ORIGINAL ARTICLE

Challenges and patient strategies in seeking health services for chronic stroke: A qualitative study

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ABSTRACT

Objective: Previous healthcare informatics research identifies a critical need for information technologies to support the self-management of chronic illness by patients and caregivers. However, little is known about their experiences and challenges in seeking health services.
Methods: We present a qualitative study with chronic stroke patients and their caregivers. Among them the 13 patients who participated in the study, 9 patients also participated together with a caregiver, who played a major role in helping the patients seek health services and the other 4 stroke patients, who dealt with stroke management independently, participated in the study by themselves. We used a grounded theory approach to analyze the interview data.
Results: Our findings revealed three main barriers that stroke patients and their caregivers faced in utilizing affordable, accessible, and satisfactory health services and the corresponding strategies they adopted to cope with these challenges.
Conclusions: We discussed that these strategies reflect patients' creative appropriation in making services affordable and could inform technology design that builds around patients' creation. In addition, patients' collaborative and yet onerous strategies to access health services imply the opportunities of designing technologies that leverage local social resources. Moreover, to offer satisfactory health services, it is valuable to provide individualized treatment plans that consider patients' treatment goals, symptoms, and home environment. The findings could apply to similar neurological diseases that require long-term rehabilitation.

Key Words: Chronic care, Chronic conditions, Patient provider communication, Health services, Stroke, Rehabilitation, Patient strategies

1. INTRODUCTION

1.1 Problem statement

Chronic diseases are leading causes of mortality and incurring a significant economic burden on society. In the recent decade, there has been increasing attention to developing information technologies that improve the health and well-being of chronic patients,[1] with a focus on assisting patients' home-based self-management practices.[2] These systems are mainly designed to help patients: monitor the symptoms of their diseases and adjust treatment plans;[3,4] share in-

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formation and coordinate with informal caregivers;[5,6] and gain support from peer patients to better manage their conditions.[7,8]

Besides actively self-managing chronic conditions at home, patients also need to seek health services that require professional assistance, such as diagnosing and treating illnesses, and promoting, maintaining, and recovering of health.[9] Seeking health services usually requires accessing healthcare systems, reaching the health service locations, and finding a healthcare provider that patients trust and can communicate with.[10] However, it was found that many patients encounter barriers to seeking health services such as high cost of services and inadequate insurance coverage. The barriers to accessing and utilizing health services result in patients' unmet health needs and delay or discontinuation in receiving appropriate care.[10] Despite the challenges, little is known about how patients with chronic conditions and their caregivers cope with the challenges.

1.2 Background: Chronic self-care

The chronic care process usually involves both self-care by patients and caregivers and professional care by healthcare providers.[2] Researchers have been designing technologies to support patients' (and sometimes with caregivers) self-care activities at home and gain support from peers with the same conditions. To help patients manage conditions on their own, technologies have been designed to monitor disease together with contextual information.[3,4] Monitoring such information helps patients reflect on their symptoms and possible contributing factors, and thus enhance their ability to make healthcare and lifestyle decisions.[1] By sharing information with family members enabled by technologies,[5,6] patients feel accountable in their disease management, and family members could better engage in patient care and provide support.[1] In addition, actively searching for support from peers with the same conditions in online health communities is also extensively studied.[7,8]

Besides patients' self-care at home, medical visits are also a critical part of chronic care.[2] A great deal of literature revealed multiple barriers when patients communicate with providers during medical visits, e.g., different perceptions of illnesses between patients and clinicians,[11] patients withholding information from providers.[12] The communication between patients and care providers heavily influences their relationships, such as trust, and vice versa.[13] Although these prior studies on chronic care have primarily focused on either home-based self-care practices by patients and caregivers, or clinical care encounters between patients and their healthcare providers, little is known about patients' barriers in accessing the services and the associated coping strategies.

1.3 Related work

1.3.1 *Stroke and information technologies*

Stroke is a type of brain injury usually leading to short-term or long-term disability, depending on the part of the brain that is affected. People who survive a stroke often suffer from weakness or paralysis on one side of the body, communication disorders, and cognitive deficits (e.g., memory, thinking, and attention). The recovery process usually involves treatment and rehabilitation.[14] Treatment begins with acute care in a hospital, aiming to help patients survive and prevent another stroke. Rehabilitation usually begins in the acute stage aiming to help patients maintain abilities and regain lost abilities and continues after patients transition to the home environment. The most common three types of rehabilitative therapies are physical therapy, occupational therapy, and speech therapy, with the purpose of improving patients' ability to perform body movement, conduct activities of daily living, and communicate. Caregivers sometimes play an important role in stroke care. Besides taking care of patients' basic living, caregivers may also coordinate healthcare services, assist with mobility and transportation, and provide emotional support.[15]

Researchers have designed a variety of technologies for home-based stroke rehabilitation. Some integrate robotic devices to automate therapy procedures.[16] Others used virtual reality and video games[17–19] to make the repetitive rehabilitation exercises more engaging. Sensors are deployed to track patients' motion and monitor rehabilitation.[20–22] For example, Balaam et al.[20] have prototyped sensor-based rehabilitation systems that accord with patients' hobbies, e.g., reading, playing chess, doing exercise, and playing games. A few studies also leveraged tablets and touchscreen for hand and arm exercise.[18,23,24] However, the above systems are mainly designed for patients to conduct rehabilitation by themselves without interacting with the healthcare providers.

1.3.2 *Stroke and health services*

Oftentimes, the responsibility of accessing health services (e.g., treatment and rehabilitation) falls on the shoulders of stroke patients and caregivers,[25] who usually lack power over which services they qualify for and have insufficient knowledge to access the services.[25] Previous research has reported a few main challenges stroke patients and caregivers perceived in seeking healthcare services. First, they feel that discharge occurs too early and inadequately prepares them for the next steps, leaving them only able to perform basic functions, feeling abandoned and unsure about what to do next, and unaware of available services.[25–28] Second, the various services that stroke patients usually need to interact with are not well coordinated within or between institutions.[25] Third, the care delivery systems they accessed usually suffer from financial burdens because of the lack of facilities and the need for costly special equipment.[29]

Previous studies have documented a variety of stroke survivors and caregivers' coping strategies of challenges after transitioning to the home environment, such as: setting priorities believed to promote health;[30] finding new goals; beginning to learn what they used to do;[30] engaging in leisure activities or hobbies;[31] establishing routines;[32] self-affirmation and seeking affirmation from others; reaching a sense of acceptance;[31] maintaining active social relations;[33] and gaining comfort from religious beliefs.[31]

Given the increasing interests in studying health services for stroke recovery, however, a majority of them still focus on either the acute or the transition from hospital to home settings; how health services are provided and perceived by patients in the chronic stroke period is less examined. It is unclear what unique challenges chronic stroke patients and caregivers are facing in utilizing health services, whether and how they tackle the challenges.

1.4 Purpose and aims of this study

This study aims to address this important question and gain insights to design information systems and technologies to support patients' needs. To do so, we conducted an interview study with stroke patients and their caregivers to investigate the challenges and coping strategies in seeking health services among individuals with chronic stroke — a leading cause of disability and a fifth leading cause of death in the United States (AHA, 2021). We chose to study stroke patients because they usually experience functional impairment following stroke,[34] and thus need treatment and rehabilitation services from multidisciplinary healthcare providers. We focus on stroke patients at the chronic stage, because during this period patients primarily manage the health conditions by themselves or with their caregivers, compared to the acute stage, when healthcare providers are mostly.[14] Thus, the chronic stage offers a great opportunity for us to study patients' barriers to utilizing health services, and how they manage to cope with the barriers. For readability purposes, we refer to chronic stroke patients as stroke patients.

