Just In Time: Challenges and Opportunities of First Aid Care Information Sharing for Supporting Epileptic Seizure Response

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There are over three million people living with epilepsy in the U.S. People with epilepsy experience multiple daily challenges such as seizures, social isolation, social stigma, experience of physical and emotional symptoms, medication side effects, cognitive and memory deficits, care coordination difficulties, and risks of sudden unexpected death. In this work, we report findings collected from 3 focus groups of 11 people with epilepsy and caregivers and 10 follow-up questionnaires. We found that these participants feel that most people do not know how to deal with seizures. To improve others' abilities to respond safely and appropriately to someone having seizures, people with epilepsy and caregivers would like to share and educate the public about their epilepsy conditions, reduce common misconceptions about seizures and prevent associated stigma, and get first aid help from the public when needed. Considering social stigma, we propose design implications of future technologies for effective delivery of appropriate first aid care information to bystanders around individuals with epilepsy when they experience a seizure.

CCS Concepts: • **Human-centered computing → Collaborative and social computing**; *Human computer interaction (HCI)*; *Ubiquitous and mobile computing*; • **Applied computing → Consumer health**; **Health care information systems**; Health informatics.

Additional Key Words and Phrases: epilepsy; seizure; caregiver; bystander; social support; first aid; information sharing

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1 INTRODUCTION

Epilepsy is a common neurological disease [41], and it is estimated that there are over three million people with epilepsy (PWEs) in the U.S. [41, 104, 108]. Most PWEs (about 70%) can control seizures by taking proper medications and treatment options [54]. However, PWEs and their caregivers still face challenges that include the risks of having social isolation, social stigma, experience of physical and emotional symptoms, medication side effects, cognitive and memory deficits, care coordination difficulties, and risks of sudden unexpected death in epilepsy (SUDEP) [30, 70]. Even more challenging is that as symptoms and severity of seizures differ among most PWEs, they must conduct self experimentation in order to discover their symptom triggers and to learn, adapt, and develop complex and personalized coping strategies for epilepsy management. To overcome these challenges, PWEs and their caregivers actively seek information and resources that could inform them of their conditions and adaptations of those common coping strategies [98]. PWEs are often in trouble when they are having a seizure in an uncontrolled environment without their caregivers or a bystander with sufficient medical knowledge to take care of them. Experiencing a seizure in this situation could also have grave consequences. For example, an individual who experiences a seizure in water could causes submersion injury and drowning [8, 28].

Prior research on epilepsy and seizures has focused on epidemiological aspects of epilepsy [27, 41, 108] as well as burdens placed on PWEs and their caregivers [47, 85]. More recently, research in information and communication technologies (ICTs) has focused on seizure detection and management [14, 43, 80]. There is a higher likelihood for PWEs to experience a sudden seizure when they are in a public environment where the bystanders are less likely to have the knowledge and know-how's for seizure response. However, there is a lack of studies on how to design ICTs that could provide information sharing and coordination with bystanders to provide proper first aid care for PWEs experiencing a seizure.

Our research questions are: (1) What challenges do PWEs and their caregivers experience when they or their care recipient have seizures at different places?; (2) What are their coping strategies for handling their seizures in different environments?; (3) How do PWEs inform the bystanders to get appropriate and timely first aid care when they are having a seizure?

The goal of this research is to understand current challenges and coping strategies devised by PWEs and caregivers to inform future ICT designs to support effective information sharing and communications for seizure response. In this paper, we define three main stakeholder groups around PWEs who can provide care. A ***primary caregiver***, such as a parent, has the responsibility to take care of a PWE who is not independent. Managing epilepsy and related information of their care recipients is one of their main responsibilities. A ***secondary caregiver*** personally knows a PWE and can provide care on occasions. Compared to the primary caregivers, they might have less knowledge of epilepsy and responsibility for taking care of the PWE. ***The public*** are any individuals or bystanders around PWEs in public areas who are not their caregivers. Public bystanders do not know PWEs and have no responsibilities of taking care of PWEs. Our identification of these stakeholder groups around PWEs aligns with that of Ridsdale et al. (2012), which identifies PWEs' experiences of getting help from family members, significant others, accompanying friends, work colleagues, police, and bystanders [84].

In the remainder of this paper, we review prior literature on epilepsy and seizure management, then we report our data collection process that involved 3 focus groups. The first focus group had 5 participants, the second 3 participants, and the last 3 participants. We also conducted follow-up questionnaires with 10 participants to further confirm and clarify focus group findings. Then we report our study findings on how PWEs differently experience seizures and their respective coping

strategies in different settings. We discuss design implications for future ICTs to share and educate bystanders so they could be more involved in providing effective first aid care for seizure response.

2 RELATED WORK

2.1 Epilepsy and Seizures

Epilepsy is a chronic noncommunicable brain disorder that brings about unprovoked seizures. Many PWEs have more than one type of seizures and other neurological symptoms [16, 104]. Along with migraine, stroke, and Alzheimer's disease, epilepsy is "one of the most common neurological diseases globally" [104]. About 50 million people in the world and 3.4 million people in the U.S. have epilepsy [41, 104, 108]. It is estimated that 1 in 26 people will have epilepsy during one's lifetime [6, 40]. For children, the estimated prevalence in a lifetime is 1%, and 6 of 1,000 children in the U.S. are estimated to have epilepsy [16, 87, 108].

A seizure is caused by a sudden, uncontrolled electrical activity in the brain that could last for a few minutes [64]. In addition, the symptoms could differ drastically across different types of seizures. For instance, while some people have visible signs such as falling or shaking, some people have undetectable signs such as having a blank out and unfocused sight with no recollection of when it had occurred. The impact of seizure in the brain can also vary widely, from a single particular spot to both hemispheres. According to the new classification by International League Against Epilepsy [31, 90], seizures can be categorized depending on where seizures begin in the brain, the level of PWEs' awareness during a seizure, or other behavioral features (e.g., twitching, jerking, staring, etc.).

2.2 Experiences Living with Epilepsy

Various types of seizures can influence the lives and health conditions of PWEs in different ways. Although there is a higher risk of premature death among PWEs [100], it is a manageable chronic condition, and it is possible for PWEs to live without seizures if they are appropriately diagnosed and treated [104]. Also, most PWEs can manage seizures with proper medications and treatment options [54]. However, depending on its severity, both PWEs and their families could suffer from physical, psychological, social, and financial burdens caused by epilepsy [26]. Also, epilepsy is significantly less treated in rural and low- and middle-income regions of the world [68]. Even for PWEs who have seizures well-controlled, other common problems persist: social isolation, experience of physical and emotional symptoms, medication side effects, cognitive and memory deficits, as well as stigma [26, 30, 45, 63, 92]. PWEs could be negatively affected by many negative emotional burdens, such as anxiety, frustration, depression, and fear from stigma, public misunderstanding, and uncertainties of social situations. In terms of public misunderstanding and stigma, epilepsy has been negatively perceived and discriminated against by the general population. Stigma against PWEs can make them feel afraid of being alone in public, and be concerned about how the public would view or treat them if they have a seizure in public [26]. Physically, they could experience fatigue and limited mobility that cause lower concentration and performance at work and other restrictions [98]. Also, challenges such as low quality of care, difficulties in care coordination, medication side effects, unstable employment, and risks of SUDEP all adversely impact the lives of PWEs [30, 70].

