TITLE: DESIGNING A DIGITAL HEALTH ADVISOR FOR PATIENTS WITH COMPLEX NEEDS

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Introduction

Twenty years ago, Peter Szolovits and colleagues proposed a digital "Guardian Angel" built on the notion that information systems designers might shift focus from serving health institutions to empowering the individual patient [1]. The Guardian Angel (or 'digital health advisor') would collect individual patient data, monitor health conditions, interpret health information for patients, help customize treatment plans, share information with the care team, and provide reminders and alerts about medications and appointments. With recent technological advances, the capacity to achieve a digital health advisor is now within reach, but it has yet to emerge. One barrier to the development of a digital health advisor might be the lack of a clear set of requirements to inform its design. Though there are a range of tools that perform some related functions, and a few studies that cover some needs, they have not been presented in a way that is actionable for developers [2]. The Commonwealth Fund is a foundation focused on improving access to health care, particularly for the most vulnerable groups. It recently launched an initiative on the IT enabled consumer, to bring the patient’s voice into the design of the health care delivery system. One of the first projects was to apply user-centered design to understand the requirements of high-need, high-cost (HNHC) patients and their caregivers; determine how these needs might be met through digital health tools; and communicate this to the stakeholders who can create and distribute these tools. This paper describes the use of persona development, key use cases for high need, high cost patients and an illustrative prototype to promote the creation of a digital health advisor for the people who could derive the most benefit.

Solutions to Improve the Care of High Need, High Cost Patients

Information and communication technologies (ICTs) have transformed many industries, often by reconfiguring services around the needs of consumers. But health care has lagged behind. Many of the current consumer-facing applications target people who are relatively healthy [3]. There has been less
focus on the 5% of the population who account for nearly 50% of all system costs in the US [4]. These HNHC individuals often have multiple chronic conditions, are more likely to be lower income, and face housing and food insecurity [5-8]. They are poorly served by a health system built around diseases and institutions that often results in fragmented and competing care [9,10]. Patients with multiple chronic conditions have to engage in a variety of activities to improve their health, [11, 12] and digital technologies may be able to assist. HNHC patients include many seniors, a group that is increasingly adopting technology, with 76% using cell phones, and 64% using computers, while 43% use the internet and 40% email and texting [13]. They are already engaging with some of these new approaches in healthcare: 16% of seniors search the internet to obtain health information, 8% to fill prescriptions, 7% to contact physicians and 5% to handle insurance matters [13]. However, while there are over 165,000 health apps currently available, a 2016 review found most available digital tools for chronic disease are piecemeal, have limited functionality, and do not address the needs of patients with complex chronic conditions [3, 14]. Furthermore, a review of evaluations of apps for conditions associated with higher needs found that most studies were small and few assessed process or outcome measures [15]. Another review compiled proposed functions from different studies, and highlighted that tools should be developed with user needs in mind [2].

**Human-centred Design to Understand and Communicate User Needs**

Human-centred design (HCD) has been used to develop many transformative ICT solutions, it is routine in a range of industries, and is now starting to be applied to health care [9, 16-25]. HCD is a problem-focused method that emerged from the fields of industrial design and (more recently) software development [26-28]. Strengths of design thinking include rapidly developing a deep understanding of user needs and then communicating them in ways that are emotionally engaging and actionable. This approach often involves interviews, observation, and immersion in a user’s context to develop user personas or archetypes, and
use cases [20, 25]. A persona is a detailed description of a fictional person (often a composite of real individuals) that is used to represent a user group and helps identify their key motivations, concerns, and interests [9, 24, 25]. Related to the persona is a use case or user story, which is a story with a plot describing the actions and decisions of a user in a particular context [24, 25]. These representations can help designers foster empathy, better understand user needs, and develop new service options and tools [24]. Personas have been used to design a digital peer support service for childhood cancer survivors, [29] and developed for older adults with heart failure, [30] but not for the design of comprehensive solutions for frail elderly or patients with multiple chronic conditions and their caregivers.