2. METHOD

2.1 Research design

We conducted an interview study to understand the challenges stroke patients and caregivers face and the coping strategies they develop when utilizing health services. Prior literature has suggested many stroke patients closely manage their diseases with the help of caregivers, e.g., a parent, spouse, or an adult child.[15] As such, we designed the study to either interview a stroke patient independently or interview a patient with his/her primary caregiver as a pair. The choice interview was determined by whether the patient navigated health services alone, or with the help of a primary caregiver. The procedure was the same between individual and pair participants: patients mainly answered questions and caregiver supplemented answers, especially for patients with speaking constraints or for activities conducted by caregivers.

2.2 Participant recruitment and characteristics

Patients were recruited at their chronic stage through a large public event for stroke education held in an urban setting in the Greater Los Angeles area in California as a convenience sample. Institutional Review Board approval was obtained prior to recruitment and data collection. In the end, 13 patients participated in the study. Among them, 9 patients also participated together with a caregiver, who played a major role in helping the patients seek health services; the other 4 stroke patients, who dealt with stroke management independently, participated in the study by themselves.

All patients had their first stroke at least 1.5 years prior (max:8, min:2). They include eight males and five females. Their age ranged from 25 to 84 (mean: 58), and they represented a diversity of ethnic backgrounds, levels of education, and experiences with technology. Eight described their occupation as disability and five as retired. They included six Caucasians, four Hispanics, and three Asians. Five patients were impacted on the left side of the body, seven on the right side, and one patient was affected on both sides of his body. Four patients suffered from aphasia – a type of brain damage that leads to language barriers – and their caregivers answered most questions and assisted in communicating the patients' answers. For the nine caregivers who participated in the study, their ages ranged from 36 to 70, including five females and four males. Their education background ranged from receiving a few years of college to holding graduate degrees.

2.3 Study procedure and data analysis

The interviews were conducted at places preferred by our participants. Among them, seven interviews were held at the patients' homes, one at boarding care where the patient was living, two at a wellness center, two at a coffee shop, and one via Zoom, an online meeting software. To paint a whole picture of patients' recovery journey and identify themes related with our research goal, we asked participants what types of treatment and rehabilitation services the patients had received, what challenges they had met since the stroke onset, what techniques they had used for stroke rehabilitation. With participants' permission, we audio-recorded and transcribed the interviews, and photographed artifacts related to chronic self-care. Each semi-structured interview lasted around one hour.

We used a grounded theory approach to analyze the interview data.[35] We conducted memoing during the interviews and theoretical sampling[35] afterwards. Two authors first performed open coding to identify common challenges that our participants perceived, as well as the strategies they developed. We then conducted a systematic axial coding[35] to identify and categorize naturally emerging themes. During the entire coding process, to validate the codes, the two authors double-coded the data, compared the codes, discussed to resolve disagreements, and conducted iterations of coding until saturation was reached. The two authors then consolidated codes into themes we will report in the next section. When reporting interview quotes, we use pseudonyms to protect our participants' identities.

3. RESULTS

Overall, our participants expressed frustrations in utilizing health services. They frequently mentioned they had difficulties finding sufficient and affordable rehabilitation services through their insurance. Even with insurance, some participants still faced numerous barriers in accessing services. These challenges were usually associated with patients' functional impairments following stroke, such as immobility that prevented them from traveling to the health service facilities, and speech deficits that caused barriers in communicating with healthcare providers. Even when patients and caregivers could access affordable services, they were sometimes frustrated in finding satisfying services, especially when their providers' treatment goals and plans did not fit their situation. In this section, we report three types of health service breakdowns resulting from patients' challenges in finding sufficient and affordable health services, accessing services, and finding satisfactory services. We chose these three challenges, and the corresponding coping strategies, because they were the main themes reported by participants.

3.1 Service insufficiency and unaffordability

Rehabilitation plays a vital role in helping patients maintain their current abilities and regain their lost abilities. However, patients and caregivers in our study frequently mentioned their challenges in finding rehabilitation services due to the limited rehabilitation benefits they received or the high cost of such services. We refer to the barrier of patients' and caregivers' inability to find sufficient or affordable rehabilitation services as **service insufficiency** and **unaffordability**.

3.1.1 *Challenges in finding sufficient and affordable services*

One major challenge most patient participants reported was that they did not receive sufficient rehabilitation service because their insurance had restrictions on their benefits. Regardless of patients' situation and preferences, patients were assigned a fixed amount of rehabilitation as default, ranging from zero coverage to 25 therapy sessions per year for each type of therapy (e.g., physical therapy, occupational therapy) depending on their insurance benefits. Because of this limited service number, all of the participants felt the gap between what they needed/wanted and what they actually could receive, and often hoped for a higher amount of rehabilitation to gain satisfactory progress in their functional recovery. To make this situation even worse, when the therapist reports failed to show a patient's continuous progress, insurance companies stopped providing further benefits, which worsens the service unavailability even more. For example, one patient participant (Michael, age: 81) was cut off the insurance benefits to receive occupational therapy because he was not showing progress during the past year, caused by his leg surgery. Therefore, participants frequently mentioned they had to find additional services.

The other significant challenge was to find affordable services, when patients did not have or had exhausted their insurance benefits for rehabilitation. Many patients and caregivers had to pay out-of-pocket and complained that the services were too expensive. For instance, a caregiver participant (Karolyn, age: 50) reported that she was desperately looking for therapy for her father (a patient participant), since he had already run out of insurance benefits for rehabilitation. She had to find therapies for which she could pay out-of-pocket; the least expensive physical therapy session at a rehabilitation facility would charge 75 dollars for half an hour. Karolyn could not afford these services, especially since her father needed not only physical therapy, but also occupational and speech therapy every week. As participants reported, when patients did not receive sufficient rehabilitation after stroke, their recovery stagnated or even retreated.

3.1.2 *Strategies in finding additional and affordable services*

To cope with the challenges with limited services, our participants deployed various strategies to maximize their benefits through their own investigation and persistent negotiation with their insurance companies, as well as developing their own ways to conduct rehabilitation.

The first strategy that patients and caregivers used to cope with the restrictions caused by their insurance was, instead of passively waiting for bills, to actively investigate the insurance policies to advocate and continue their benefits. For example, a female patient participant (Sheryl, age: 53) hired a professional case manager to negotiate and reclaim the rehabilitation benefits that she should be able to claim from her insurance, and to ensure that the benefits she deserved were indeed reimbursed. She did so because it was too complicated for her to understand the insurance policies and negotiate with the insurance company. The case manager understood the importance of therapies for stroke patients as well as the insurance policy, and served as a bridge between the insurance company and the patient. Besides reclaiming the benefits, patients also strived to remain insured by working closely with their therapists. Most participants gradually became aware that the insurance company would discontinue the rehabilitation benefits if the patient failed to show improvement in their recovery. Since therapy reports are sent to the insurance company by therapists, patients tried to express their concerns to their therapists to ensure the reports would reflect their continuous progress.

