System engineering approach of the home self-management of type 2 diabetes: a work in progress

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ABSTRACT

Developing usable technology that is effectively integrated into the daily management of type 2 diabetes (T2D) requires an in-depth understanding of how people living with (PT2D) perform their tasks. This research adopts a systems approach to address this goal, and to ultimately support the development of technologies that contribute to the safe and effective management of T2D. This exploratory ethnographic study of PT2D using insulin in their homes employs semi-structured interview photo-walkabouts. Interviews are recorded and transcribed verbatim for analysis with photos using deductive and inductive content analysis approaches based on Systems Engineering Initiative for Patient Safety (SEIPS) 2.0. To date, 18 participants have been recruited and data from 7 have been analyzed. This work-in-progress report provides a preliminary characterization of the way the work system's components shape PT2D's and informal caregiver's distributed cognition and action.

CCS CONCEPTS

• **Applied computing** → Life and medical sciences; Consumer health; Law, social and behavioral sciences; Psychology; • **Social and professional topics** → User characteristics.

KEYWORDS

Type 2 diabetes, Systems engineering, Home, Diabetes technology

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1 INTRODUCTION

People living with a chronic illness face difficulties in initiating and maintaining medication adherence over time. Therefore, only approximately 50% of chronically ill people take their medication as prescribed which limits their treatment efficacy and contributes to poor health outcomes [11]. Health technologies may facilitate long-term adherence [4]. Managing a chronic illness comprises physical (e.g., practicing exercises), organizational (e.g., making appointments) and cognitive tasks (e.g., calculating doses). Consequently, developing a usable technology that fits well into a chronic illness management context requires an in-depth understanding of how people cognitively perform the tasks involving technology.

Chronic illness-related tasks are complex and shaped by multiple factors. Understanding those tasks goes beyond the individual cognition level of analysis. It requires analyzing the work system in which patients perform their tasks [7]. Therefore, developing health technologies based on an individual cognition approach without considering contextual factors risks failing to improve patients' chronic-illness management performance [16]. To develop technology that supports a patient's complex tasks, one needs to understand how the patient's actions are shaped by the components of this work system: one needs to adopt a systems approach to distributed cognition, investigating the way that an information-bearing structure is propagated through a system [7].

The present research adopts a systems approach to distributed cognition to understand how people manage a chronic condition – insulin-treated type 2 diabetes – at home with health technology. It ultimately aims to help develop technology that fits patients' and their informal caregivers' needs and work systems to ultimately support safer and more efficient type 2 diabetes (T2D) management, including adherence, without increasing the chronic illness management burden.

2 STUDY CONTEXT: TYPE 2 DIABETES AND PATIENT WORK

Injections of hypoglycemic drugs (e.g., Trulicity) and insulin are reserve agents to manage T2D when diet, lifestyle and oral hypoglycemic drugs have not achieved the desired effect. From a cognitive ergonomics perspective, diabetes is a dynamic situation [9] in which blood glucose concentration must be maintained within acceptable limits in order to avoid either hyperglycemia or hypoglycemia, both of which can put PT2D at risk [2, 13]. Therefore, managing glucose level is like managing a high-risk situation. For PT2D using insulin, frequent readings are required to regulate blood glucose level, informing the insulin dose to be injected. An error in insulin dose calculation or injection can be life-threatening.

Diabetes technologies provide the opportunity to improve diabetes self-management and glycemic control [1] and are expected to reduce the diabetes management burden and improve PT2D quality of life [14]. However, when used by PT2D or informal caregivers in their work system, even technologies considered easier to use (ex. continuous glucose monitor, CGM) can compromise patient safety and the expected improvement in glucose control. For instance, CGM readings can be distorted due to misuse such as incorrect sensor position and calibration or age [6]; injecting insulin also faces several issues (e.g., skipping injection, reusing needle, not rotating injection sites) [12].

Despite the stakes in terms of daily burden, patient safety, and the size of the population concerned, very few studies have investigated the behavior of PT2D from a systems approach [17]. Wahbeh et al. analyzed diabetes self-management applications to identify their strengths and weaknesses in terms of fit between the technologies and the patient work system [15]. Werner et al. used virtual reality to investigate personal health information management at home [16]. Nowak et al. investigated the role of everyday objects in the construction and maintenance of routines [10]. These studies provide a better understanding of how PT2Ds distribute their cognition in their environment to manage their diabetes. However, they did not analyze the actual use of technologies and how those technologies are integrated into PT2Ds' work systems. In addition, they considered all types of diabetes and all types of treatment. Yet, there are major differences between those who experience each type of diabetes in terms of demographics, co-morbidities and risks, as well as between the different modes of diabetes treatment in terms of levels of disease evolution and risks associated with taking these treatments.

To the best of our knowledge, no studies have investigated the actual use of diabetes technologies by PT2Ds treated by insulin and their informal caregivers in the home setting using a systems approach. This study aims to fill this gap to better understand the work associated with technologies, how the work system's elements shape PT2D's and informal caregiver's distributed cognition and action, and to provide support to develop technologies that better fit PT2D's and their caregiver's work systems. For this purpose, we perform an exploratory ethnographic study. This paper reports on the preliminary results.

