
Exploring Opportunities for Social Infrastructure in Congestive Heart Failure Management

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Abstract

As population ages and chronic disease increases, new models of health care delivery are inevitable. We propose to interweave the concept of chronic care management into social infrastructure to better support elderly individuals with chronic diseases. As an exemplar, we chose and investigated Congestive Heart Failure (CHF), since it is one of serious health threats among the elderly population in western society. From a preliminary investigation of literature and prior work, we suggest two implications for social care of chronic patients: increased social awareness, and social knowledge base. This is not an exhaustive list of implications, but a starting point to open up discussions towards social care for chronic diseases.

Author Keywords

Congestive heart failure, Chronic disease, Healthcare technology, Self-care, Social care

ACM Classification Keywords

H.5.m [Information interfaces and presentation (e.g., HCI)]: Miscellaneous.

General Terms

Healthcare

Introduction

As the proportion of people who are older grows and chronic disease increases, new models of healthcare delivery are inevitable. In this paper, we propose to interweave chronic care management into social infrastructure to better support elderly individuals with chronic disease.

Congestive Heart Failure (or CHF) is a leading cause of death in people older than 65 in the United States [10] (see Figure 1). An estimated 5.1 million Americans suffer from CHF, and over 550,000 new cases are diagnosed every year [6]. Characterized by an inability of the heart to pump enough blood to the rest of body, not only can CHF be a significant detriment to participants' quality of life, it also poses a tremendous cost to society, which includes the cost of health care services, medications to treat it, and missed days of work.

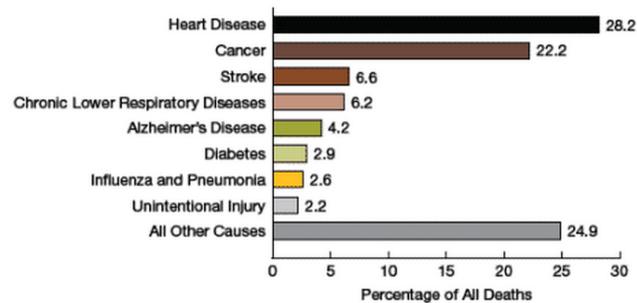


Figure 1: Causes of death among U.S. adults aged 65 years or older, 2007¹

The current practices of CHF management are primarily intended for personalized treatments and individualized

¹Source: CDC, National Center for Health Statistics, National Vital Statistics System, 2007

regimens, which combine personal medications, lifestyle and dietary change, and exercise into an integrated care plan. While these approaches are indeed critical and appropriate, we suggest a new perspective of deeming chronic diseases prevalent among older adults, like CHF, as *societal issues* to be reflected in social infrastructure for holistic care. Rethinking chronic care within social context will provide insights into how to leverage the unique capabilities of group efforts in effectively managing chronic diseases.

In this paper, we examine the landscape of current CHF management practices, aiming to open up discussions for implications towards social healthcare infrastructure for CHF.

What is Congestive heart failure?

Congestive Heart Failure is the inability of the heart to properly eject blood out of the ventricles, causing fluids to pool in areas such as the hands and feet as well as the lungs and liver. Two of the leading causes are muscle and valve failures, which typically present in aging populations. As our population matures, the incidence of CHF will increase, especially in populations with easily ignored, unmanaged or undiagnosed precursors, such as hypertension, diabetes, obesity, and smoking.

CHF is a spectrum disorder, whose symptoms range widely from mild ones, such as shortness of breath and fatigue, weight gain and swelling, to severe conditions, including chest pain, fainting, and heart attack. Because it is manageable but not curable, the treatment requires a continuous monitoring of the condition on a daily basis. A significant challenge that patients with CHF encounter is that it is critical but difficult to self-monitor due to its complicity in monitoring and lacking equipment.

Lastly, hospital readmission rate of CHF is high, putting excessive financial burden for healthcare: over 20% of Medicare beneficiaries were readmitted within 30 days after hospitalization for the same CHF condition in 2012 [7]. To reduce the readmission rate, the Affordable Care Act started regulations to penalize hospitals which readmission rate exceeds the annual average [3]. In 2012, Medicare levied \$227 Million in fines to 2,225 hospitals [13]. The combination of an increasing prevalence of CHF and high readmission rate presents a strong case for additional investigation beyond patients and hospitals.

The current practices in CHF management

We investigated the current practices of CHF management from two perspectives: 1) patients' self-care practices, and 2) technology interventions for remote monitoring.

Patients' self-care practices

As CHF is a chronic illness that requires continuous monitoring on a daily basis, effective CHF self-care is critical. Self-care on behalf of the patient entails verbalization and self-monitoring of goals, objectives, and behaviors. Self-care is typically performed at the patient's home, without the assistance of monitoring technologies.

Despite its importance, however, self-care among patients with CHF is commonly poor. In an effort to understand why self-care fails so often, studies have investigated how patients performed self-care (e.g., [1, 11, 9, 18]). One is Riegel & Carlson's work that identified personal traits, physical and emotional condition, health literacy, and prior experience as major barriers to CHF self-care [14]. Heo et al. investigated combined impacts of psychosocial status, knowledge, and physical factors on self-care in patients with CHF [8].