The second strategy patients used, given their existing insurance benefits, was to search for additional rehabilitation opportunities through their social networks. To find additional therapy sessions, patients and caregivers employed diverse approaches. As mentioned earlier, some paid out-of-pocket for extended therapy sessions. To lower the cost, some secretly hired students or interns in the service facilities, rather than licensed therapists. Others actively searched for clinical trials offered by university research studies, which not only helped them enhance their health outcomes, but also learn about the latest stroke rehabilitation research. Community-based exercise programs also provided channels for patients to seek cost-effective rehabilitation opportunities. Such services helped patients and caregivers connect to other patients with similar chronic conditions and situations. By sharing experience and learning from peers, patients and caregivers become more resourceful in accessing additional and affordable health services.

The third strategy patients used to cope with insufficient or unfordable health services was to create cost-free rehabilitation opportunities themselves. Several caregivers proactively observed and learned rehabilitative exercises from their therapist that they could perform with their patients at home to help them gain gross motor skills (e.g., basic movement and coordination of arms and legs). As patients gradually gained motor skills, they started to leverage everyday objects to train their fine motor skills – refined movement and coordination skills. For example, during the interview, we observed a patient participant (Bryan, age: 37) frequently use a water bottle (see Figure 1(a)) to practice the coordination skills and strength in his hand, a pen to enhance the dexterity of his fingers (see Figure 1(b)). While using the water bottle, he could also adjust the intensity of the exercise by changing the volume of the water and thus the weight of the bottle. Additionally, to remind themselves to exercise frequently, some participants designated a physical space in their house as a rehabilitation table (see Figure 1(c)). Conducting the exercises using everyday objects and associated with daily activities helped create more frequent opportunities for exercises.

Lastly, patients also leveraged tools and information technologies to deal with the lack of affordable services. Participants video-recorded their sessions with therapists using their smartphone cameras for home practice later and created the video documentation to monitor their progress over time (see Figure 1(d)). Some participants utilized professional and patient videos on YouTube to learn new exercises or apps to use as supplementary help. For instance, a patient who could not follow timely speech therapy in Spanish found an iPad app to practice his language skills. As patients reflected, these tools were affordable, and they could use them as frequently as they wanted to conduct rehabilitation at home.

In summary, patients and caregivers faced challenges in searching for sufficient amounts of rehabilitation and affordable health services. The common strategies they developed included: 1) maximizing insurance benefits through self-advocacy and negotiation; 2) searching for additional rehabilitation services through social networks; and 3) conducting low-cost, home-based rehabilitation with the help of family caregivers, rehabilitation toolkits, and information technologies.

3.2 Service inaccessibility

Even when health services were available, sometimes it was still difficult for patients to access them due to their functional impairments that occur after stroke, such as immobility and communication disorders. We categorize these barriers as **service inaccessibility**.

3.2.1 *Challenges in accessing health services*

The first challenge, caused by patients' immobility, involved patients traveling between residences and health services locations. Even though all our participants live in urban areas, they reported transportation to be extremely burdensome and time-consuming. Many stroke patients suffered from loss of or difficulty with ambulation and needed wheelchair assistance at the early stage of recovery. Therefore, finding and securing special transportation that could accommodate wheelchairs on time was crucial to access health services. However, most participants found that transportation services were often too expensive (e.g., at around 70 to 100 dollars for a round trip), considering that patients sometimes needed to visit therapists or doctors multiple times per week. Besides the high cost of transportation services, participants also experienced unreliable and unpunctual services, which caused them to miss their appointments. Without appropriate and affordable transportation, it is difficult for patients to get to healthcare facilities.

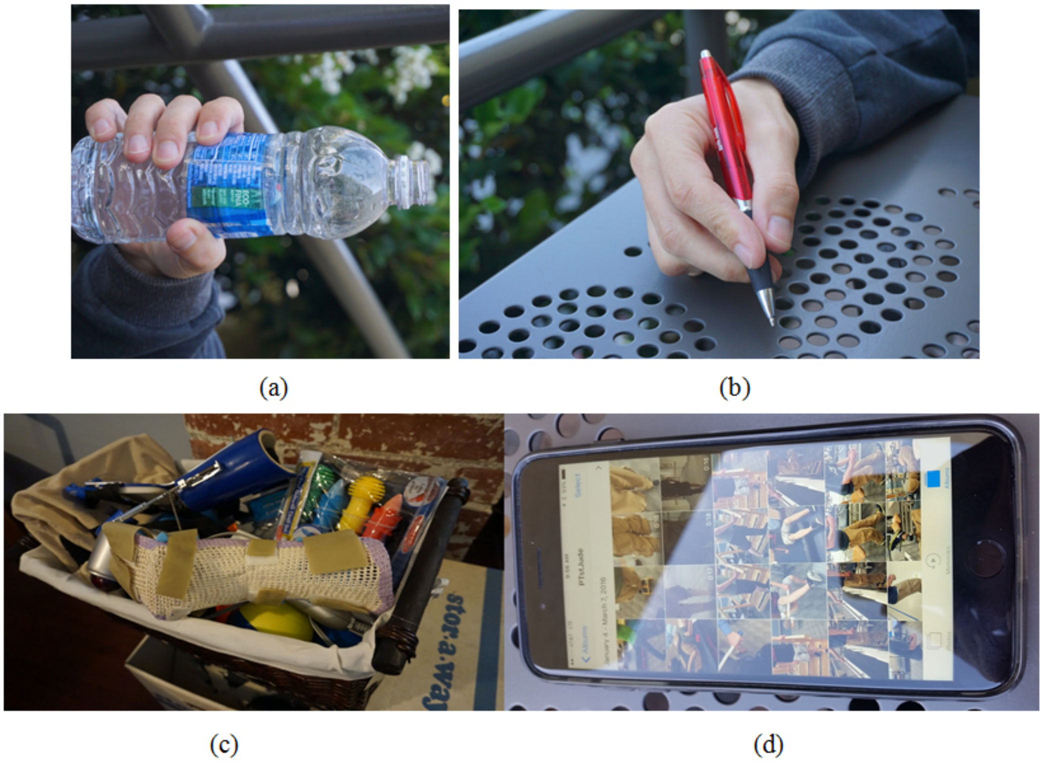

Figure 1. Photos of sample rehabilitation tools
(a) a water bottle, patient self-invented exercise tool; (b) a pen, patient self-invented exercise tool; (c) a rehabilitation table with various tools; (d) the album on a smartphone with all past rehabilitation videos

Even when transportation service was available and affordable, sometimes it took a considerable amount of time to access the services. Most patients used comparably affordable public Access buses – a ride-sharing service for commuters facing challenges in using regular public transportation because of physical disability. However, patients and caregivers found it too time-consuming to schedule around the Access busses. This is particularly challenging when caregivers work full time, as shown in this interview quote of a caregiver (Claudia, age: 52):

> Sometimes you take three hours just to go to the doctor. You have to make sure you make it on time to your appointment so you have to schedule for an hour before but they give you a window and you have to be outside from the beginning of the window… and they don't go straight to your appointments; they may have two to three people so sometimes you end up in another city picking someone else… this is too many hours when you have to work… and you have to go to other doctors every other day…

Despite available health services and a more affordable transportation option, Claudia complained about the difficulty of using the public disabled-access bus, because she had to allocate waiting and carpooling time to ensure an on-time medical visit. These challenges became greater when patients had to visit multiple therapists or doctors in one same week. As caregivers mentioned, the transportation barrier sometimes forced them to forgo some health services, or only attend the most essential appointments.

