Understanding the Dynamics of Long-Term Chronic Disease Family Caregiving Experience: Using Caregiving Reddit as a Probe

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1. Introduction

Chronic disease is defined as a long-term condition that requires ongoing medical monitoring [1, 85] and is usually caused by multiple factors (e.g., genetic, physiological, environmental, and behavioral) [46]. According to the CDC, six in ten Americans have at least one chronic disease, including heart disease, cancer, and diabetes [1]. In many cases, people develop two or more chronic diseases [4] in their aging process [86]. People with multiple chronic diseases are more likely to experience a decline in their capacity to adhere to treatment or carry out effective self-management [95].

To support patients with chronic diseases, informal caregivers (ICGs) are often involved [9, 12, 48, 74]. As reported in 2010, 80% of care for older adults in Canada is provided by informal caregivers [96] (i.e., people who are socially related to the patients [40], taking on the role of providing care to patients [41], such as spouses, parents, children, etc.). Family caregivers can take an active role [74] in involving patients in physical activities, assisting in their daily lives, and providing emotional support [16, 65]. Some family caregiving even involves intimate physical interaction with patients. For instance, caregivers who are taking care of patients with diabetic foot ulcers [32, 84] need to inspect patients' feet regularly [78].

Due to the intimate nature of informal caregiving, it brings lots of challenges and introduces conflicts between patients and caregivers. Tensions emerge when patients and caregivers hold different perspectives [6, 61]. Patients' negative reactions and behavior issues (e.g., being aggressive, wondering, disorientation, etc.) have a significant impact on caregivers' lives [51], which further adds to the mental burden that caregivers face [9, 89]. Apart from the disease itself [60], multiple factors influence the caregiving experience, including financial, time management, and patient attitudes [57]. Several constraints (e.g., locational and temporal constraints [77], access to facilities, lack of knowledge [60], etc.) also limited caregivers' ability to resolve conflicts in caregiving. The problem space of long-term informal caregiving is complicated, as those factors might be interconnected. For example, transferring patients to facilities is helpful in reducing caregiver's mental burden [41]. But caregivers might hesitate to make such a decision when facing a financial burden [87]. Thus, a solution at the surface level might not be helpful to address the deeper issue in their lives. Still, we lack an understanding of how those factors and constraints, which mediate the caregiving experience, are related.

On the other hand, providing informal care for chronic patients is a long-term journey that leads to constant changes in all factors as well as their interconnection. Research shows that time or a chronological factor causes changes in individuals' social connections [83] and patients' conditions [66, 68, 87], which introduces new challenges for both patients and caregivers [67]. Patients' being diagnosed would bring a profound change in caregivers' lives by introducing new tasks and constraints [72]. The duration of patients' diseases might affect their caregivers strain [10], costing time for caregivers to get familiar with their roles [33, 59]. Critical circumstances (e.g., the care-transition period [2, 63]) will occur during the caregiving journey and pose emerging issues for caregivers. In this sense, informal caregivers have different needs [50, 58] and face different challenges [94] over time. For example, caregivers may find conflicts between caregiving duties and their work. However, dealing with emergencies, such as managing patients' fluctuating situations, may lead to constant work absences, which eventually cause them to lose their job. In this case, the previous conflict disappeared. But the caregivers need to bear both the financial burden and caregiving duties in this new situation. Thus, a solution that works for now might not work for future stages of long-term informal caregiving. While prior literature unpacked the caregiving experience by addressing different values and needs [5–7, 26, 49, 69], most of the works didn't have such a chronological perspective [42].

The online forums offer a place for people to reach out to their peers, providing a perfect space for researchers to qualitatively analyze informal caregiving experiences [31]. On the online forums, users learn from their peer's experiences [30, 92] and seek emotional support

and advice [44]. The anonymity of online discussion makes it more likely for caregivers to share their experiences in depth [3, 29]. Investigating caregivers' engagement in online forums can help reveal the nuances of the caregiving experience, which might be hard to capture by traditional data collection methods [23, 75]. Looking at people's posts on online forums helps researchers access hard-to-reach populations [29, 34, 43]. Most importantly, online forums provide convenience for caregivers to access them in their daily lives and allow for long-term participation [34], providing a promising opportunity for researchers to investigate the chronological perspective of their caregiving experience. Thus, we proposed to use online caregiving forums as probes to understand the dynamics of long-term informal caregiving. In doing so, we aimed to answer the following questions:

- What are the factors and constraints that mediate a long-term caregiving experience (information, interaction)?
- How do those factors and constraints relate to each other?
- How do those factors and constraints change over the long-term informal caregiving journey?