While findings were different in each work, the common

theme across was a salient influence of *personal knowledge and experience* on CHF self-care. This personal knowledge and experience is an incremental value that a person gains over time through trial and error in practice. In this sense, there is an opportunity for social infrastructure that would help people to easily archive, systematically conceptualize, and effectively distribute practical knowledge regarding personal CHF management experiences as a social capital.

Remote monitoring technology

Remote monitoring allows clinicians to remotely diagnose a patient's condition and intervene promptly in the case of signs of deteriorating health. CHF is a disease that requires continuous monitoring of symptoms and conditions for the rest of the patient's life. This is why in-home remote monitoring technology is crucial, and has been a primary research focus (e.g., [2, 17, 16, 15]). Several studies demonstrated that effective remote-monitoring systems could significantly enhance the quality of life of patients with chronic heart failure [12].

Despite its potential, however, a handful of studies have shown that remote monitoring often does not contribute to the improvement of CHF care in practice (e.g., [4]). This might be because the problem does not necessarily exist solely within the effectiveness of a technology. While a technology can serve as a useful resource, issues beyond the technology that influence technology adoption and use practices also need to be taken into consideration. Particularly, we deem factors that comprise of a society to be important issues, namely general practices, social knowledge, community services, social norms, public policy, and other environmental aspects.

Discussion: Implications for Social Infrastructure in CHF management

Thus far, we explored the landscape of CHF from literature and prior work in a preliminary manner. The focal issues included the definition of CHF, its symptoms, and treatment practices from personal self-care and technology perspectives. While the study was preliminary, the investigation still shed light on valuable implications that reframing social infrastructure might help better cope with chronic health care, providing us a starting point to open up discussions towards social care for CHF. We refer to *social infrastructure* as a subset of the infrastructure that accommodates the direct provision of social services as well as any systems to enable the provision of social services to community members.

Increased social awareness

The first step in concretizing social care for chronic diseases is to foster a social consensus: the management of chronic diseases prevalent in the elderly populations can be much more effective when approached from a social structure rather than as an individual responsibility. This will yield (or require) not just a change in individuals' perspectives on chronic health care, but reformation of many components that comprise a society, such as the social determinants of health and enhanced community participation, social norms, public policies, and so forth. Studies have examined various types of social supports, including marital status, family relationships, and social networks, emotional support (e.g., [8, 5]). And, they showed that social support has great potential to reduce symptoms and improve health-related quality of life.

Moreover, chronic disease is not only a costly and common health problem, it is also the most preventable; many conditions are caused or exacerbated by behavioral

risk factors and unhealthy lifestyle choices that can be modified. Thus, we need to work together to address challenges such as misinformation and misconception, and harness the potential of community.

It can be through helping people and communities discover and develop their own skills, capacity, and interests, and on connecting them with the resources they need to achieve their goals. It can be through either offline activities within a community or online advocacy campaigns. It can be part of formal school education or through reshaping practices in everyday life. Then, social awareness will burgeon in the process or as a result of working together, which will empower patients to actively seek proper information for healthy behavior. Concrete solutions to increasing social awareness have yet to be explored, but we argue that a deeper contemplation and active discussion will help expedite advancement in social chronic care.

Social knowledge base

From our literature review, we found a salient influence of *personal knowledge and experience* on CHF self-care. People gain such knowledge over time through trial and error in practice. Thus, our findings suggest an opportunity for social infrastructure that would support people to easily archive, systematically conceptualize, and effectively distribute practical knowledge regarding personal CHF management experiences as a social capital.

A knowledge base should allow for a free flow of information so that members can quickly retrieve experiences and feel like a part of the larger CHF community. There are online communities to support information exchange among patients with similar health

concerns, such as PatientsLikeMe² or CureTogether³. Extending the idea, we envision a future system that can advance the practice of generating and sharing personal knowledge of chronic care within a community and further a society.

One thing to keep in mind though is that knowledge sharing might not come in the form of traditional computer interfaces. Mature populations may have limited physical capabilities (e.g., eyesight, eye/hand coordination, etc.) or less experiences in using computing devices or convoluted user interfaces. Moreover, mobile technologies may not be effective computing environments for hospitalized elderly populations and may not be a good fit for populations that need continuous monitoring and social engagement. Deeper exploration about innovative ways to effectively capture and easily share knowledge is needed.

In closing

We started this paper with a premise that chronic diseases prevalent in older population are not just a health issue that individual patients need to care for, but a problem that our society is responsible for effective care and management. The journey for chronic disease managements may be deeply personal, but its process can be greatly facilitated by the support from other individuals, community, and a society.

We envision social care for chronic conditions as a broader framework of chronic care service delivery, which should contribute to not just proper health care services, but also improved accessibility to information, more timely interventions, easy sharing of personal experience, increase

in prevention, greater flexibility in service provision, a broader range of service providers from whom they can choose their care, and care closer to home with minimal disruption to their daily lives. To achieve this, it is required to review and fundamentally redesign the process of care for those with long-term conditions. It will be a systems-wide perspective which includes a wide range of social, cultural, and economic factors that might impinge on the quality and quantity of care.

From our preliminary investigation, we proposed two potential implications that social infrastructure might incorporate for effective social chronic care: increased social awareness, and social knowledge base. Of course, this is not an exhaustive list of implications. Using this paper as a starting point, we hope to open up discussions to extend our views towards social CHF care, such as reframing the conceptual framework and exploring design solutions of chronic diseases.

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