The second obstacle in accessing health services was difficult patient-provider communication caused by patients' aphasia, characterized by "the loss of ability to understand or express speech, caused by brain damage."[36] This condition introduced barriers for patients to communicate with their clinicians or to follow clinicians' instructions without help from caregivers. For instance, one caregiver participant (Royce, age: 55) mentioned that it took a considerable long time to understand what her husband was trying to express when interacting with the therapist or at home. The deficiency in the speech was quite common for stroke patients, which caused great barriers in communicating with clinicians and therapists.

3.2.2 *Strategies for accessing health services*

To overcome the barriers to reaching the health service facilities, patients and caregivers actively searched for affordable transportation through their social networks and coordinated with their social networks to accompany patients. Further, to cope with the communication barrier between patients and providers, the caregiver actively served as a communication ambassador. In such cases, caregivers played a crucial role in helping patients overcome those barriers to accessing services.

First, patients actively sought affordable and appropriate disability transportation through their social networks. While they could find information online, most participants contacted their expanded social networks for personal tips and experiences. Trying to identify appropriate and affordable services required a lot of phone calls and email exchanges, so caregivers tried to use the same services in the long term if possible. However, since such transportation services usually fill up quickly, to secure a long-term transportation service our participants tried to make a recurring appointment. Second, given that caregivers had limited time to accompany patients to their healthcare services, caregivers coordinated tasks with other people in their networks. Caregivers sometimes divided the task into multiple activities, and then delegated the activities to multiple people, thereby forming a streamline of helpers between the residences and the health service facilities. For example, Karolyn (caregiver, age: 50) had a full-time job, and could not take her father to every class and medical visit. She persistently sought for help from her network:

> I make sure that when he gets a ride, there's somebody at the other end to meet him. His sister is retired so she volunteers to meet him twice a month on Mondays for the communication class. If he's going to the therapy class I have to make sure his sister knows. She has to be there at 9:15 in case the bus is early. And she'll wheel him to class and then when he's done she will come out at 12 and make sure the bus comes back. But they [landlord] are always here so I don't have to worry about him coming back ...

Karolyn arranged multiple caregivers, each responsible for sending the patient on the Access bus, meeting the patient at the rehabilitation unit, accompanying a patient in the rehabilitation session, sending the patient back on the bus, and getting the patient from the Access bus to home. Dividing the tasks helped Karolyn, because they could often take a considerable amount of time due to the patients' physical constraints and public transportation services. As patients gradually regained their physical functionalities, they could be driven to the rehabilitation units without the need for wheelchairs. This eventually alleviated many of their transportation problems later on.

To cope with communication challenges when patients access health services, caregivers usually served as a communication mediator between the patients and the care providers. For patients who had language impairments, their caregivers encouraged the patients to use pictures instead of words for self-expression. Sometimes, when patients could not speak in long sentences or recall certain words, caregivers would ask patients multiple-choice questions to receive an answer. Some participants also developed their own terms to make their communication workable and understandable between the patient and the caregiver. Caregivers developed the techniques to communicate with patients through learning from patients' speech pathologists or in their daily interaction with the patients. For example, a caregiver (Garry, age: 58), whose wife suffered from aphasia, described his strategy:

> I watched how her speech pathologists communicated with her, I was able to pick up on that. Plus her speech pathologist would give me hints on what to do... For the first eight months, I was taking her to all doctor's appointments and I had to pay attention to what they were saying. ... if I need an answer from her, I ask her multiple-choice questions, so that it is easy for her to answer.

In this case, the caregiver played an important role in translating and facilitating communication between the patient and healthcare professionals. The caregiver quickly adopted some effective methods (e.g., asking multiple-choice questions) to communicate with the patient from the initial sessions with a speech pathologist, and then applied and adapted them to translate in other situations, including other healthcare service visits.

In summary, patients and caregivers faced barriers to access health services due to their physical and communication limitations. To overcome such limitations, they deployed various strategies, using their trustful networks to find affordable and reliable transportation and trustworthy helpers, and developing their own skills to facilitate communication between patients and healthcare providers.

3.3 Unsatisfactory service

Even when patients managed to access health services, participants often still reported that the services they received were **unsatisfactory**. Over time, patients experienced frustrations when the providers' treatment plans did not fit patients' individual situations or did not align with their expected recovery goals.

3.3.1 *Challenges in receiving satisfactory services*

The first frustration occurred when healthcare providers' treatment plan did not fit patients' individual conditions. As explained earlier, stroke is a complex disease; each stroke patient has heterogeneous symptoms, and thus it is critical to treat each stroke patient based on his/her individual condition and situation. However, sometimes doctors only provided general prescriptions without personalizing them. For instance, one patient (Evelyn, age: 58) suffered from aphasia, but did not have mobility issues. The caregiver understood that his wife was different from other stroke patients, in that she only had recovery needs in communication but not mobility. The patient and caregiver reported to the doctors that when they saw a support group or class filled with patients with physical disabilities, they did not feel a sense of belonging. The only rehabilitation the patient needed was speech, and she expected to receive support from patients like her.

> I had no physical impairment other than the right hand. It was a little weak... When I went to the stroke group, there were wheelchairs, walkers, canes all over the pace. And I didn't have any of that . . .

When our patient and caregiver participants felt the treatment plan did not accord with patients' unique conditions, they tended to doubt their healthcare providers' professionalism and lose trust in them.

The second common cause of dissatisfaction in health services occurred when patients and caregivers experienced conflicting treatment goals and plans with their healthcare providers. Some participants believed that stroke rehabilitation could be a long process with slow progress and hoped for a longer treatment time for recovery, while providers considered the effectiveness or efficiency of treatment foremost. When health providers' recovery goals differed from the patients', patients felt frustrated and dissatisfied with the health services. One caregiver (Jack, age: 54) expressed his frustration due to the gap:

> The neurologist took one look at her [patent's] hand and heard her story. He said, ". . . if you want, I can cut the tendons so that at least your hand won't be curled up because your fingernails are going to grow and they're going to cut into your palm..." At that point, he didn't even consider that she would get better. He didn't even consider there was a possibility that she would gain movement again and use some functionality. He just dismissed her out of hope.

While the doctor suggested a treatment based on the patient's health condition, the caregiver and patient believed there could still be a potential improvement of the patient's hand, with a longer and more dedicated rehabilitation effort. With the conflicting perceptions between the patient and healthcare provider, the caregiver became angry with the treatment plan. The disparities between the patient and the care providers usually made the patients and caregivers feel dissatisfied, and even drop out from the health services.

3.3.2 *Strategies in receiving satisfactory services*

When patients felt health providers' treatment plans did not fit their individual needs, the most common patient strategy was to self-advocate for their own needs. Our participants frequently emphasized that each stroke patient had different deficits and levels of severity; some expressed their preferred rehabilitation priorities (e.g., speech over physical). To better collaborate with the health providers, it was important to self-advocate their needs proactively. In the earlier case of Evelyn who suffered from aphasia without any mobility-related problem, the caregiver realized the differences between his wife and other patients, and thus they expressed their needs to the doctor:

> We talked to the lady who runs this Communication Recovery Group program. I was able to talk to her [the doctor] and express Evelyn's needs (only speech therapy). And that's when she invited Evelyn down for an assessment determined that she would fit into this one particular Monday group.

By proactively asking the provider to re-evaluate the patient's needs, the caregiver managed to help the patient be assigned to the right rehabilitation class for her needs.