2. Related Works

Support chronic caregiving experiences

Awareness of responsibilities [6, 32], has been found to play a role in family caregiving.

The caregiving experience usually causes a disruption for carer and patient's lifestyle which set constrains for activities (e.g., social activities, travel, etc.) that they can handle before [82]. Caregivers usually face challenges from different aspects (e.g., emotional, financial, physical, etc.) [2].

In an informal caregiving relationship, the informal caregiver's role is complicated [9, 81]. Caregivers not only help with health related tasks (e.g., reminding patient to take medicine, setting appointments with doctor, etc.) but also involve with household tasks (e.g., cooling, house cleaning, etc.) [36].

Caregiving experience may have negative impact on different aspects of caregiver's lives (i.e., physical, mental, and social experiences) [60]. Caregivers are found to have depression, stress and low self-efficacy [56].

Caregiver usually plays a role as patients' surrogate [41], which might cause patients' value to be neglected [61].

In a caregiving relationship, caregivers' mental state has been affected by patients' behavior and attitude [89].

Technology may help caregivers'access information and resources [66]. Revealing the latent data in the caregiving journey shows an impact on the caregiving experience. ActEarlyMEX supports caregivers to track children's developmental milestones to help caregivers prevent developmental disabilities and communicate with health professionals [25]. Study showed that visualizing the occurrences of communication issues helps the parental caregiver avoid overestimating the difficulties of caregiving [71]. Sharing heart rate in a social context has been found to influence people's perceptions of intimacy [76]. Bossen et al. proposed Carecoor as a tool to help coordinate in-home caregiving for elder adults and pointed out the importance of reciprocity in division of labor [12].

Still, to solve those conflicts, caregivers and patients may face different constraint (e.g., financial constraint [37]).

Liminality/Dynamics/Change of states

The chronological perspective is important but often ignored when investigating long-term family caregiving. Prior studies argue the importance of considering long-term effects when designing interventions [15, 28]. It's been found that long-term caregivers are less happy in their marriages [7]. In managing long-term mental well-being, Kleunen et al. found that the roles played by people in individuals' social connections are constantly changing, causing a dynamic in their relationships [83]. For instance, caregivers must play their role differently depending on whether the patient is hospitalized [72]. The dynamics of patients' and caregivers' changing lives and work cause challenges for caregivers to coordinate with patients' needs [67]. As time goes on, patients' conditions may change significantly [66, 87], which requires caregivers to cope with it differently. Long-term caregiving could become increasingly challenging and complicated with the progression of patients' conditions [66] and is more likely to cause negative outcomes [80] compared to short-term caregiving. Still, we know little about how those changing factors influence the caregiving relationship, nor do we know how different stakeholders in family caregiving work out the challenges in different stages of chronic care.

Patients' disease progression contributes to the dynamic of the caregiving experience [68].

The wear-and-tear hypothesis suggests that caregivers are more likely to develop mental issues during long-term caregiving [80]. Family caregivers with long-term caregiving experience were reported to be less happy and having more marital role inequity, compared to new informal caregivers [8]. Due to the change of mood, medication and weather, patients have fluctuations in their symptoms [60, 72], which requires caregivers to adjust their ways of taking care of patients [48].

Prior study proposed a chronic disease care trajectory to illustrate the different caregiving tasks and their effect on caregivers through the long-term caregiving journey [66]. Another study categorizes the informal caregiving journal into three stages based on how well caregivers adapt to their role [87]. Tracking has been found as a way to support caregiver developing coping strategies and improve mutual communication [90, 91]. In facing the dynamics in caregiving experience, prior work addresses the importance of considering the constant evolving condition when design solutions for caregivers [65].

Using caregiving forums as probes

The online caregiving forums are spaces that involve interactions between people with different roles (e.g., patients, caregivers, health professionals, etc.) [38].

There is a lack of instruments for accessing the changing needs of informal caregivers throughout the caregiving journey [47].

By posting and browsing information from caregiving forums, informal caregivers are able to learn insights from their peers regarding taking care of patients and gain further information that's helpful for their caregiving [82].