2.3 Caregiver

Caregivers offer informational, social, instrumental and emotional support, and they also represent their care recipients and help with their decision making and care management [69]. In 2013, about 470,000 children in the U.S. are expected to have active epilepsy. Living with epilepsy is temporary for some PWEs, but it could be a lifelong issue for other PWEs needing transition from pediatric

epilepsy care to adult care [16, 32, 87, 108]. Primary caregivers for children with epilepsy are their parents or legal guardians. These primary caregivers would know their care recipients better in terms of the needs, health conditions, routines and personalities [9]. However, taking care of the children with illness could be a long-term obligation as well as burden for family caregivers, which might cause physical and mental health issues [99]. Caregivers of children with epilepsy have also faced the issues of low quality of life, physical and mental health and financial burden [5, 44, 49].

Current HCI and CSCW studies on caregivers have focused on caregivers' roles, burdens, challenges, ICT use, communication, information sharing, and social support in diverse contexts of caregiving [9, 69, 72, 97, 106]. In addition, caregivers' cooperative work with other stakeholders such as clinicians and patients has been emphasized. To achieve better care, care stakeholders should coordinate, collaborate, and balance their care responsibilities [22]. While technologies and systems for supporting one's health management have been designed and proposed in prior CSCW and HCI studies, many have resulted in adding unintentional burdens on caregivers to actively manage and maintain technology in addition to performing their routine care work for their care recipients and this subsequently led to frequent technology abandonment [19, 71, 105].

2.4 Information Sharing

Information sharing is one of the significant communication behaviors that not only provide knowledge to others but also facilitate collaboration and coordination. It is defined as exchanging, giving, or accessing information to others [24]. It has been actively studied in the domain of knowledge sharing, cooperative work, and group performance within a team, organization, or government. In the context of care, sharing more information with other stakeholders is crucial to discussing critical issues and needs, supporting collaborative care work, and eventually enhancing self-care [15]. Effective communication is required for effective care [55], and communicating and understanding each others' values are important for better care even though they might not share the same values [9]. People share their information either within a group of people like them or between them and others. On PatientsLikeMe, a web-based online platform, people share their health-related information with other patients like them. By learning other patients' experiences, they can improve their health outcomes [101]. On the other hand, the main purpose of health information sharing with other people is to prevent one's wrong responses based on their misconceptions. Previous research shows that sharing student's diagnosis and epilepsy-related facts with teachers resulted in their correct attributions about health-related issues [103].

Many studies in CSCW and HCI have focused on designing ICTs that support individuals to manage their illness by providing health and contextual information or recommendation for care, sharing information with healthcare providers, informal caregivers, other people with similar diseases, or supporting collaboration with care teams [55, 56, 69, 75, 106]. When it comes to the context of epilepsy and seizure management, it has been revealed that managing and sharing the right information about epilepsy and seizures with other people could prevent PWEs from getting inappropriate care [36, 82, 84]. In this sense, there would be design spaces for ICTs that could facilitate information sharing to improve PWEs' health care.

2.5 Epilepsy Management Technologies for People with Epilepsy and Caregivers

People who have chronic conditions track their health condition and collect data, notes, and other types of information (e.g., article) [57]. Prior literature has emphasized using technologies for personal health information management [81]. Current epilepsy management technologies aim to record and manage seizures or epilepsy-related information (e.g., My Seizure Diary, Seizure Tracker, Epilepsy Journal), to provide relevant information (e.g., Neurology Now), or to help in emergencies (e.g., Seizure First Aide, SeizAlarm) [74]. For instance, *Seizure Tracker* is a smartphone

app to log and video-record the type, length, symptoms, and triggers of seizures [91]. *Seizure First Aide*, which was developed by the Epilepsy Foundation of Minnesota, provides basic instruction of first-aid care for the most commons type of seizure. When a user sees an individual experiencing a seizure, the user can follow the vital steps for first-aid care, along with recording the episode [1]. Most technology-related studies have focused on developing technologies to detect seizures [14, 43, 88], such as wearable devices (e.g., *SmartWatch Inspyre™* [94]) and apps to detect seizures (e.g., *Embrace2* [29]). Also, despite the existence of apps to help PWEs manage their conditions, children or adolescents with epilepsy are often not the intended audiences of these apps [33], with only a few technologies providing emotional, social, and tangible support to help PWEs and their caregivers cope with their daily challenges or to inform others on how to provide first aid care to PWEs.

In our research, we focus on the issue of having seizures and getting support from other people around PWEs at different places. We also pay attention to the potentials of information sharing that could support PWEs and caregivers' effective epilepsy management and cooperative care with other people. In the following section, we introduce our data collection and analysis process.

3 METHODS

This section reports the data collection process with PWEs and their caregivers in focus groups and follow-up questionnaires. Our aim was to understand how PWEs and their caregivers manage and share information to get support and how they experience having seizures differently in different places.

3.1 Data Collection

We recruited participants by advertising on social media, including social support groups on Facebook, and the Epilepsy Foundation website. Interested participants were asked to complete an initial screening survey that determined their epilepsy condition and whether they are patients or caregivers. Three focus groups sessions were held with 5, 3, and 3 participants attending each of the focus groups. This was deemed to be an appropriate sample size as prior research on focus group methodology has demonstrated that 2-3 focus groups could discover over 80% and 3-6 focus groups could find over 90% of all themes [37].

The focus group was conducted over a video conferencing platform. We conducted focus groups with a semi-structured interview questionnaire, each lasting approximately an hour. The participants consisted of 4 PWEs and 7 primary caregivers (all females). The focus group focused on questions about their daily challenges related to seizure management, transportation usage, and public awareness. After the focus groups, we conducted follow-up questionnaires to specifically probe, clarify, and confirm the focus group findings. The follow-up questionnaire focused on where they have experienced seizures, whether they are worried about having seizures at various places (e.g., *Are you often afraid of having a seizure in public areas?*), who typically accompany them at these places, who do they rely on for help when they experience seizures at these places, and whether they share information with other people to deal with having seizures (e.g., *Do you want to give first aid information to your colleagues/friends at your workplace/school?).* We conducted the follow up questionnaires either synchronously (via 3 virtual interviews) or asynchronously (via 7 surveys) with 7 PWEs (4 females, 1 male, and 2 non-disclosed) and 3 caregivers (2 female and 1 non-disclosed) based on participants' preference.

