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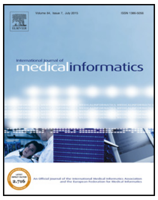

Good or bad, ups and downs, and getting better: Use of personal health data for temporal reflection in chronic illness

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ABSTRACT

Background: Time is a central component of the experience of illness. Yet, little is known about how chronically ill patients and their family members use temporal information (i.e., information that is dependent on some measurement of time) to reflect upon the illness experience.
Objectives: The purpose of this study is to explore what temporal information chronically ill patients and their family members need, where they obtain it, and how they use it, along with related temporal reasoning processes and challenges.
Methods: A series of five qualitative, semi-structured interviews were conducted during a two-year longitudinal study of 38 families (97 individuals) with at least one chronically ill member (HIV/AIDS or type 2 diabetes).
Results: Patients and family members had temporal information needs related to identifying: patient status; trends; optimal timing, optimal frequency, cause and effect; and what to expect. They used a wide range of information sources to meet these needs, including clinical test results, at-home health monitoring technologies, patient physical appearance and physical sensations, and information about other patients' experiences. Participants employed several forms of reasoning to reflect on temporal information: criteria reasoning (i.e., comparison to a standard), comparative reasoning (both to oneself in the past and to other people), cause-to-effects, effects-to-cause reasoning, conditional reasoning (i.e., if-then reasoning), and deductive reasoning. They used temporal information to carry out instrumental illness management, and to meet emotional and social needs. Patients and families confronted challenges in selecting relevant data, recognizing patterns in those data, and in drawing conclusions based on inferred patterns.
Conclusions: Patients have six main temporal information needs, and they use a variety of information sources and reasoning strategies to meet these needs. They also confront important challenges in using temporal information. Based on our results, we offer design principles for systems that support patient and family member temporal reflection. We recommend that such technologies: (1) minimize user burden; (2) leverage existing dissemination channels; (3) include both clinical and non-clinical information; (4) meet informational, emotional and social needs; and (5) facilitate collaborative sense-making among patients and family.

1. Introduction

Time is a central concern for chronically ill people and their family caregivers [1]. Time is significant both in instrumental illness management (i.e., "illness work," or daily activities to mitigate physical disease effects [2]) and in illness experience (i.e., the psychosocial effects of living with a disease [3]). However, patients' and families' unique time-based information needs are largely unaddressed in current health informatics applications and research. We posit that a nuanced understanding of time-related personal health data usage can illuminate opportunities for information technology design that is beneficial to chronically ill people and their family members.

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1.1. Related work

Although chronic illness experiences are often considered at the level of the individual patient, they are commonly shared with family members. Family members' support takes various forms, ranging from instrumental illness management [4], to information-seeking activities [5], to helping patients interpret the greater meaning of the illness in context of family life [6]. Family members play such an integral role in a patient's experience that their behaviors and attitudes are associated with patients' chronic illness outcomes [7]. Thus, time-based information behavior is important to understand in the context of a family group. Therefore, we consider both patients and their family members when investigating time-based information needs and uses in context of chronic illness.

1.1.1. Time and illness experience

Medical sociologists have long studied the temporal aspects of illness experience [8]. Researchers have developed a phase-based chronic "illness trajectory" model that considers temporal dynamics such as disease progression and prognosis, the rhythms of experienced symptoms, and shifts between active illness and remission [9]. This research indicates that as patients live with their illness, they accept and settle into a flow of "good" days (few or no illness symptoms) or "bad" (symptomatic) days, and develop ideas about causal relationships between their behavior and their symptoms [1]. Altogether, this research suggests that patients make sense of their illness experience by reflecting upon temporal patterns related to their illness. Additionally, sociological research emphasizes the temporal experience of "biographical disruption" experienced by chronically ill people, whereby taken-for-granted features of one's life and future are fundamentally disrupted [10]. The sociological concept of "narrative reconstruction" further highlights the active efforts of chronically ill people to account for their changing life stories and the place of illness within those stories [11]. Although this previous research has identified the central role that temporality plays in the personal biographies of chronically ill people, there is a dearth of research on how time-based information contributes to such meaning making. Furthermore, while a range of existing technological systems (e.g., calendaring applications, personal health records, etc. [12]) assist with temporal aspects of illness-related self-care, they serve primarily to support instrumental illness management rather than the broader illness experience.

1.1.2. Reasoning with time-based information

An important aspect of temporal information use concerns what conclusions patients and family members draw about temporal patterns, and how they arrive at them. Yet little is known about the reasoning processes patients and families use as they interact with time-based information. A limited body of research has shown that patients engage in "temporal comparison" regarding their own experiences (e.g., comparison of an individual on some criteria at two or more points in time [13]), but research has yet to directly connect this comparison process to the information needed and used during such reasoning. Furthermore, while research on patients' time-based information needs is lacking, researchers have actively examined *healthcare professionals*' related needs, and designed and built clinical informatics tools that support clinicians' temporal reasoning [e.g., [14–16]]. The applicability of this work to the contexts of patients and families is unknown, though some research shows that clinicians try to solve problems with temporal information whereas patients use it to interpret illness experiences [17]. Therefore, we consider patients' and families' unique temporal information needs with the objective of offering patient-specific design recommendations.

Table 1
Characteristics of Participants.

	Total Study Participants
Family Groups	N = 38
Diagnosis of patient	
Type 2 Diabetes	20 (52.6%)
HIV/AIDS	18 (47.4%)
Access to Technology	
Internet access (home/mobile)	32 (84.2%)
Individuals	N = 97
Age (in years) (mean (s.d.))	53.31 (13.2)
Sex	
Female	54 (55.7%)
Male	43 (44.3%)
Race/Ethnicity	
White/European American	61 (62.9%)
Black/African American	29 (29.9%)
Hispanic/Latino	4 (4.1%)
Asian or Native American	3 (3.1%)
Role	
Patient	39 (40.2%)
Caregiver Family Member	58 (59.8%)
Education ($n = 95$)	
High School or less	21 (21.6%)
Some college	30 (30.9%)
College degree	44 (45.4%)
Employment	
Employed (full or part time)	36 (37.1%)
Unemployed	30 (30.9%)
Retired/Disability	26 (26.8%)
Student (full or part-time)	5 (5.2%)
Health-Related Occupation	6 (6.2%)

1.2. Current study

To address the aforementioned research gaps, we examine the following research questions:

1.) What are the time-based information needs of chronic illness patients and their families?
2.) How do patients and their families meet their time-based information needs?
3.) How do patients and their family members use time-based information?
4.) What kinds of reasoning processes are involved in patient and family use of time-based information?
5.) What are the strengths and challenges involved in how patients and their families obtain and use temporal information?

2. Methods

Study data were gathered from a longitudinal, two-year study that included 38 families (97 individuals) with at least one member who had either HIV/AIDS (18 families) or type 2 diabetes (20 families). Families managing these two illnesses were studied together to reflect variation in symptoms, treatment focus, and social context. Recruitment took place in the U.S. Midwest, the northern central geographic region of the U.S. Participants were recruited from five sources: a Veterans Affairs Medical Center ("VA") (a national government healthcare facility for U.S. military veterans), three disease-specific non-governmental organizations ("NGOs"), and a public university online research participant recruitment system. At the VA, study team members approached potential participants as they exited clinical appointments. The three NGOs disseminated recruitment information to users of NGO services through flyers, newsletter advertisements and word-of-mouth.