Recent widespread use of various social media platforms enable researchers to use online communities as a channel to understand people who are hard to reach, such as vulnerable populations like veterans with post-traumatic stress disorder (PTSD) [93], sexual abuse survivors [3], or patients and caregivers who are difficult to reach due to sociodemographic or social and environmental characteristics [43]. Moreover, the role of social media in providing necessary social support for health and well-being has become more important than ever before [35, 93]. At the intersection of social computing and health research has been conducted around two types of social support, informational support, and emotional support, which are categorized by the Social Support Behavioral Code (SSBC) framework Cutrona and Suhr [17] proposed [93]. Patients and caregivers seek support from online communities and support each other [18, 39].

Donnellan et al. leveraged an online discussion forum to study the language use of informal caregivers, and the results suggest that the increased caregiver burden caused a deteriorating emotional state [22].

3. Method

While previous works identified many factors that mediate the caregiving experience, few of them tried to make connections between them. Additionally, though prior studies indicate the importance of looking at the chronological perspective of informal caregiving, we know little about how the chronological aspect could bring changes to those connected factors. Thus, to unpack those multiple layers of the dynamic of the informal caregiving experience, our data collection and analysis have been divided into different stages.

Data Source

Reddit has become an emerging space for researchers to gain insights regarding particular populations [13, 14, 24, 45, 53, 54, 54, 73, 93]. By the time this paper was written, Reddit was ranked as the 11th most visited website in the world and the 5th most visited website in the U.S. [62], providing access to a large population, including traditionally hard-to-reach populations, and their content [93].

As social media is becoming a space to facilitate conversations around health-related topics [21, 44, 55], we proposed to use Reddit as a probe to understand the informal caregiving experience for patients with chronic diseases. Reddit is made up of Subreddits where users' discussions are organized around specific themes (e.g., dementia [14, 45], depression [53], parenting [24], PTSD [54], caregiving [73]). Within each Subreddit, users can start an original post with their stories or concerns. Under the original post, other users can leave comments to address the content of the original post. This community structure was found to facilitate self-disclosure and a sense of belonging [3, 19, 93]. With this sense of belonging, users are more likely to post multiple times in the same Subreddit to share their caregiving experiences, seeking informational or emotional support [3, 20, 70, 93], which provides researchers with an opportunity to investigate their caregiving experience retrospectively.

Phase I: Collecting and Coding Posts Regarding Caregiving Experience

The initial phase of data collection and analysis focused on specific moments in the informal caregiving experience of chronic family members. By doing so, the research team hoped to have an overview of what's happening in this space and identify factors and constraints that mediate caregiving experiences. We identified four general caregiving Subreddits from prior literature [73]: r/caregivers (3.9K members), r/caregiversofreddit (775 members), r/caregiving (1.7K members), and r/caregiversupport (14.6K members). We aimed to collect 120 original posts (i.e., the first post within a thread posted by the original poster or OP), as well as their comments [24, 53, 73, 79]. Since r/caregiversofreddit is a small community, the team went through all the existing posts without being able to collect enough posts. Thus, we additionally included r/carer (679 members). The posts under those caregiving forums usually cover all sorts of topics, from sharing caregiving resources to fun pictures. To include the posts that specifically mentioned informal caregiving experiences, the team applied the following criteria when collecting those posts:

- Post contains emotional response
- Post contains description of their caregiving experience
- Not posted by professional caregiver
- Not posted by the users in the existing collection

Based on this criteria, the team members manually collected XXX posts (XXX from r/caregivers range from date 1 to date 2, XXX from r/caregiversofreddit range from date 1 to date 2, XXX from r/caregiving range from date 1 to date 2, XXX from r/caregiversupport range from date 1 to date 2, XXX from r/carer range from date 1 to date 2). The length of each posts range from XXX to XXX.

☐ [Put other characteristics regarding the data here...]