Most caregivers in the study are responsible for caring for one PWE, while one caregiver takes care of 3 PWEs. The care recipients are aged between 2 and 30 years old (mean = 13.3), and they have had epilepsy for 9 years on average. All but 3 care recipients are children under 18 years

Table 1. Demographics of Participants. (FG = Focus Group, Q = Follow-Up Questionnaire, PWE = Person with Epilepsy, CG = Caregiver, F = Female, M = Male, X = Prefer not to say)

Participant		Gender	Age	Age (CR)	Since diagnosed	Employment	Area (US)
FG1-1	PWE	F	25	N/A	5 years	Full-time	Midwest
FG1-2	PWE	F	35	N/A	X	Self-employed	North East
FG1-3	CG	F	40	9	4 years	Home maker	Midwest
FG1-4	CG	F	67	30	21 years	Part-time	Midwest
FG1-5	PWE	F	43	N/A	2 years	Unemployed	Midwest
FG2-1	CG	F	43	15	13 years	Disabled	South West
FG2-2	CG	F	31	5	3 years	Student	Midwest
FG2-3	CG	F	39	9	7 years	Part-time	Midwest
FG3-1	CG	F	31	3	1 year 2 months	Part-time	Midwest
FG3-2	PWE	F	35	N/A	15 years	Unemployed	North East
FG3-3	CG	F	36	17	5 years	Full-time	
Q-1	PWE	M	29	N/A	11 years	Full-time	Midwest
Q-2	CG	F	31	5	3 years	Student	Midwest
Q-3	PWE	F	35	N/A	15 years	Unemployed	North East
Q-4	PWE	F	40	N/A	15 years	Full-time	Midwest
Q-5	CG	F	55	22	15 years	Full-time	Midwest
Q-6	PWE	X	X	N/A	35 years	X	X
Q-7	CG	X	X	18	10 years	X	X
Q-8	PWE	F	42	N/A	12 years	Full-time	Midwest
Q-9	PWE	X	37	N/A	30 years	Unemployed	North East
Q-10	PWE	F	48	N/A	12 years	Full-time	Midwest
Average	PWE		37.1	N/A	15 years		
	CG		38.3	13.3	9 years		

old. Table 1 shows the detailed participant demographics. All focus groups and interviews were recorded and transcribed for analysis.

3.2 Data Analysis

We analyzed the focus groups and follow-up questionnaires by using thematic analysis, content analysis, and affinity diagramming techniques [12, 21, 48, 52] to iteratively identify emerged themes such as information sharing and getting proper help at different places and explore future ICT design implication that could mitigate these issues.

4 FINDINGS

We classified four places where PWEs have differently experienced seizures and coping strategies (See Figure 1). ***Home*** is a comfort zone for PWEs and their caregivers to manage epilepsy. ***Workplace/school*** are the places where PWEs routinely visit in their daily lives, which can also be a semi-comfort zone for them. They are more likely to be able to successfully manage epilepsy seizures in a familiar environment or with a secondary caregiver. ***Public areas*** are places where PWEs visit relatively irregularly, such as grocery stores, shops, and public parks. PWEs are more

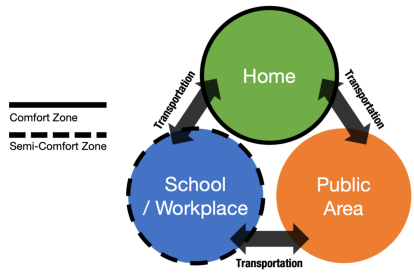

Fig. 1. Classification of Places & Comfort Zones for PWEs

likely to meet strangers in these areas, and oftentimes alone without their caregivers. ***Transportation*** is what PWEs rely on to travel between these places. PWEs may or may not feel comfortable depending on whether they trust they could receive proper care if they experience a seizure. When they travel with their caregivers, they might not be worried about having a seizure. However, without their caregivers, PWEs may not feel completely safe if a seizure were to occur. Across these modes of transportation, participants are most worried about public areas and parts of their workplace/school because they feel uncertain about whether they or their care recipients will get any help when experiencing a seizure. Below, we describe their experiences in these environments, from one end of the comfort spectrum (i.e., home) to the other end (i.e., public area) before we delve into the more nuanced in between places such as transportation and routinely visited places (i.e., workplace/school).

4.1 HOME

An Individual's home can be considered a comfort zone for PWEs and primary caregivers. The comfort zones could include home and a place where PWEs are accompanied by their primary or secondary caregivers, who know how to manage epilepsy. PWEs are more likely to manage epilepsy in these more controlled and familiar environments. Primarily, home is the most comfortable and safe place for PWEs. PWEs said that most of the time, they have someone who can take care of them if they have a seizure at home. Also, they responded that they are relatively less afraid of having a seizure at home, compared to other places.

4.2 PUBLIC AREA

We found that the participants feel very uncertain and worried about whether anyone around them knows epilepsy and first aid if they or their child have a seizure. Below, we summarize these concerns in two broad categories, the lack of public awareness of epilepsy and the lack of effective mechanisms to deliver first aid information to bystanders in public areas.

4.2.1 A Lack of Public Awareness. Participants expressed that they are afraid if they or their children have a seizure in public or any place without someone who is capable of dealing with epilepsy. They believe that the general public do not know how to treat seizures. They feel that people at school or workplace are more likely to have been introduced to knowledge of epilepsy care and management as they gain familiarity from having interacted with PWEs. However, bystanders that PWEs would encounter at grocery stores or malls are not likely to know the person has epilepsy. Moreover, participants answered that they had the unwanted experience of a bystander calling 911 while they were having a seizure when it was not necessary.

> *"(After having a seizure) I just woke up and then people were like standing around me. They don't know what to do. It was too crowded and they just carried me to the clinic or to the hospital." (Q-3)*

When PWEs have seizures, the bystanders around them often do not know how to provide proper help. Moreover, even though some people might be familiar with certain types of seizures and how to care for them, they might not know and notice the nuances between different kinds of seizures. Our PWEs and caregiver participants also elaborated on the diversity of seizures and the difficulty of learning other types of seizures that they have not encountered.