To cope with the disparate views with providers' treatment goals and plans, patients and caregivers actively looked for opinions from healthcare providers they trusted. For example, a caregiver (Susan, age: 66) said:

> If we didn't feel comfortable with the treatment plan, [the patient] has a sister in the medical industry in [another state]. So we always consult with her and she then would consult with her

> team, because we trusted her. And she most of the time concurred with the treatments that were recommended, or she would say maybe offer us alternative advice, but in most cases I think she did concur. She agreed with the doctor's treatment method. So that just reinforces what they were doing was right.

In this case, trust became a crucial factor in the patient's and caregiver's decision-making. For the same medical advice, patients expressed more confidence when it was offered by a healthcare professional they trusted. As our patients frequently mentioned, when they received health services from a therapist or doctor whom they could trust, they naturally adhered to the recommended treatment plans.

In other cases, when our participants were not satisfied with the treatment plan, they tried to change doctors and look for those who held the same beliefs in treatment. As Susan continued to recall their experience:

> They [doctors] say typically after two years you stop improving and that's not true. Because every day you can have an improvement. . . . So yes, you need to change doctors and we had several very encouraging very positive doctors.

In this story, facing conflicting beliefs with their doctors about treatment goals, the patient decided to find a different doctor who aligned with their treatment beliefs. When they agreed on goals and plans, patients and caregivers reported feeling more trustful and motivated to cooperate with the healthcare providers.

To summarize, patients and caregivers faced challenges when they perceived that the treatment did not fit their individual situation, and when they experienced conflicting views with the providers about the treatment goal and plans. In such situations of unsatisfactory service, patients and caregivers would directly advocate for their own needs, consult health professionals they trust, or find care providers who share the same beliefs in treatment.

4. DISCUSSION

Our findings revealed three major barriers that stroke patients and their caregivers face in utilizing affordable, accessible, and satisfactory health services and the corresponding strategies they adopted to cope with these challenges. In this section, we first emphasize the importance of designing patient-centered health services for chronic stroke recovery. We then present how strategies patients and caregivers used could be seen as creative and collaborative engagement to cope with challenges and meet their unique needs. On the flipped side of patient engagement, we further argue that the process of actively managing chronic conditions and strategizing solutions also introduces patients and caregivers a burden of engagement — a series of activities that patients and their caregivers perform to receive affordable, accessible, and satisfactory health services. Finally, we present implications for health service and IT design that supports engagement while reducing burden.

4.1 Designing patient-centered health services

The challenges reveal three major unmet needs that patients encountered. First, patients' needs for rehabilitation services at the chronic stage frequently manifested in our findings, as patients reported the unavailability of rehabilitation services. Formal rehabilitation services are mainly offered during the first three or four months after stroke, but less during the chronic stage, during which the health services focus on helping patients prevent the next stroke and treating other medical problems.[37] Second, patients reported the need for facilities that help them access health services. Patients usually experience functional impairments following stroke, such as deterioration in motor skills, cognitive skills, and speech abilities, which make accessing services difficult for them. Current services mainly focus on the provider delivering healthcare at the service facilities, but little on patients' challenges and needs in accessing the services. Third, patients also expressed their needs in integrating their preferences during health services. As mentioned earlier, our participants sometimes had their own preferences in the treatment plans, e.g., long-term recovery, the priorities in certain aspects of recovery. When participants experienced conflicting treatment plans with their care providers, they tended to lose trust in their health providers.

These barriers patients and caregivers faced reveal the lack of patient-centered health services meeting the needs of stroke patients and their caregivers. Patient-centered care is defined as "providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.[38]" Similarly, a study[39] conducted in the Seatle and New York in the U.S also reported that patients of traumatic brain injury (TBI) wished that health providers could know more about their unique symptoms and the impact of BI on their quality of life. In our study, we found that patients' needs, such as additional rehabilitation, facilities to help them access the services, and being considered for their preferences in treatment plans and goals — remain largely unmet. Therefore, it is necessary to provide patient-centered health services that address patients' unique needs that we discussed above.

Implications

The aforementioned patients' needs might also be applicable for other chronic conditions that involve rehabilitation for functional regain, such as brain injury, spinal cord injury, and senior care. To this end, we suggest designing health IT and policies that support patient-centered health services. First, to provide continued yet affordable rehabilitation, service providers could integrate a central information repository that offers patients additional rehabilitation resources, such as technologies for home-based rehabilitation and community rehabilitation. Such resources could also be archived and accessed in the information repository for both patients and service providers to contribute and search for resources. This has been reported in studies of other similar conditions such as Alzheimer's. For example, a recent study[40] investigated the information sought by caregivers of Alzheimer's' patients on online peer support groups called alzconnect.org and identified that the major themes are about symptoms and caregiver wellbeing. Similar online support groups, forums, and information repository might be developed for stroke rehabilitation as well. Second, health services need to consider facilitating patients with functional impairments in accessing health services. Policymakers and insurance companies could integrate transportation facilities in health services, facilitate insurance reimbursement, or provide telerehabilitation services, which allow patients to receive rehabilitation services at home from therapists via telecommunication technologies.[41] Finally, to enhance patients' service satisfaction, health IT systems could elicit patient preferences in treatment goals and plans, and then suggest providers who match their preferences, or facilitate the communication between patients and providers to reach consensus in treatment plans and goals. Doing so might reduce patients' frustration in changing care providers and enhance satisfaction in health services.

Recommendation: Designing health IT and policies that support patient-centered health services that are accessible, affordable, and personalized.

4.2 Patient and caregiver strategy as creative and collaborative engagement

The existing health services and insurance systems often overlook patients' individual capabilities and situations, and thereby impose burdens on patients to obtain services that they need. Our study has also shown that, despite these obstacles, many stroke patients and caregivers developed various strategies to address the problems they experience in pursuing health services. These strategies are brought by the active engagement of the patients and caregivers.

The significance of patient engagement has been recognized by prior literature in the Health Informatics communities. Many studies have examined ways in which health IT, such as patient portals, personal health records, and mobile applications, can be designed and developed to facilitate patient and caregiver engagement in chronic illness management. A few recent studies[42–44] show the active role patients and caregivers play to deal with their problematic care situations and ensure their safety during their care process. This engagement primarily comprises patients becoming aware of their health and making informed decisions, by accessing their health-related information, monitoring their care progress, and better communicating with their providers during their hospital stay. However, what we uncovered in our study is more patient- and caregiver-driven, creative and collaborative engagement, which involves proactively learning and practicing rehabilitation, and finding help from available and trustworthy resources.

In developing various coping strategies, stroke patients and caregivers took a highly creative approach – they generated a creative replication of their health services. Since the needed services are often not easily accessible, patients and caregivers had to be resourceful: either to find adequate and relevant rehabilitation services, or to replace the available services with alternatives to maintain their recovery progress. As seen in the findings, for instance, patients tried to replicate their therapy sessions by learning, interpreting, and practicing on their own. Sometimes, they performed these on their own, or found a similar but less costly option, like a student therapist. These proactive patients and caregivers were also able to make further improvements, such as creating a new tool (e.g., using everyday objects). Some creative activities can be seen as similar to Do-It-Yourself (DIY) health,[45] as our participants also engaged with making their own tools for homecare. However, they were not simply customizing their health technologies and tools to their needs, but also creating their own services through learning, practicing, reflecting, and, more importantly, replicating of the activities when there was no service readily available. In particular, it was crucial for our stroke patients to make the rehabilitation services available, affordable, accessible, and satisfactory. Similarly, in a study examined TBI patients' barriers and strategies of accessing health services,[39] patients and caregivers devised creative methods to manage their chronic conditions, such as using physical and electronic devices for reminders of appointments, inviting someone else to keep track of progress in a medical appointment, changing their daily activities to ensure a safe environment, etc. Patients' strategies to creatively replicate health services were essential to their engagement in long-term stroke care during the absence of such services and healthcare providers.