3 METHOD

The protocol has been approved by Lille University's Behavioral Sciences Ethics Committee (reference: 2023-723-S120).

3.1 Patient and Public Involvement

We formed a PPI panel of PT2D, informal caregivers, a diabetologist and a community pharmacist. Panelists were invited to participate on an ongoing basis throughout the research project (e.g., [5]). Prior to starting the study, the PPI committee reviewed and revised participant documents. They commented on the study protocol to optimize consideration of the key points for PT2Ds.

3.2 Participants, sampling and recruitment strategy

We considered for inclusion adult participants (over 18), fluent in French, living at home, diagnosed with T2D, using insulin as part of their treatment for at least six months and using at least one diabetes technology for monitoring or treatment. PT2D who live in a care facility or whose insulin use is managed, even partially, by healthcare professionals were excluded. As the aim of the study is to understand a complex phenomenon, we opted for a purposive sampling method. We target the recruitment of 30 PDT2s through social media advertising and by contacting associations and healthcare professional networks. Participants and their caregivers are not compensated for their participation. We employ a matrix of participant demographic characteristics to iteratively support recruitment of less well represented groups [5].

3.3 Data collection

Data are collected using semi-structured interviews and photographs. Individual interviews are performed at the PT2D's home by an ergonomist, unless the PT2D invites an informal caregiver, in which case the dyad is interviewed together.

After the interviewee(s) expresses their oral consent, the interviewer collects sociodemographic participant data. Then the interview elicits a description of how participants manage their diabetes at home on a daily basis, task by task. For each task, questions target who performs it, how, when and where, what precedes and what follows it, what needs to be prepared, what tools are used. For each answer, the interviewer asks the participant to explain why the task is performed this way. Finally, for each task, the interviewee is invited to describe remarkable situations (e.g., difficulties, errors, omissions, their consequences and how they are overcome) and to show where those tasks are performed. Photographs are taken to collect visual information on behaviors, tools and places of use and complement the interview data [3]. Interviews are audio-recorded and transcribed verbatim, and photographic data are stored securely, accessible only by the research team.

3.4 Data analysis

We describe the study sample through descriptive statistics. After a familiarization phase with the material from the first three interviews, the researchers (interviewers) read the transcripts and examine the photos from the first three interviews to deductively

Table 1: Examples of work system elements described by participants.

Element	Example	Illustration
People	Healthcare professionals	"*It is the doctor who writes the prescription. He gives us a prescription for three months in fact. And then in the pharmacy we take the medications month by month.*" P5
	Domestic pet	"*I go to bed, but last time I didn't have any sugar. And I didn't know it [. . .] Then there is my cat who woke me up at 11:30 pm, who came on top of me, which he never does. And then I said to myself, what does he want? And he insisted that I wake up. And I woke up, I felt all weird. I was not well. I checked. I was at 70 and going down. This is the first time this has happened to me.*" P2
Internal environment	Home	"*Oh yes, I go to the pharmacy and as soon as I get home [. . .] Already, there are products to put in the fridge, so they don't hang around. And then, as we still have a good bag, I prefer to put it away straight away because it takes up space.*" P5
External environment	Weather	"*She [pharmacist] had just given it to me, I put it [sensor] on and it popped out. Because of the heat and then she wouldn't give me another one.*" P2
	Statutory health insurance	"*We have them [sensors stickers that don't itch], but the problem [. . .] we'll say, the first price, we don't pay anything. But the first price [. . .] the brand that is reimbursed by the insurance is the one that itches. And when it itches [. . .] It's annoying.*" P14
Organizations	Frequency of monitoring	"*I no longer take my blood sugar levels every day, but I try to do it at least every three days, at several times of the day. [. . .] then otherwise, I may take it if I feel a little sleepy and I say to myself oulala that maybe I have too much [blood sugar] or when on the contrary I feel a bit unwell in the other direction. [. . .] These are feelings, to check that I am not in hypoglycemia.*" P1
Tasks	Administering	"*I take out my [insulin] pen, I prepare, I screw in the needle (...) without opening it, and then afterwards I set it to 35. And I leave it there [on his bedside table]. At one point or another, it makes me think I need to inject myself.*" P3
	Disposing	"*We bring back to the pharmacy the medicines that are out of date. But, when it comes to needles, lancets and all that crap, I have to admit that I put them in the garbage can.*" P15
Tools and technology	Insulin pen	"*It's true that I could inject myself twice, using 5 with one, and then only 25 with a second, but I don't want to inject myself twice.*" P1
	Blood glucose meter	"*I already have my set ready on the table. So, I prepare my compresses, I prepare my needles. So, I [measure my blood sugar]. After that, I begin to write down on [his notebook]. And then, once I have written everything down, I take my shot.*" P14

apply a Systems Engineering Initiative for Patient Safety (SEIPS) 2.0-based coding scheme [8]. This SEIPS model facilitates exploration of the work system's outcomes, elements (i.e., people, tasks, technologies, environments, organizations), and the interactions between these elements in the form of processes to produce outcomes. Disagreements over coding are discussed by the research team. Subsequent interviews are coded by a unique interviewer and cross-checked by a second. The coding process is supported by qualitative research software, NVivo™.