> *"I want other people in the area and community that may come in contact with our daughter to know. Not all seizures look the same. Here's what to do if you think someone's experiencing a seizure. [...] I'm a nurse and I'm still learning about what to do to help PWEs. So, I thought that is important that other people know (there are different kinds of seizures)." (FG1-3)*

Our participants have different kinds of seizures ranging from absence seizures to grand mal seizures. One reason why epilepsy education is difficult is the complexity and the nuanced knowledge required in recognizing and dealing with different forms of seizures. The lack of knowledge about epilepsy often caused bystanders to overreact or seek inappropriate treatment for PWEs. Our participants wish that there was a way to deliver individually relevant information to bystanders. Some participants have attempted to carry information cards or using apps, but these methods have their own challenges that we will report below.

4.2.2 Delivering First Aid Care Information to Bystanders in Public Area. Participants compare epilepsy awareness to learning CPR (Cardiopulmonary Resuscitation), where it is highly likely that an educated and attentive individual in the crowd would know how to perform general first aid knowledge to respond to situations such as a heart attack. Participants express the desire to raise epilepsy awareness so that first aid care response to a seizure could one day be as common as knowing how to perform a CPR.

> *"Educating the public in general, like if everybody knew CPR, people wouldn't die of heart attacks as often. [...] That the public helps you was paying attention." (Q-2)*

In addition, participants would like to deliver first aid care information to people in public areas so that the public can adequately deal with seizures. Some PWEs participants said they have tried to provide first aid care information to people around them when they felt they are going to have a seizure. However, they also expressed its difficulty. For example, the general public rarely knows to look for a medical ID on a person having a seizure. Similarily, even if a PWE has a phone that displays their medical condition, the general public is not always aware of the need to look for such information.

> *"My phone has the medical ID. Even if my phone is closed, if they click that emergency medical ID, actually it shows there. 'She has a seizure. This is what you need to do.' But people rarely see (and check)." (Q-3)*

Sharing care information and getting proper help in the public areas are the most challenging issues to PWEs and their caregivers. Having seizures in public areas without being near their caregivers poses risks and uncertainty and is a significant concern for our participants. Participants have been looking for ways to inform proper first aid care information to people around them in public areas. However, there has been no sure way to deliver it yet. Therefore, PWEs are often exposed to the risk of having a seizure without proper help in public areas.

Educating secondary caregivers around them in advance would be relatively more feasible by using various means such as e-mail and social media. However, educating public bystanders that

they might encounter would be difficult. We found that our participants have neither a clear solution to these concerns nor any other convenient and safer ways to go somewhere alone. In order to reduce their concerns and possible risks, it is needed to increase public awareness of epilepsy. Even though some seizure-detectable technologies can send a notification to their caregivers or emergency centers near them, people around them could provide the fastest first aid care. If there was just one type of symptom and one trigger in the world, people could easily deal with it, just like most people are aware of the need for CPR when someone has a heart attack. However, PWEs do not always have the same type of seizures. Some types of seizure are visible, but others may be undetectable. Therefore, it is more difficult to educate bystanders in public areas, and it makes PWEs more hesitant to go into the public areas.

4.3 TRANSPORTATION

4.3.1 Risk of Having A Seizure While Driving. The situation could be more complex and dangerous if PWEs are moving somewhere, such as commuting to their workplace. One of the worries of PWEs is having a seizure while driving by themselves. Depending on the severity of their symptoms, PWEs may or may not be able to hold a driver's license legally and drive by themselves. However, although some PWEs could hold a driver's license and that they are aware of the triggers of their seizures, they can still experience unexpected seizures. They are afraid of having seizures while driving and putting themselves and other cars or pedestrians in dangerous situations. Some participants reported having caused seizure-related traffic accidents. For this reason, PWEs told us that their prefer mode of transportation is still getting rides from family or friends despite having a driver's license.

> *"For me, I am able to drive so I can drive myself to work. But during the times when I've had seizures, I've been looking at having parent drive me places." (FG1-5)*

> *"I had a couple of periods where I actually had seizures in automobiles so then I had to live with my parents. [...] I've had a couple of times when family has been able to drive me. And a couple times when work would pay for someone to come and get me." (Q-1)*

Participants also claimed that sometimes it is harder for them to get a ride from their family or friends, depending on when they need it and where they are. In this situation, the participants would seek to find out information on ride-sharing services or public transportation that are available in their area.

4.3.2 Delivering First Aid Care Information to Bystanders on Public Transits. Similar to the public areas, there are also uncertainties of having a seizure and getting appropriate help. Some PWEs expressed their concerns about taking public transportation. If they take the transportation alone, there would be other passengers who are less likely to be aware of who has a seizure, what seizure is, how it is triggered, and how they can deal with it if the seizure happens. The key difference between taking public transportation and being in public area is that the PWEs could inform the responsible person (e.g., the driver of a bus or a ride-sharing service) that they have epilepsy or seizure disorder when they get on so that the person can learn how to help in case if a seizure occurs. However, it is not always possible for them to find a responsible person in public transportation.

> *"If it is a bus, then I can talk to the driver right away, but if it is a subway, I don't know if there is anyone I can talk to. I would talk to a passenger, but they would not know.. and I don't know anyone else in the subway. So it's easier for me in the bus." (FG3-2)*

As FG3-2 mentioned, in some public transportation, such as trains and subways, PWEs might not have access to a driver or staff. This situation could also present challenge in delivering first aid care information for seizure management.

4.3.3 A Lack of Alternatives. Depending on where PWEs live or where they go, they might not be able to choose the safest transportation for them. For example, participants think the ride-sharing service is one of the safest transportation for them, but they cannot get it if they live in relatively rural areas where the services are not available.

> *"It's really hard to get on the ride sharing services." (Q-1)*

Given that most ride-sharing services are only available in larger cities, our participants (e.g., Q-1) who live in rural areas complained frequently about this issue. Similarly, one of the participants said that she prefers bus over the subway because she could communicate with the bus driver about her conditions, but she cannot take the bus to work because there is no bus route to her workplace.

> *"It's very difficult for those who have epilepsy to travel and then the commute. [...] But lately, I don't have any other options. [...] That's why we don't go out.. it's hard to go to work, you are never sure when you gonna have seizure, and if people will know about it." (Q-3)*

It shows that the lack of transportation options often frustrates PWEs and makes it difficult for them to find a person who can help them during a seizure. If the responsible person is not accessible, another passenger near them might become a potential person who can be informed about their health conditions and first aid instructions. However, PWEs might not feel comfortable and could hesitate to share their health condition with strangers and ask them to take care of them. Their diagnosis is very private, and PWEs might fear stigma from other passengers. Just telling someone beforehand in transportation would be not easy for them.