In addition, our work reveals patient and caregiver engagement in stroke management results from collaborative efforts, involving requesting and receiving trustworthy help from their social networks. In the study, many participants extensively used their networks to come up with different solutions. These networks include not only their existing social circle, such as other family members, friends, and neighbors, but other human resources, such as therapists they previously met or worked with, case managers, other patients or caregivers they met at different therapy sessions or community programs, and acquaintances who might have helpful knowledge or resources. These social networks become highly valuable for three main reasons. First, the lengthy recovery stage of a stroke affords opportunities for patients' and caregivers' participation to be social and collaborative. Compared to the acute care stage, when the services are often structured, standardized, and predictable,[46] which mostly requires patients to be aware of and follow the care instructions, the services in the chronic stroke stage are more unstructured, adaptive, and unpredictable. Thus, there is more opportunity, time, and even need to flexibly create and use these strategies: to reach out to all potential networks to request and gain as much help as they can.

Secondly, the breakdowns patients experience in using their health services are sometimes not easily noticeable, but rather hidden and fragmented, requiring others' guidance and cooperation. For example, if a patient's progress does not meet their insurance company's expectations, the patient can lose benefits for guaranteed or persistent therapy sessions. However, this problem can be hard for patients to find out when navigating such complex health service systems. Moreover, since barriers usually occur at various points in the care activities, collaborative support is necessary for locating the right resources and solutions (e.g., finance, transportation, helpers).

Lastly, collaborative engagement is also crucial in identifying satisfactory service for patients. We observed that patients and caregivers faced difficulties in finding a trusted provider who was willing to listen to and change their viewpoints to meet the patient's beliefs and expectations, which sometimes led patients to simply stop seeing their doctor or give up on their therapy. In such cases, collaborative coping helps for seeking personalized solutions and connecting to other trustworthy resources, such as getting second opinions.

Implications

To support the creative engagement, technologies could be designed to facilitate patients and caregivers to create their own service through learning and replicating services. For example, a central information repository, as mentioned earlier, can help patients and caregivers connect with other patients who are in similar conditions and situations to create, share, and disseminate their methods (e.g., tips to customize home care tools or exercise) and learn from each other. Within that peer network, patients can also share and give out their tools to peers who want or need them since their recovery makes progress eventually during a long-term rehabilitation period. To better support the collaborative aspect of engagement, a collaborative help system can be designed for patients and caregivers to search for local helpers. Previous literature discussed how patients seek and receive collaborative informational and emotional support from online communities;[8] however, our study shows that stroke patients and caregivers also require physical help, such as giving a ride and checking their safety. Since such assistance is often location-dependent, we suggest designing the collaborative help system using people-nearby applications (PNAs) that allow users to connect with trusted people nearby[47] and share their resources, such as knowledge, ability, and time, to help each other. For example, neighbors who are available may help drive the patients to the care facilities in ad-hoc or volunteer for a certain time. The system might help patients and caregivers connect with other patients and share the ride to service facilities to reduce the cost. They might also attend community-based rehabilitation together and support each other in home-based rehabilitation. To incentivize the collaborative help, one approach is to adopt Timebanking,[48] in which users could earn credits by the time they spend in helping others and in recognition of their services; the earned credit could be utilized for further services they need. These solutions could provide patients and caregivers accessible physical support from trustworthy people with location convenience.

Recommendation: Consider designing technologies and services that facilitate patients and caregivers to create their own service through learning and replicating services.

4.3 Engagement burden

Patient engagement is often referred to as "patient empowerment," "patient involvement," and "self-efficacy" in the medical literature;[49] and it is increasingly recognized as an integral part of health services.[50] A number of studies have reported the benefits of patient engagement, such as promoting mutual accountability between patients and providers and thus enhancing patients' abilities in making health decisions and better treatment adherence.[34] Many patients in our study strived to extend their treatment period, increase the amount of rehabilitation, and believe that the potential in the recovery through dedicated efforts. These activities, together with various strategies we discussed earlier, form a set of engagement efforts that patients and caregivers used to achieve better outcomes in stroke recovery. However, despite such benefits, in our study we find that engagement brings an unintended burden to the patients and caregivers. We call this engagement burden. This is the flip side of the beneficial engagement that patients are often encouraged to pursue in their health services. The engagement burden involves an enormous amount of complex effort, which requires considerable capacity. As our participants reported, they had to access, navigate, and work with complex insurance systems and uncoordinated health services on their own. To do so, they had to reach out to many different people and resources. For instance, as seen in the findings, to help patients transit between their residences and healthcare facilities, a caregiver spent countless hours on the phone or had to carefully map out each step of the patient's commuting journey and arrange multiple helpers to be available at each time. Patients also had to speak to others who were more knowledgeable with the insurance systems, or hire a professional to negotiate for their rehabilitation therapies. These activities, which may be necessary multiple times on a weekly or daily basis, are highly demanding in terms of time, effort, and domain knowledge and literacy, which all cause huge frustration and place undue stress on patients and caregivers.

As aforementioned, existing literature on patient engagement have shown the various benefits of engaging patients in their healthcare and suggested ways to foster patient engagement in their care, such as clinicians actively inviting patients' participation, or organizational-level efforts (e.g., changing policies or designing specific patient role and workflow).[51,52] Besides patients' voluntary active engagement, in our study they also had to engage in the barriers caused by healthcare service design.

Engagement burden is a new insight from our study, and differs from previously known burdens, such as disease burden (the burden caused by a disease)[53] and caregiver burden (the burden caused by caregiving activities).[54] The engagement burden our patients and caregivers experienced mostly originated in the series of active and involuntary activities that they performed to obtain available, affordable, and satisfactory health services.

Implications

Recognizing the existence of the engagement burden can be crucial for the patients' engagement and empowerment initiatives that are increasingly advocated in recent years. Our study suggests a nuanced balance in promoting patient engagement and the associated burden. To maintain such balance, it is necessary to assess the burden. When patients and caregivers are overwhelmed by the burden, it is crucial to help them reduce the burden and disseminate it to the public to raise the awareness of this burden among not only healthcare providers but also insurance companies and policymakers. For example, health services could facilitate patients to streamline appointment schedules that are nearby so that patients and caregivers could complete multiple health service visits with one trip. Health providers could also connect patients with community services for extensive rehabilitative care and expose them to more resources and helpers. Meanwhile, health IT could be designed to reduce the burden by easing the process of searching for resources. A central information repository, as mentioned earlier, can integrate the resources that patients and caregivers collected to avoid further efforts from future patients. The system could suggest the best resources based on patients' characteristics, such as health conditions, locations, caregiver availabilities, economic status, treatment goals, based on the strategies adopted by patients with similar conditions and situations. It could also connect patients with other patients to learn from each other's experiences.

Recommendation: Consider balancing between patient/caregiver engagement and burden during stroke rehabilitation.