Designing a Prototype for a Digital Health Advisor

The Commonwealth Fund was interested in developing a vision of a digital health advisor that could meet the needs of HNHC patients, and using this to encourage its development in the healthcare marketplace by developers, entrepreneurs, investors, health system providers, funders, and regulators. The Fund worked with the design firm gravitytank to identify the needs of HNHC patients and their caregivers and create a low-fidelity prototype, which simulates key features of interest to this group without building out any of the functions [31, 32]. This involved interviews with experts, 8 patient-caregiver pairs of people with multiple chronic conditions or frail elderly, and mapping the workflow of 3 care managers with similar patients [31, 32]. Based on analysis of this data, a rough prototype of a digital health advisor was created and shared with patients and caregivers so they could provide feedback on the usability and functionality of the tool. This informed different outputs to make the insights more actionable. First, the needs of patients with multiple chronic conditions and the frail elderly, as well as their caregivers, were characterized, focusing on the intersection of functional and emotional needs with medical and personal needs (see Figure 1). Patients felt that a tool that addressed functional needs could improve health outcomes, but if a tool addressed emotional needs they would be more likely to use it on an ongoing
basis. Next, a set of 4 patient personas and 2 caregiver personas were developed (see Table 1), along with 4 use cases (see Figure 2 for an example). Lastly, a low-fidelity prototype of a digital health advisor was developed with a number of key features (see Table 2) [33].

Figure 1: Characterizing the Needs of High Need, High Cost Patients
### Table 1. Overview of patient and caregiver personas

<table>
<thead>
<tr>
<th>Patient Personas</th>
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<tbody>
<tr>
<td>&quot;John&quot;, an 87-year-old frail elderly man dealing with arthritis, hypertension and mild cognitive impairment</td>
<td>• He needs a mechanism to reach out to with loved ones when he needs help, manage medical appointments, and prompts about key medical information</td>
</tr>
<tr>
<td>&quot;Elizabeth&quot;, a 70-year-old elderly patient with multiple chronic conditions</td>
<td>• She needs help managing her medications, tracking her health status, and learning about activities to improve her health</td>
</tr>
<tr>
<td>&quot;Karen&quot;, a 65-year-old patient with multiple chronic conditions</td>
<td>• She needs help coordinating her care with her providers, managing her symptoms, and accessing relevant health and social services</td>
</tr>
<tr>
<td>&quot;Jasmine&quot;, a 44-year-old patient with a major chronic condition</td>
<td>• She needs help communicating with her family about her health, managing symptoms, and learning about new treatments</td>
</tr>
</tbody>
</table>

<table>
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<tr>
<th>Caregiver Personas</th>
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<tbody>
<tr>
<td>&quot;Beth&quot;, a 79-year-old caregiving spouse</td>
<td>• She needs help managing her spouse’s medications and appointments, and connecting with medical and community resources</td>
</tr>
<tr>
<td>&quot;Lisa&quot;, a 45-year-old caregiver for her elderly mother</td>
<td>• She needs help coordinating her mother’s care, remotely monitoring her health status, and communicating with family members regarding her mother’s health</td>
</tr>
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### Figure 1: Sample Use Case for Digital Health Advisor

**Caption:** John is an 87-year old man living in San Mateo, California with hypertension, arthritis and mild cognitive impairment. He has been feeling more tired, anxious and clumsy recently. He lives with his wife, who is his primary caregiver along with support from his daughter. He has an upcoming appointment with a geriatrician and he’s concerned whether this new doctor will understand what his needs are. He would like to update his doctors, and highlight his activities and goals to share a more holistic picture of his life with the care team. He also wants to manage his doctor’s appointments and keep track of what his doctor tells him.
Table 2: Key features of a digital health advisor for HNHC patients and their caregivers

<table>
<thead>
<tr>
<th>Feature</th>
<th>Description</th>
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<tr>
<td><strong>Tracking and insights:</strong></td>
<td>- A metrics dashboard that collects health data from sensors and connected devices, such as blood pressure, oxygen levels, and gait, or receive manual input on symptoms to track patterns over time and provide recommendations to patients and inform the care team of changes in health status.</td>
</tr>
<tr>
<td><strong>Advice and information:</strong></td>
<td>- Personalized advice on health-related questions either through integration with a digital assistant, or by connecting to a medical practitioner by text, voice or video, drawing on information from medical records, personal metrics, and available community resources.</td>
</tr>
<tr>
<td><strong>Holistic picture:</strong></td>
<td>- A care journal and patient profile where patients can provide a brief image, a written summary of their story, a set of goals and milestones they want to track, and a checklist of care preferences to help create a comprehensive picture of their life to share with practitioners and foster deeper connections with their medical team.</td>
</tr>
<tr>
<td><strong>Coordination and communication:</strong></td>
<td>- A shared calendar with all appointments, a document centre, and a task manager to improve coordination and communication between patients and their care team, including help with scheduling and transportation.</td>
</tr>
</tbody>
</table>