4.4 WORKPLACE/SCHOOL

Unlike bystanders in public areas and on public transits, people that PWEs may encounter in a workplace or a school might have more knowledge about the PWEs' conditions. They are more likely to be aware of their health condition as they meet the PWE in their routines frequently and regularly. These people could be their friends, colleagues, supervisors, teachers, or other family members such as siblings or relatives. We categorize them as secondary caregivers. Educating secondary caregivers about epilepsy and the appropriate coping strategies might be relatively easier than educating the public and delivering first aid information to bystanders in public areas. However, it is still challenging to share knowledge with secondary caregivers who have less responsibility for taking care of the PWEs.

4.4.1 Care Information Sharing Challenges. PWEs are often able to engage in normal life activities. They regularly go to their workplace or school, eat, and hang out with their friends. Our participants reported that they are afraid of having seizures at these places. Most participants find that their or their children's colleagues, peers, or teachers do not know how to deal with seizures properly, and they would like to give first aid information to them. Thus, PWEs are trying to find out the way to deliver the information to people in their daily routines. Some participants have taught people first aid for seizures verbally. However, those participants would like to deliver the information using digital tools (e.g., e-mail) as they consider that it would be useful.

> *"Like emergency treatment. If I were to have a seizure at work or something, I've been able to give that [information about the treatment] to people surrounding me at work." (I-P1)*

Adults with epilepsy live more independently than children with epilepsy. They know how to manage their symptoms and seizure. They are more likely to know what to deliver to their friends or colleagues. On the other hand, for children with epilepsy, their parents, who are primary caregivers, often become responsible for epilepsy management. Parents of PWEs said that they are worried when they send their child to a place such as a school or a camp. In this case, a teacher can

often serve as a secondary caregiver for the children who need special care. The parents believe that if teachers and school nurses learn about epilepsy, they can take care of their children in an appropriate way.

> *"If they're educated, they can help but otherwise they don't know what to look for." (FG2-2)*

Caregiver participants have tried to convey important information about their children's health conditions to school staff. They wanted the teacher or the school nurse to learn how to deal with the children's symptoms. For example, one of them prepares information sheets with detailed epilepsy information to the teachers.

> *"I make ... there's an 'All About Me' page. So, I put my son's picture on there. So, it's kind of like, here's my name. Here's who I am. Here are the things I'm really good at and here are the things that I may struggle with because of my epilepsy and here's how you can help me. ... This is something tangible that she(a teacher) can have and she can go back and look at it which is an excellent resource." (FG2-1)*

Another caregiver participant educated their teachers and school nurses by sharing video resources about a specific type of seizure. She believes that it prepared them to be able to deal with seizure-related incidents.

> *"Going for a school nurse or a teacher or someone who might watch my kids then I typically give them seizure first aid care. [...] they're really quite manageable and so it's like if they were to have a seizure this is what you need to do. Please call me here. For one who has the abson seizures it's a lot more like advocating, making the teachers aware that the epilepsy foundation provides free training providing them YouTube resources of this is what an absence seizure might look like. [...] teachers handled it really well because I had taught them." (FG2-2)*

However, in most cases, they had to make extra efforts to emphasize the need for special care for their children because some teachers do not pay close attention to the information they gave. One participant claimed that she kept trying to call and visit her child's school to talk with responsible people so that they could be more aware of the need of knowing epilepsy and coping strategies.

> *"We have a lot of open conversation with the school and with, those involved in her care. It's not really anything digital or anything like that. It's mainly of advocating for her in person because I have found that it doesn't do any good just to send them anything or provide hard copies of her care or anything when they don't look at it or read it or put it in a folder or whatever so I have found face to face conversations.(FG2-3)*

Our participants reported that just giving information to a teacher at a school or a supervisor at a workplace is not enough to educate them. The reason why they did not pay attention to the information may be because they are already busy with other work responsibilities, and they might consider having deep knowledge about epilepsy and ways to deal with seizures are not immediately urgent to them at that moment given that seizures may or may not occur in some distant future. Learning new information about epilepsy is an additional burden to them because they are also in charge of overseeing other students/employees. In order to reduce their burden and increase the chance of just-in-time support when an emergency happens, people at the workplace/school other than teachers or supervisors should be also educated.

4.4.2 Education & Awareness Challenges. Participants reported having experienced the misconception, negative attitude, and discrimination from other people, which discouraged them from informing their colleagues or peers of epilepsy and the way to care. While some participants' supervisors and colleagues know that they have epilepsy, other participants answered that nobody

at their workplaces know as they have chosen against revealing their conditions. One PWEs participant did not let her colleagues know she has epilepsy except for her advisor because she is worried about potential discrimination.

> *"Most of the time, it's just my supervisor that I tell about. So whenever I'm not doing well, then I have to reach out to my supervisor [...] I don't tell everyone. [...] I wouldn't mind if people really know about it, but from experience I've had discrimination." (Q-3)*

Caregiver participants show their worries about discrimination and misconception from other people to their children. Q-2 witnessed that some teenagers teased her children with epilepsy because of their seizures. Moreover, the teachers at her school aren't supportive of promoting awareness in order to dispel the stigma against epilepsy.

> *"I corrected some kids making fun of people having seizures. [...] I'm still trying to convince the teachers to do the student training. They are a little more hesitant because they're like, 'We don't need to scare the children.'" (Q-2)*

In addition, the less educated populations of the general public continues to mystify the seizure experience, some even falsely believe it to be a supernatural phenomenon akin to a curse or a demon possession.

> *"One of my kids have a seizure one time and they literally thought it was like demon possession. [...] There is that stigma. [...] Some cultures will be like, 'Oh, you're not praying hard enough,' 'You've done something to deserve it.' " (Q-2)*

Regarding their suffering from other people's misunderstanding and negative attitudes, the caregiver participants emphasized the need for education of other people, including students, to reduce any misconception and discrimination on children with epilepsy.

4.4.3 Financial, Organizational, and Policy Challenges. Participants also pointed out the limited resources and support in organizational and policy levels. A caregiver participant said that she has a daughter who is photo-sensitive. Her child's school, a private school, made infrastructural investment to improve their fire alarm system for her. Although her child has received proper support from the school, she argued the needs of organizational support for children who need special care for all schools including the public ones.

> *"I was an advocate for getting the seizure safe school bill passed in (the state where I live). [...] Public schools aren't going to spend like $10,000 to fix a fire alarm system that they hopefully will never have to use." (Q-2)*

Other caregiver participants were also worried if institutions do not have policies in place to take necessary care of their children, and if that could result in inadequate action. For this reason, parents often wonder whether the school or institution has established any proper programs for first aid care such as the Individualized Educational Programs (IEPs), or 504 plans that provide support to children with special needs.