4.4 Limitations

First, it will be optimal to conduct pretesting before deploying the formal study. Additionally, we are aware that participants' experiences were recalled retrospectively. In the future, we will conduct longitudinal observational studies to investigate their experience in real-time. Furthermore, since our study was conducted in the Greater Los Angeles area in the U.S., there might be varied social-economic factors and health services and policies that might differ in other regions or countries. However, we believe our study still contributes to the literature since it serves as a starting point to study stroke patients' strategies of seeking health services in other countries. Finally, the study was only based on the subjective experience of patients and caregivers. To gain a comprehensive understanding of this topic, it would be ideal to also interview healthcare providers and associations, such as the American Stroke Association, rehabilitation centers, therapists, policymakers. We will extend our research in this direction in the future.

5. CONCLUSIONS

We report a study on chronic stroke patients and their caregivers to investigate their experiences in seeking health services. We found that chronic stroke patients and caregivers frequently encountered barriers in finding affordable, accessible, and satisfactory services. To overcome the barriers, they adopted DIY and collaborative coping strategies. We show that the strategies could be seen as positive patient engagement, but also as placing a burden on patients and caregivers. Finally, we present implications for designing information technologies that facilitate the engagement while alleviating the burden.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare no conflicts of interest.

REFERENCES

[1] Nunes F, Verdezoto N, Fitzpatrick G, et al. Self-Care Technologies in HCI: Trends, Tensions, and Opportunities. ACM Transactions on Computer-Human Interaction. 2015; 22(6): 1-45. `https://doi.org/10.1145/2803173`

[2] Chen Y. Health information use in chronic care cycles. Proceedings of the ACM 2011 conference on Computer supported cooperative work (CSCW '11). 2011; 485-488. `https://doi.org/10.1145/1958824.1958898`

[3] Mamykina L, Miller AD, Mynatt ED, et al. Constructing identities through storytelling in diabetes management. Proceedings of the 28th international conference on Human factors in computing systems (CHI '10). 2010; 1203-1212. `https://doi.org/10.1145/1753326.1753507`

[4] Storni C. Multiple Forms of Appropriation in Self-Monitoring Technology: Reflections on the Role of Evaluation in Future Self-Care. International Journal of Human-Computer Interaction. 2010; 26(5): 537-561. `https://doi.org/10.1080/10447311003720001`

[5] Bossen C, Christensen LR, Grönvall E, et al. CareCoor: Augmenting the coordination of cooperative home care work. International Journal of Medical Informatics. 2013; 82(5): e189-e199. PMid:23127539. `https://doi.org/10.1016/j.ijmedinf.2012.10.005`

[6] Eschler J, Kendall L, O'Leary K, et al. Shared Calendars for Home Health Management. in Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW '15). 2015; 1277-1288. PMid:28758163. `https://doi.org/10.1145/2675133.2675168`

[7] Liu LS, Huh J, Neogi T, et al. Health Vlogger-Viewer Interaction in Chronic Illness Management. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13). 2013; 49-58. `https://doi.org/10.1145/2470654.2470663`

[8] Eschler J, Pratt W. '"I'M So Glad I Met You": Designing Dynamic Collaborative Support for Young Adult Cancer Survivors. Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW'17). 2017; 1763-1774. `https://doi.org/10.1145/2998181.2998326`

[9] WHO | Health services. World Health Organization. 2014. Available from: `http://www.who.int/topics/health_services/en/` (Accessed: 9 September 2017).

[10] HealthyPeople.gov. Access to Health Services. 2017. Available from: `https://www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services` (Accessed: 13 September 2017).

[11] Büyüktür AG, Ackerman MS. Information work in bone marrow transplant: Reducing misalignment of perspectives. Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW'17). 2017; 1740-1752. `https://doi.org/10.1145/2998181.2998361`

[12] Lim C, Berry ABL, Hirsch T, et al. "It just seems outside my health": How Patients with Chronic Conditions Perceive Communication Boundaries with Providers. Proceedings of the 2016 ACM Conference on Designing Interactive Systems - DIS '16. 2016; 1172-1184. `https://doi.org/10.1145/2901790.2901866`

[13] Berry ABL, Lim C, Hartzler AL, et al. Creating Conditions for Patients' Values to Emerge in Clinical Conversations: Perspectives of Health Care Team Members. Proceedings of the 2017 Conference on Designing Interactive Systems (DIS '17). 2017; 1165-1174. PMid:28890950. `https://doi.org/10.1145/3064663.3064669`

[14] US Agency for HealthCare Research and Quality. Recovering After a Stroke: A Patient and Family Guide. AHCPR. 1995; 16: 1-17.

[15] Cameron JI, Gignac MAM. "Timing It Right": A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. Patient Education and Counseling. 2008; 70(3): 305-314. PMid:18155388. `https://doi.org/10.1016/j.pec.2007.10.020`

[16] Lee N, Lee YH, Chung J, et al. Shape-changing robot for stroke rehabilitation. Proceedings of the 2014 conference on Designing interactive systems (DIS '14). 2014; 325-334. `https://doi.org/10.1145/2598510.2598535`

[17] Alankus G, Proffitt R, Kelleher C, et al. Stroke Therapy through Motion-Based Games: A Case Study. ACM Transactions on Accessible Computing. 2011; 4(1): 1-35. `https://doi.org/10.1145/2039339.2039342`

[18] Boulanger C, Boulanger A, de Greef L, et al. Stroke rehabilitation with a sensing surface. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13). 2013; 1243-1246. `https://doi.org/10.1145/2470654.2466160`

[19] Khademi M, Hondori HM, McKenzie A, et al. Free-hand interaction with leap motion controller for stroke rehabilitation. in Proceedings of the extended abstracts of the 32nd annual ACM conference on Human factors in computing systems (CHI EA '14). 2014; 1663-1668. `https://doi.org/10.1145/2559206.2581203`

[20] Balaam M, Egglestone SR, Fitzpatrick G, et al. Motivating mobility: designing for lived motivation in stroke rehabilitation. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI'11). 2011; 3073-3082. `https://doi.org/10.1145/1978942.1979397`

[21] Beursgens L, Boesten F, Timmermans A, et al. Us'em: Motivating Stroke Survivors to Use Their Impaired Arm and Hand in Daily Life. CHI '11 Extended Abstracts on Human Factors in Computing Systems (CHI EA '11). 2011. 1279-1284 p. `https://doi.org/10.1145/1979742.1979761`

[22] Ploderer B, Fong J, Withana A, et al. ArmSleeve: a Patient Monitoring System to Support Occupational Therapists in Stroke Rehabilitation. Proceedings of the Designing Interactive Systems Conference (DIS '16). 2016; 700-711. `https://doi.org/10.1145/2901790.2901799`

[23] Jacobs A, Timmermans A, Michielsen M, et al. CONTRAST: Gamification of Arm-Hand Training for Stroke Survivors. CHI '13 Extended Abstracts on Human Factors in Computing Systems (CHI EA '13).