The coded data are then synthesized to generate a description of the work system and the interactions that facilitate positive and negative outcomes, including through distributed cognition. This includes describing modifiable elements, therefore providing insights into opportunities for safer and more efficient T2D self-management from a systems perspective.

4 PRELIMINARY RESULTS

Recruitment is on-going. Eighteen participants have been included so far (mean age = 64.9; 9 women). On average, interviews lasted 65.24 min (range: 32-118 min). Data from seven have been analyzed and a synthesis is presented here.

4.1 Work system elements

Participants' descriptions identified elements across all categories of people, internal and external environments, organizations, tasks, tools and technology (Table 1). The people described as being involved in the work system were the PT2D themselves, informal caregivers, healthcare professionals, and domestic pets. Participants described that their cat or dog appeared able to detect and alert the participant to hypoglycemia. Participants also reported needing to store medicines or related devices out of reach of pets. The internal environment primarily involved the participant's home, but also places for work, leisure or for receiving healthcare. The external environment included the weather, statutory health insurance and the supply chain for medicines or technologies. The tasks reported included acquiring, storing, administering or disposing of medications or technologies, or monitoring blood glucose levels. There were cognitive tasks or sub-tasks reported within each of these, e.g., calculating a dose, selecting the correct insulin, monitoring supplies, monitoring blood glucose levels, deciding where and how to store supplies. The technology described was predominantly the medicine itself (e.g., insulin), or the devices for administering the injection or for monitoring the blood glucose level.

4.2 Work system outcomes

The outcomes reported were categorized as those affecting the PT2D themselves, or affecting the household. For the PT2D, the outcomes were thematically categorized as (1) emotions and wellbeing (e.g., quality of life) (2) workload burden (e.g., effort or ease of the work, extra-tasks) (3) healthcare outcomes such as diabetes and glycemic control or therapeutic adherence and (4) resource management (e.g., sustainability, cost of care). For the household, the workload associated with managing the PT2D's care was the primary outcome described.

4.3 Work system interactions

Participants described PT2D's interactions with multiple work system elements such as their environment – internal (e.g., home cluttered with medication packaging) and external (e.g., medication supply chain problems), their organization (e.g., working hours incompatible with pharmacy opening hours), and their technologies (e.g., sensors falling off). Distributed cognition emerged from interactions with technologies (e.g., CGM documenting blood glucose), or people (e.g., spouse reminding to take medication, pet detecting hypoglycemia and then taking steps to alert PT2D to this). In turn, distributed cognition influences outcomes.

Participants emphasized the quality-of-life benefits [outcome] of diabetes technologies [technology]. Some are seen as solutions to major problems: e.g., CGMs connected to smartphones [technology] reduce the cognitive load [outcome] associated with the need to remember to test blood glucose levels [task] (P5). Blood glucose meter memories [technology] reduce workload [outcome] by allowing users to stop taking notes on their blood glucose levels [task] (P15).

However, technologies are also sources of a large variety of undesirable issues. Although the blood glucose sensor [technology] represents an improvement, in wet conditions [environment] (e.g., showering, swimming, sweating) it falls off easily [outcome], which raises questions for some users as to whether they should continue with their sporting activities [outcome] (*"Last week, during the pool, it drops (...) I'm thinking about stopping the pool. Because if every 15 days I phone up and say I need a sensor, they [the manufacturer] might get fed up over there."* P6). Insulin dosing problems [outcome] due to perceived defects in the design of the pens [technology] were described ("*once you exceeded [the desired dose], there was no going back*." P1). Medication error [outcome] was attributed to a PT2D's confusion between rapid- and slow-acting insulin pens [technology] ("*I woke up, feeling all weird. (. . .) I checked myself. I was at 70 and it was going down. (...) maybe I put 30 on the fast one. [instead of the slow one]*" P2). Blocked injection issues due to clogged or bent needles [technology] are reported, forcing the needle to be changed during injection [outcome]. (*"I go to inject myself and (. . .) then it gets stuck (...) I change the needle and then it's gone again. Maybe the needle gets blocked."* P17).

5 DISCUSSION

The findings-to-date highlight that the interactions between work system elements influence the way cognition is distributed between PT2D and the work system and, ultimately, affects outcomes. Preliminary design recommendations can be made at this time, although these should be further confirmed in the analysis of subsequent interviews. CGM technologies that support the automated measurement and recording of glycemic level seem to reduce work burden and support wellbeing. However, their reliability in humid or hot environment needs to be improved; water-proof technologies need to be developed or comfortable protective stickers made affordable. The usability and reliability of pens and needles should also be improved to reduce workload and improve safety; they should be more tested in a variety of real-life contexts with a wide range of populations with different physical abilities and skin properties. Finally, interventions should be designed to avoid confusing rapid- and slow-acting insulins even when PT2Ds experience diabetes-related cognitive fatigue.

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