> *"(I am) looking for help at school. Kind of how to navigate with a 504 and IEP and things that maybe we should be having in school and not have. We've just kind of done more of the educational route with it this year as she's getting older and school's getting more challenging." (FG3-1)*

In the case of adults with epilepsy who are employees of a company, they argued that, unlike schools, many workplaces do not have the appropriate protocol or a medical emergency plan to take care of them. Thus, they want companies to be more aware of the people with special needs and have a plan in place to support them.

> *"Actually they don't know what they can do to deal with a seizure, so I let them know what they can do. I wish more organizations know how to deal with people who have epilepsy [...] There are prepared plans for schools, but they don't have it for organizations or companies." (Q-3)*

Overall, participants have concerns about a lack of awareness and proper care even from the people at the workplace/school where they routinely visit. Moreover, it is unlikely that their colleagues/peers could fully understand epilepsy due to the lack of institutional support and personal unwillingness to learn about seizure care.

5 DISCUSSION

Our findings show that PWEs and their caregivers encounter difficulties when sharing first aid information with other people and getting proper first aid care in different places. Moreover, their concerns about those challenges could influence their mental health and well-being, and it eventually affect their seizure occurrences as anxiety is associated with seizures [11]. While people with other chronic diseases might experience provoked seizures by acute brain disturbance (e.g., diabetes with hypoglycemia, stroke), PWEs experience recurrent and unprovoked one [3]. This relapsing and uncertain nature of seizures hinder their day-to-day life [35]. Future technologies should consider these attributes of epilepsy as well as its daily impacts and stigma-related issues. Thus, it is important to take a holistic perspective when designing technologies that could help PWEs receive proper care in different places.

5.1 Seizure First Aid Care Framework

We suggest a new framework regarding stakeholders around PWEs, and controllability of information sharing and first aid management for seizure in different places. Figure 2 visualizes the framework positioning each place at two dimensions – public vs. private, and uncontrolled vs. controlled. The controllability depends on where a seizure happens. ***Home*** is the most controllable area. ***Workplace/school***, a part of PWEs' routines, is controllable but less stable than the home environment. ***Transportation*** is a more public and less controllable environment than home and workplace/school. It can be considered a controllable area when transportation occurs in a private vehicle or taking transportation with their caregivers. Public transportation such as buses and trolleys are semi-controllable due to the presence of a professional driver, whereas trains that often do not have dedicated staff stationed in each car are less controllable. Obviously, ***public area*** is the most uncontrollable area populated with strangers and many dynamic environmental factors that make epilepsy management difficult.

Figure 2 and Table 2 identify where each caregiver group is potentially available based on our findings. Although the boundaries are not clearly distinct, this framework could inform for future design considerations to focus on who PWEs may involve for first aid care in each place. In addition to the availability, we found that the more public a place is, the more difficult it is to (1) share information about their conditions and first aid care, (2) find a responsible person, and (3) get proper care (See Table 3). Also, depending on the place, different types of information are useful to be shared with other people to get proper aid (See Table 4). For providing appropriate care, information on first aid care for seizures should be shared at all places. What and how it should be shared will depend on the context.

Previous research has studied seizures in general or focused on specific contexts such as having seizures while driving [18, 51, 96], at schools [2, 42], or at hospitals [76, 102]. In our research, we classified four areas PWEs have experienced seizures in their normal lives. We also considered the

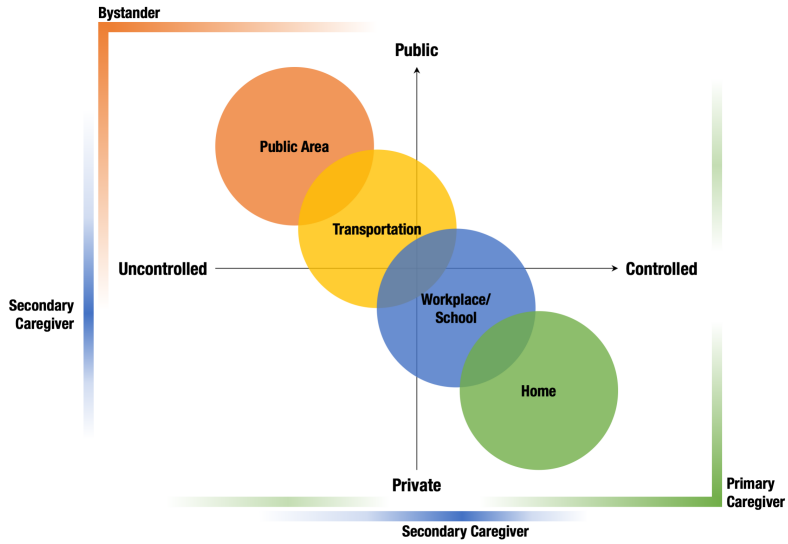

Fig. 2. Seizure First Aid Care Framework. The color gradient around the edges indicates the general availability of each caregiver group in each place, with solid color indicating higher availability.

Table 2. Likelihood of Available Person Who Can Provide Aid at Different Places

	Home	Workplace/School	Transportation	Public Area
Primary caregiver	High	Low	Mid	Mid
Secondary caregiver	Mid	High	Mid	Mid
Bystander	Low	Mid	High	High

Table 3. Controllability of Information Sharing and Care Management at Different Places

	Home	Workplace/School	Transportation	Public Area
Share care info in advance	High	High	Mid	Low
Find a responsible person for care	High	Mid-high	Mid-low	Low
Get proper first aid care	High	Mid-high	Mid-low	Low

Table 4. Usefulness of Types of Information to Share at Different Places

Information about	Workplace/School	Transportation	Public Area
Epilepsy Awareness and Education	High	Mid	Mid
Anonymized PWE	High	Mid	Mid
Specific PWE	Mid	Low	Low
Triggers of seizures	High	Low	Low
First aid care for seizures	High	High	High

challenges at transportation and public areas where bystanders can be involved in care. Our framework would contribute to identifying potential design opportunities for leveraging technologies to involve caregivers in providing epilepsy management and support in various places.

5.2 Ad Hoc First Aid Care Collaboration with the Public

Sharing information with the public bystanders in advance and finding any responsible people may be challenging. However, if the general public can learn how to deal with a seizure at the moment when a person having a seizure without their caregivers, they can serve as first aid caregivers. They can provide immediate help to the person. Our findings align with the research that shows the association between bystanders' lack of knowledge and awareness of seizures and their inability to provide appropriate help [84]. In this sense, prompt delivering first aid information to those bystanders has the potential to improve PWEs epilepsy management in public places.