2013. 415-420 p. `https://doi.org/10.1145/2468356.2468430`

[24] Kirk P, Grierson M, Bodak R, et al. Motivating Stroke Rehabilitation Through Music: A Feasibility Study Using Digital Musical Instruments in the Home. Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI'16). 2016; 1781-1785. `https://doi.org/10.1145/2858036.2858376`

[25] Anderson S, Whitfield K. An Ecological Approach to Activity After Stroke: It Takes a Community. Topics in Stroke Rehabilitation. 2011; 18(5): 509-524. PMid:22082701. `https://doi.org/10.1310/tsr1805-509`

[26] Bendz M. Rules of relevance after a stroke. Social Science and Medicine. 2000; 51(5): 713-723. `https://doi.org/10.1016/S0277-9536(99)00486-4`

[27] Proot IM, Abu-Saad HH, Esch-Janssen WP, et al. Patient autonomy during rehabilitation: the experiences of stroke patients in nursing homes. International Journal of Nursing Studies. 2000; 37(3): 267-276. `https://doi.org/10.1016/S0020-7489(00)00008-0`

[28] Wottrich AW, Aström K, Löfgren M. On parallel tracks: newly home from hospital–people with stroke describe their expectations. Disability and Rehabilitation. 2012; 34(14): 1218-24. PMid:22200192. `https://doi.org/10.3109/09638288.2011.640381`

[29] Hartke RJ, Trierweiler R, Bode R. Critical Factors Related to Return to Work After Stroke: A Qualitative Study. Topics in Stroke Rehabilitation. 2011; 18(4): 341-351. PMid:21914598. `https://doi.org/10.1310/tsr1804-341`

[30] Pound P, Gompertz P, Ebrahim S. Social and practical strategies described by people living at home with stroke. Health and Social Care in the Community. 1999; 7(2): 120-128. PMid:11560628. `https://doi.org/10.1046/j.1365-2524.1999.00168.x`

[31] Ch'ng AM, French D, McLean N. Coping with the challenges of recovery from stroke: long term perspectives of stroke support group members. Journal of Health Psychology. 2008; 13(8): 1136-1146. PMid:18987086. `https://doi.org/10.1177/1359105308095967`

[32] Silva-Smith AL. Restructuring life: Preparing for and Beginning a New Caregiving Role. Journal of Family Nursing. 2007; 13(1): 99-116. PMid:17220384. `https://doi.org/10.1177/1074840706297425`

[33] Carlsson GE, Möller A, Blomstrand C. Managing an everyday life of uncertainty - A qualitative study of coping in persons with mild stroke. Disability and Rehabilitation. 2009; 31(10): 773-782. PMid:19350431. `https://doi.org/10.1080/09638280802638857`

[34] Winstein CJ, Stein J, Arena R, et al. Guidelines for Adult Stroke Rehabilitation and Recovery: A Guideline for Healthcare Professionals from the American Heart Association/American Stroke Association. Stroke. 2016; 47(6): e98-e169. PMid:27145936. `https://doi.org/10.1161/STR.0000000000000098`

[35] Corbin J, Strauss A. Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory. 4th ed. SAGE Publications, Inc. 2015.

[36] Mayo Clinic. Aphasia - Mayo Clinic. Available from: `http://www.mayoclinic.org/diseases-conditions/aphasia/basics/definition/con-20027061?utm_source=Google&utm_medium=abstract&utm_content=Aphasia&utm_campaign=Knowledge-panel` (Accessed: 10 September 2017).

[37] Huang HC, Chung KC, Lai DC, et al. The Impact of Timing and Dose of Rehabilitation Delivery on Functional Recovery of Stroke Patients. Journal of the Chinese Medical Association. 2009; 72(5): 257-264. `https://doi.org/10.1016/S1726-4901(09)70066-8`

[38] Wilkerson L, Fung CC, May W, et al. Assessing patient-centered care: one approach to health disparities education. Journal of General Internal Medicine. Springer. 2010; 25: 86-90. PMid:20352499. `https://doi.org/10.1007/s11606-010-1273-5`

[39] Dams-O'Connor K, Landau A, Hoffman J, et al. Patient perspectives on quality and access to healthcare after brain injury. Brain Injury. 2018; 32(4): 431-441. PMid:29388840. `https://doi.org/10.1080/02699052.2018.1429024`

[40] Scharett E, Madathil KC, Lopes S, et al. An Investigation of the Information Sought by Caregivers of Alzheimer's Patients on Online Peer Support Groups. Cyberpsychology, Behavior, and Social Networking. 2017; 20(10): 640-657. PMid:29039697. `https://doi.org/10.1089/CYBER.2017.0274`

[41] Chumbler NR, Quigley P, Sanford J, et al. Implementing telerehabilitation research for stroke rehabilitation with community dwelling veterans: lessons learned. International Journal of Telerehabilitation. 2010; 2(1): 15-22. PMid:25945169. `https://doi.org/10.5195/ijt.2010.6047`

[42] Miller AD, Mishra SR, Kendall L, et al. Partners in Care: Design Considerations for Caregivers and Patients During a Hospital Stay. CSCW '16: Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing. 2016; 756-769. `https://doi.org/10.1145/2818048.2819983`

[43] Mishra SR, Haldar S, Pollack AH, et al. "Not Just a Receiver": Understanding Patient Behavior in the Hospital Environment. Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16). 2016; 3103-3114. PMid:28345079. `https://doi.org/10.1145/2858036.2858167`

[44] Park SY, Chen Y. Patient Strategies as Active Adaptation: Understanding Patient Behaviors During an Emergency Visit. Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17). 2017; 880-892. `https://doi.org/10.1145/3025453.3025978`

[45] Kane AAO. Advances in DIY Health and Wellbeing. Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '16). 2016; 3453-3460. `https://doi.org/10.1145/2851581.2856467`

[46] Marcu G, Dey AK, Kiesler S, et al. Time to reflect: Supporting health services over time by focusing on collaborative reflection. Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work and Social Computing (CSCW '16). 2016; 952-962. `https://doi.org/10.1145/2818048.2820079`

[47] Hsiao JCY, Dillahunt TR. People-Nearby Applications: How Newcomers Move Their Relationships Offline and Develop Social and Cultural Capital. Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing - CSCW '17. 2017; 26-40. `https://doi.org/10.1145/2998181.2998280`

[48] Carroll JM, Chen J, Yuan CWT, et al. In Search of Coproduction: Smart Services as Reciprocal Activities. Computer. 2016; 49(7): 26-32. `https://doi.org/10.1109/MC.2016.194`

[49] Prey JE, Woollen J, Wilcox L, et al. Patient engagement in the inpatient setting: a systematic review. Journal of the American Medical Informatics Association. 2014; 21(4): 742-750. PMid:24272163. `https://doi.org/10.1136/amiajnl-2013-002141`

[50] WHO. Technical Series on Safer Primary Care, Geneva: World Health Organization. 2016. Available from: `http://www.wipo.int/amc/en/mediation/` (Accessed: 12 September 2017).

[51] Barello S, Graffigna G, Vegni E. Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. Nursing Research and Practice. 2012; 1-7. PMid:23213497. `https://doi.org/10.1155/2012/905934`

[52] McDonald KM, Bryce CL, Graber ML. The patient is in: patient involvement strategies for diagnostic error mitigation. BMJ Quality & Safety. 2013; 22(Suppl 2): ii33-ii39. PMid:23893394. `https://doi.org/10.1136/bmjqs-2012-001623`

[53] Doyle P, McNeil M, Hula W, et al. The Burden of Stroke Scale (BOSS): Validating patient-reported communication difficulty and associated psychological distress in stroke survivors. Aphasiology. 2003; 17(3): 291-304. `https://doi.org/10.1080/729255459`

[54] Tooth L, Mckenna K, Barnett A, et al. Caregiver burden, time spent caring and health status in the first 12 months following stroke. Brain Injury. 2005; 19(12): 963-974. PMid:16263639. `https://doi.org/10.1080/02699050500110785`