To first understand informal caregivers' experiences in general, the team coded those posts qualitatively using an in vivo coding [64] method. The team created a shared codebook, named as **Original Posts**, by referring prior literatures on different aspects of informal caregiving experiences, including unmet needs and challenges (e.g., lack of knowledge, lack of resources, financial issues, etc.) [10, 52, 60, 81, 82, 87, 94], facilitators in caregiving experience (e.g., social support, arranging time for yourself, expressing opinions, etc.) [36, 48, 57, 60, 81, 82, 87], interpersonal conflicts between patients and caregivers (e.g., uncooperative patients, conflicts between patients' and caregivers' different perspectives, conflicts between caregiving duty and personal lives, etc.) [57], caregivers' emotions (e.g., feeling stressed, depression, burnout, etc.) [82], use of online support (e.g., online interaction, self-disclosure, etc.) [82], patient-caregiver relationships [6, 36, 48, 81], types of support (informational support vs. emotional support) [52]. For the aspects in their posts that haven't been covered in the existing literature, we open-coded [88] them into a few new themes (e.g., Patient being demanding, Feeling unfair about how caregiving tasks are distributed among family members, unpleasant living environment, etc.). To address RQ2, we want to first understand how those factors mediate the challenges of long-term caregiving experience and how they are related. Thus, we further organized those themes into a few categories:

- Issues
- Factors: Things that mediate caregivers' caregiving experience (e.g.,)

Phase II: Collecting and Coding Comments

Under the original posts, other users usually post comments [38, 52, 54] to address the OP's experiences or concerns. In our dataset, XX% of the comments were about sharing their experience, providing another lens for us to look at the informal caregiving experience. Thus, we applied the same **Original Posts** codebook to code caregiving experiences shared in comments. In our dataset, the number of comments under each post ranges from XX to XX. We collected all the comments under each original post. In total, we collected XX comments, and XX of them shared their caregiving experiences. Apart from sharing experiences, comments help provide additional information. Users commonly include solutions in their comments. Through the interaction with comments, some OP (n=X/X) identified better solutions to address their challenges. Investigating the interaction in the comments might reveal insights regarding how to construct posts to induce valuable perspectives from their peers and how to utilize online social networks as a means to improve the caregiving experience. Thus, we formed a second code book, called **Comments** to specifically address users' online interaction on the caregiving forums. This codebook contains the following categories:

- Solutions:
- Interactions:

Phase III: Collecting and Coding Consecutive Posts

Reddit allows users to post multiple posts in the same or different Subreddits [54]. One user might submit multiple posts across the caregiving journey, offering an ideal way to address RQ3. To collect those consecutive posts from the same user, researchers looked into the post history of each account in the collection of original posts. As those posts may or may not relate to individuals' caregiving experiences, we applied the following criteria to filter out caregiving-related posts:

- **Involve all the posts under the original caregiving Subreddit**

- Involve posts in other Subreddits if the content is related to caregiving

To collect those posts, we went through OP's whole posting history. To be noticed, though all posts in this collection are relevant to the caregiving experience, some of them don't necessarily from a caregiving forum (e.g., individuals who experience depression under the caregiving stress may choose to post under r/depression). From the 120 original posts, we identified XX posts whose OP also composed those consecutive posts. For those users, they submitted XX consecutive posts on average (min=XX, max=XX), which cover their caregiving experiences range from XX (days) to XX (days).

As those are time-series data, we adopted a different coding method. We first organized those posts in chronological order. We then referred to the issues and factors we identified in the Phase I data analysis for each specific post. By looking at the issue, we tried to unpack it using those factors. For example, if one post mentioned overwhelmed caregiving stress (issue), we further attributed this issue to the financial burden (factor 1), caregiving duty (factor 2), and work (factor 3). To study how factors are related to each other, we tried to identify different ways to connect those factors. In the previous example, it might be the case that the caregiver chose to work more due to the financial burden, which further exacerbated the conflicts between caregiving duty and work. We applied this method to each consecutive post. With this information, we further examine how things changed by looking at those consecutive posts. When analyzing the consecutive posts, in addition to issues and factors, we collected the following information to help us understand their experience at certain points:

- Changes:
- Solutions:
- Needs:

Ethical Considerations

As the data is publicly available, we were informed by the institutional review board that this study is exempt from review. Still, concerning the fact that informal caregivers are a vulnerable population who fight with constant life challenges, we are aware of any negative impact of using their data. Thus, we de-identified the data by removing all the identical information (e.g., user name, location, etc.) and rephrasing the quote to make it not searchable on Reddit, as suggested by prior literature [11, 27, 54, 93]. Readers should be cautious that some content may cover very negative aspects of their experience and could be emotionally-triggering.

4. Findings

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