aims: to employ evidence-based decision making which incorporates personal values and preferences and encourages autonomy [20]. Patients using decision aids have more knowledge regarding screening and treatment, feel more informed about their options and certain of their priorities. They have more realistic expectations, communicate more with their practitioner and have higher participation rates in decision making [20].

Although these initiatives take different approaches, the ultimate goal is the same: helping patients navigate their care journey and improving patient and system outcomes. Moving forward, it would be most effective to amalgamate elements from the aforementioned tools and deliver them via a contemporary platform for both patients and caregivers.

3. Bringing technology into the equation

As the penetration of mobile devices **becomes more universal**, it is timely to update and optimize health systems decision support technologies and information dissemination pathways [21]. There is a divide between healthcare and industries such as banking and retail, who have become skilled at creating a user-friendly experience [27]. Employing text messages has already increased treatment adherence, and appointment attendance and decrease missed medication doses and treatment interruptions [21,22]. A recent systematic review showed positive effects using mobile-phone based technologies in low and middle income countries [23]. Smart devices too have shown promise with smoking cessation, depression [24], stroke [25], weight loss and management [26], diabetes, and in preventing and managing sexually transmitted infections [22].

Still, **the effectiveness of health applications remains unclear** [27,28] leaving room for improvement. Some technology-based interventions show no difference to patients, and a few even show harm [29]. There has been some work attempting to determine what patients want from their patient support applications. For example, US mHealth Report [30] found that the expectation from consumers was to supplement traditional care in mostly an administrative capacity. Remote monitoring devices, access to test results and patient records and emergency alerts were among the top preferred features. Fengler, Estupinan and Chan [31] conducted a survey with similar results indicating a preference for basic, administrative features such as out-of-pocket cost estimators and payment portals, access to health records and follow-up notifications as well as appointment scheduling as most preferred features.

There has also been some research to determine what health applications offer to patients and what needs they meet. Mosa [32] states that the few applications for patient use fall into one or several categories including drug reference, medical calculators, clinical communication and consultation, and applications focusing on disease management for those with chronic conditions. Price Waterhouse Coopers, the China division [33] has found that healthcare applications broadly fit into one of six categories: concierge services for appointments and payment, assessment and diagnosis for remote medical assessment, educational information, e-commerce for drug sales, medical information sharing and chronic disease management. Many independent applications exist, run by start-ups, hospitals, health insurance companies and universities, which utilize smartphone technology to aid in some aspects of patient journey navigation and facilitating shared decision making. Grander initiatives, such as the National Health Service in Britain and Choosing Wisely Canada, have begun to disseminate their findings and recommendations using mobile platforms as well [34,35].

4. Currently available options

Healthcare applications with the aforementioned features, as well as many others, crowd the marketplace, however, they do not meet expectations. A recent systematic review found a significant positive correlation between the usability of technology-based platforms and patient engagement [28]. However, Sarkar [36] found that a diverse sample of participants could only complete 43% of tasks on their healthcare apps without assistance; participants experienced frustration with application design features and navigation, and felt that the technology did not sufficiently support self-management.

Our impression of the literature is that there are several areas in which patients need support. The first is logistics: the patient experience is a continuous journey, not a series of episodic encounters, thus, patients should be provided with adequate support. Appointment scheduling, medication reminders, knowing wait times and physician profiles, and information consolidation are simple yet effective tools to facilitate a smooth experience. The second area is clinical; patients should feel like they are informed about their options at each crossroad. Decisions aids, guidelines, and pathways generated by clinical experts and informed by other users are examples of tools that would reinforce this aspect. A third area is patient experience; patients want to hear from individuals who have had the same diagnoses about the entirety of their experience. Improving these areas would positively affect the perceived quality of delivered services as well as patient cooperation, helping individuals understand and adhere to their treatment plans.

5. Filling the gaps

Scholars have noted the relative dearth of literature concerning the relationship between technology-based platforms and patient engagement due to the novelty of the field [9,37]. One systematic

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