As mentioned earlier in this paper, although several smartphone apps provide first aid information, our participants do not find these apps to be very useful in actual practice. Similarly, a person who is in cardiac arrest is also vulnerable when nobody can help immediately. However, cardiopulmonary resuscitation (CPR) is a well-established practice for restoring spontaneous blood circulation and breathing in a person who is in cardiac arrest. Several apps have been developed to notify volunteers who are trained to perform CPR to nearby emergencies. For example, PulsePoint Respond is a 911-connected app that informs trained volunteers of emergencies occurring nearby, and PulsePoint AED is a smartphone app that maintains a public AED (Automated external defibrillator) registry in a local community [83]. Mixed Reality (MR) technology has also been suggested as a tool to guide untrained people to perform CPR in emergency situations by using visual and spatial cues. Research shows that an MR application (HoloCPR) reduced an individual's reaction time and improved the accuracy of procedure [46]. Similar to CPR, there is a potential to develop similar apps that could connect volunteers who are familiar with seizure management to nearby epilepsy-related incidents as well.

The general public does not typically stigmatize a person suffering from a cardiac arrest or a heart attack. CPR is widely accepted, and many institutions have mandates to have trained onsite staff who can perform CPR in emergencies. Washington, D.C. and 38 states in the U.S. have required CPR training for high school students to graduate [4]. To the best of our knowledge, there is no research concerning public stigma toward people having a cardiac arrest or a heart attack. However, the general public tends to misunderstand seizures and are not trained to recognize diverse symptoms of epilepsy and to perform first aid treatments. Prior literature has addressed epilepsy-related stigma and its association with the lack of knowledge and familiarity [7, 26, 86]. Moreover, the public might not consider installing epilepsy-related smartphone apps both in advance and at the moment when they encounters a person having a seizure. Also, searching and downloading the app can be time-consuming. In this sense, future systems should be designed with a simple user interface, which does not require much effort to search for information. On the other hand, some apps could show emergency-related information on the lock screen when they detect a user's emergency due to a seizure. Someone around this person might see the phone and follow the displayed first aid instructions. This functionality is similar to existing medical ID bracelets or necklaces that are common form factors for delivering one's basic health information via QR code or NFC (e.g., MyID [73]), and future designs for medical accessory could also make them more visible. However, a primary issue is that the general public rarely knows to check PWEs' phones or personal accessories for possible medical information when a seizure occurs. Considering people's limited attention, the information should be easily found and seen by the public when an emergency happens. A potential solution may be a noticeable signal (e.g., audible, tactile, etc.) that draws people's attention to the phone's screen or a first aid device that the PWEs may carry. This will

likely prompt the bystanders to look for the source of the alarm and subsequently spot any relevant care information that could help the PWEs. Conversational agents could also be embedded in the first aid devices to share the information without requiring the people to look at the screen.

In addition to delivering first aid information, increasing public awareness in general is another key part of the solution. Previous studies on epilepsy have claimed the importance of improving public awareness of epilepsy. The general public does not typically stigmitize a person suffering from a cardiac arrest or a heart attack, but that is achieved by deliberate policy changes and decades of public education. Without knowledge of epilepsy and seizures, the general pubilc might still be misinformed and be shocked by physical presentations of seizures and might make inappropriate decisions such as unnecessarily calling emergency services [84]. Effective ways to improve public awareness through technology could be studied in future research. It should consider user experiences and contextual factors, such as caregiver availability and environmental and situational factors, as illustrated in the design framework presented in this paper.

To summarize, future technology design should consider the potential role of bystanders in public areas. Regarding their roles, the technologies could be designed to (1) detect the exact type of seizure, (2) to deliver personalized first aid care information to the public in a fast and straightforward way, and (3) to increase the awareness of epilepsy among the public. In CSCW and HCI research areas, little research has focused on experiencing seizures in public areas and ad hoc sharing first aid information and collaboration with bystanders who could serve as first aid care responders. In order to reduce the concerns of having seizures in public areas and increase the safety and overall well-being of PWEs and caregivers, future studies should consider bystanders as potential caregivers and discuss potential technology designs for this context.

5.3 Semi-Ad Hoc Care Collaboration During Transportation

The contexts of transportation are similar to public areas. Since space could be more limited, sharing first aid care information could be a little more controllable. Transportation can be categorized into two types – public transportation and an individual's car.

5.3.1 Finding a Person in Charge & Care Information Sharing When Utilizing Public Transportation. There could be a person who can be responsible for care while PWEs are taking public transportation (e.g., bus/taxi driver). Future technologies could improve sharing information with a potentially responsible person and other passengers. For example, there could be an automated notification system for PWEs or a primary caregiver who agrees with sharing location data and their planned destinations. The system can inform the driver her/his passenger's epilepsy conditions and the basic first aid information in advance. Then, the PWE or the caregiver can avoid the burden and awkwardness of sharing information with the driver. Also, a bus or a train/subway can have public announcement systems to inform passengers of first aid information for seizure via a smartphone, a screen, or even a pre-recorded speaker announcement when a PWE is on board. The system does not reveal who has epilepsy for the sake of protecting their privacy and reducing the potential stigma toward them. However, there may be unintended consequences as previous research have identified that technologies that are designed to support people with illness and disability may draw unwanted attention from others and increase stigma toward them as it makes invisible conditions visible. [34, 77, 93]. In the case of epilepsy, it is a condition that is invisible until PWEs suffer seizures that exhibit physically visible symptoms. For example, if there are only few bus passengers, a public announcement about epilepsy that is made only when PWEs are onboard might accidentally reveal their identity. Therefore, a potential design of public announcement system may want to publicize the information at random and unspecified intervals. In general, future systems should cautiously consider diverse contexts in public transportation, from specific

situations (e.g., type of transportation, the number of passengers) to their historical, cultural, and social aspects (e.g., general perception and attitude of the public). The stigma reduction is further discussed in Section 5.4.2.

5.3.2 Seizure Monitoring & Information Sharing While Driving. A car is a primary means of transport for commuting, sustaining social relationships, and living independently. Experiencing a seizure while driving is one of the significant issues that damage the quality of life as well as safety for both PWEs and other people [18, 96]. In the U.S., states have regulated driving for PWEs. The regulations vary depending on the states and individual clinical diagnosis, such as the capability to control seizures [51]. Our findings show that our participants have their own driver's licenses but could not drive because they experienced a seizure while driving. They might still be concerned about seizures when driving even though they are legally allowed to operate a vehicle.

Other drivers or police officers could serve as potential caregivers but it would be difficult for them to directly help the driver experiencing a seizure. In this sense, possible future technologies to reduce the risks can be a smart car, which does not require control of a driver [53], or AI-based system in a car and a wearable device that can monitor and detect a driver's seizure. Depending on the type of seizure, it can automatically switch on self-driving mode if the driver loses control or falls unconscious. Also, it might send notifications to other drivers, police officers, or hospitals near the car to prevent potential accidents and provide help if needed.