**Using personas as a tool for stakeholder engagement**

The personas and prototypes of the digital health advisor were presented to a group of policymakers, regulators, clinicians, experts in informatics, advertising, and health services, as well as patient advocates, technology industry executives, and health system leaders. They felt that most components are technically feasible using current technology, though further development is needed in decision support. Health care delivery organizations were felt to be critical to the development of a digital health advisor, but it would also need to foster support in target communities, including patients, caregivers, families and their social networks. They stated that extensive collaboration is needed to develop a robust DHA, which should be an integrated suite of tools. They also highlighted that novel analytics are not sufficient; data must be made available in a usable format, and the necessary data for real-time decision-making (e.g. cost, quality and availability of services) is currently held by many different groups in different formats. They suggested a useful DHA is more likely to emerge in response to partnerships with organizations focused on consumer needs, such as consumer advocacy groups, and large retail companies. The business case and policy
incentives need to be developed to encourage broad data sharing among community, government and commercial initiatives.

Discussion

The concept of a comprehensive digital health advisor for patients, which was proposed over 20 years ago, is now technically feasible, and attractive to high-need, high cost patients in the United States. The patients highlight a range of functional, emotional, medical and personal needs that might be addressed by this tool. They also list a series of key functions such as tracking, advice, providing a holistic picture of themselves, as well as coordination and communication. The use of human-centered design helps understand these patients and the challenges they face managing their health in general as well as engaging with health and other services. It helps overcome the limitation that new designs in health care are often dreamt up by providers to be easy to implement but not necessarily use, by people who rarely use health services, and don’t resemble the people they are trying to help. Personas can promote stakeholder engagement by providing detailed information on patient needs and how a tool might address those needs, making it easier to understand key functions, possible interactions with the health system, data requirements, and potential regulatory concerns.

While some studies have employed human-centered design to develop tools for patients with multiple chronic conditions [34, 35] this approach tends to be applied to specific populations (e.g., people with diabetes) [24, 36, 37] or specific uses (e.g., communication or monitoring) [38, 39]. Our work supplements the findings of a recent review of mobile technologies for older adults, which summarized the following design features from different articles: graphs, notification systems, text and video messaging, scheduling, vision, hearing and memory aids. Even though there are many digital health tools on the market, few comprehensively address the needs of HNHC patients, and even those tend to focus on medically defined needs rather than act as general advisors. To go from an understanding of needs to a functioning tool that
meets those needs in the context of someone's life is a stretch, and it involves testing different use cases, functions and target groups before finding a good fit. The HCD approach involving persona development and rapid testing can manage this uncertainty and shorten the development and dissemination of a digital health tool by making the problems and options more tangible for stakeholders. It also helps anticipate and mitigate implementation challenges with minimal cost.

The learnings from this project about current HNHC patients could be applied to vulnerable populations that are at risk of becoming HNHC patients (another target group for the Commonwealth Fund), and even the general public. We found the highest users of the health system are interested in tools that can help them manage their health challenges, but even more in helping them live their lives to the fullest. This is likely to be true of all patients, who do not only value disease management, but also see health as a means to identify and work towards their life goals. An individual's health is intertwined with their psychological, social, and economic context, and truly useful digital tools will help people manage their needs in a comprehensive and integrated way rather than focus on a disease or issue in isolation. This has not been a major goal for health systems or a major focus of quality improvement efforts; however, it could be supported by consumer-facing tools that engage and empower individuals.

CONCLUSION

Surfacing the needs of target users is essential to designing a comprehensive digital health advisor, but to realize this vision we need to address broader system and policy constraints that will impact its development. User-centered design can help draw attention to something that is technically feasible, but has no business model, and may not be compatible with many current regulations. It helps reframe problems and suggest solutions that may be independent of existing services or processes. In the area of models of care for HNHC patients, the Commonwealth Fund has commissioned rigorous evaluations of
new models, synthesized evidence from the scientific literature, and created a playbook for health systems to help implement promising models and improve care for this group. We have also started using design thinking as a tool to generate a pipeline of new options that might constitute a breakthrough. We move this future oriented work forward through our role as a convenor and advocate for improving access to care. For the IT enabled consumer, the next steps include exploring the type of collaboration needed between stakeholders such as health care delivery organizations, patients, caregivers, technology companies, government, and consumer advocacy groups. We also need to examine the incentives and business models needed to attract entrepreneurs and developers to work in this area and for health systems to engage with consumer facing IT tools. System change is unlikely to come from those who already run it, so the Commonwealth Fund is working to address the policy and regulatory, business model, and cultural barriers to creating tools that put patients and their goals at the center of the health system.
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COMPETING INTERESTS

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Figure 1. Example of a persona use case (John) for the digital health advisor

Figure 2. Themes categorizing the needs of people with multiple chronic conditions, the frail elderly, and their caregivers