5.4 Prior Education for Secondary Caregivers at Workplace/School

In the daily routines of PWEs, they encounter a small group of familiar people in relatively stable places. Unless PWEs try to hide their health conditions, people they encounter in their routines could be educated about the person's epilepsy and become secondary caregivers. Sharing essential information with them in advance is crucial to providing the appropriate care and relieve the concerns of PWEs and primary caregivers [36, 82]. PWEs believe that informing others their conditions beforehand would increase the possibility of them making the right decisions when a seizure occurs [84]. Educating people in a patient's social network and getting help from them have also been shown to be effective coping strategies for people with migraine, which also could be unpredictable and may require assistance of others [79]. However, although seizures are the common emergencies in schools, school nurses and staff were generally not well trained to handle seizures [89]. Teachers, school nurses, and work supervisors might not pay attention to the information about PWEs and first aid care because of the uncertain time horizon and their other responsibilities and information burden. Also, stigma might hinder PWEs from informing their conditions to those people.

5.4.1 Information & Responsibility Diffusion. In order to reduce secondary caregiver's burden to learn epilepsy and provide proper first aid care, the information should be easy and simple to understand. Also, the responsibility for care, which a teacher or a supervisor of a PWE mainly has, could be diffused among other people at the workplace/school by educating them. Thus, future potential technologies could be designed at both individual and organizational levels to educate people at the workplace/school. For example, at the individual level, digital information about epilepsy and first aid care for seizures should be designed and delivered so that each individual can learn and follow the instructions more easily. At the organizational level, a company/school should embrace a culture of health and inclusion and set policies to encourage and support people to learn about epilepsy and first aid care. A smart and AI-based workplace/school system could be designed to integrate one's health condition and automatically adjust the factors that might trigger seizures, such as light or smell, depending on PWEs' location. Also, it could detect a person experiencing a seizure, and alert it to people in charge of care, and help colleagues/peers nearby by giving the aid

instruction through a close speaker or screen in the building. These systems can be extended to be used for coping with other emergencies related to one's disorders/diseases.

5.4.2 Facilitating Education & Stigma Reduction Strategies. Epilepsy stigma has been well-studied as one of the significant problems that negatively impact PWEs' quality of life [45]. The two types of behaviors that our participants have shown coincide with the theory of stigma-coping strategies by Meisenbach (2010) [67] – hiding or disclosing to get support from others. While PWEs are not likely to meet the same people again after they have a seizure in public areas, they will continue to encounter the same individuals at their workplace/school. Research has shown that colleagues/peers are frequently uncomfortable about epilepsy and tend to avoid PWEs [38]. PWEs could be hesitant about disclosing their health conditions in order to avoid facing possible discrimination. People with other chronic diseases, such as migraine and HIV, also face similar stigma-related issues. Invisible symptoms of an illness and one's lack of knowledge about it could cause other people to underestimate its severity or have negative attitudes toward it [59–62, 78, 79, 107]. In the case of epilepsy, the public could have stigma and misconception due to physically visible symptoms of seizures, which are often short but impactful, and historical and cultural perceptions of epilepsy, which might have strengthened misrepresentations of epilepsy linking it with demonic possession [25, 50, 65]. Therefore, the public may feel reluctant to help PWEs during a seizure.

In this sense, future technologies should consider the attribution of epilepsy stigma, such as the visibility of seizures and cultural perceptions, as well as the different symptoms of epilepsy, as people with chronic diseases often experience individual and social challenges differently depending on the severity of symptoms [79]. To reduce stigma effectively, multi-level approaches should be implemented across intrapersonal, interpersonal, organizational, community, and governmental level [39]. First aid educational video could reduce stigma and social avoidance toward PWEs and increase the audiences' knowledge of epilepsy and feeling of comfort [38, 86]. However, some people may have a negative perception of epilepsy due to their cultural background. Educational materials may be more effective if they are tailored and personalized based on an individual's background. Since social media platforms have also been used to combat stigma and increase social recognition [10, 23, 79], analyzing social media trends on how stigma is perpetrated on social media and actively promoting advocacy for epilepsy awareness could be an effective mechanism for epilepsy education.

6 CONCLUSION

Our research identified four main areas where they have different challenges of having seizures and getting proper first aid. Mainly, we focus on public areas, transportation, and workplace/school. Future technologies should consider different contexts and ways to involve other people as temporary caregivers. We suggest future systems for effective ad hoc information sharing and care collaboration in public areas, semi ad hoc solutions at transportation, and prior education at the workplace/school. Our study contributes (1) to shed new light on the significance of first aid care from secondary caregivers and bystanders when people have seizures at different places, which have not been well studied despite its many promising potentials; (2) to address caregivers' invisible burdens and concerns about their children having seizures in other places; (3) to articulate a design framework that offers potential design opportunities for effective first aid to PWEs; and (4) to discuss design implications for future systems to support just-in-time delivery of first aid care information to secondary caregivers and bystanders. Moreover, our design framework could be applied to and provide insights to other chronic diseases that suffer from unpredictable symptoms, needing first aid assistance, lack of familiarity of the general public, and stigma-related issues and concerns.

In this study, we focused on the common challenges and needs of PWEs and their caregivers with diverse epilepsy conditions and backgrounds. Our recruitment generally sought out any PWE and caregiver of PWEs without focusing on a specific type of seizure or their controllability. Therefore, we could not explicitly expose challenges that may be experienced differently depending on PWEs' seizure types, living conditions, and income levels. Moreover, this research was conducted in the U.S., where it is more likely to receive proper treatment for epilepsy than low- and middle-income countries where nearly 80% of PWEs live [104]. PWEs living in these countries may have different experiences due to health disparities and income inequity [13, 20]. Although our participants are predominantly females, the gender breakdown is typical of prior epilepsy research [66]. This is especially true for caregivers because women disproportionally shoulder the burden of performing care work that are typically considered as a form of invisible labor [17]. Future work could focus on broadening this research to include people from diverse backgrounds in terms of gender, living condition (e.g., rural vs. urban [58, 95], inner city vs. suburb, developing countries), income, and race/ethnicity. Also, future work could focus on a specific type of seizures. It could also compare different types of seizures as well as comparing people who can control their seizures and those who cannot.

PWEs can face dangerous situations and get inappropriate care from others when they have a seizure without their caregivers or someone who knows how to deal with seizures. Primary caregivers of PWEs also have the same concerns and whether their care recipient can get proper aid from other people. Designing future technologies involving secondary caregivers and bystanders can increase the chances of providing proper first aid care to PWEs. Ultimately, it could reduce the physical and psychological burdens of both PWEs and primary caregivers while improving their mental well-being and physical health.

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