

**Perceptions of Capability Among Female Stroke Survivors in the Context of Disaster Risk
Reduction**

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ABSTRACT

Women and persons with disabilities are at increased risks of experiencing negative health outcomes during and after disasters. The Sendai Framework (2015), published by the United Nations Office for Disaster Risk Reduction, highlights the need to strengthen disaster risk reduction (DRR) among populations at disproportionate risk, using an *all-of-society* approach that is inclusive and engaging. This research investigated the perceptions of capability among female stroke survivors, in the context of DRR. The purpose of this study was to 1) examine the role of asset literacy in the social construction of capability and lived experiences of female stroke survivors and 2) create an opportunity for female stroke survivors to share their lived experiences among themselves, and members of the stroke and DRR communities. Four women were recruited through snowball sampling. Study participants were invited to join a PhotoVoice project – a participatory method in which survivors were asked to respond to prompts using photography. Data was analyzed using qualitative, thematic analysis. Study results revealed that perceptions of capability in DRR for stroke survivors was rooted in the context of their recovery. Participants discussed 4 sets of recovery and DRR assets: 1) physical, 2) social, 3) energy and 4) personal characteristics. Autonomy was identified as a valued recovery outcome, and as needed to establish self-efficacy and adaptive capacity to cope with disasters. Social participation and asset literacy can support one another, and may enhance disaster resilience. An important aspect of Photovoice initiatives is sharing the messages with important stakeholders, as identified by the participants. This research has been shared at the annual international EnRiCH meeting (2018). We are currently planning a photo exhibit to be held in the fall of 2018. Overall, this research shows how creative tools (i.e. Photovoice, asset-mapping) can be used to foster social participation, and include populations at disproportionate risk in the DRR discussion.

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CHAPTER 1: INTRODUCTION

1.1 Problem Definition

The Sendai Framework (2015) published by the United Nations Office for Disaster Risk Reduction (UNISDR) serves as an important contribution to the field of disaster management. Its guiding principles aim to diminish disaster risk through promotion of strategies that prevent and reduce vulnerability to disasters, increase disaster preparedness, enable recovery and ultimately foster resilience (UNISDR, 2015). An important recommendation of the Sendai Framework highlights the need to include populations at disproportionate risk in disaster planning:

Disaster risk reduction requires an all-of-society engagement and partnership. It also requires empowerment and inclusive, accessible and non discriminatory participation, paying special attention to people disproportionately affected by disasters, especially the poorest. A gender, age, disability and cultural perspective should be integrated in all policies and practices, and women and youth leadership should be promoted. In this context, special attention should be paid to the improvement of organized voluntary work of citizens.
(UNISDR, 2015, p.12)

Research shows that persons living with disabilities are at increased risk of experiencing disaster-related negative health outcomes (Bethel et al., 2011) and would benefit from disaster risk reduction (DRR) plans that cater to their specific needs (Kelman, 2015). While documents such as the World Report on Disability (World Health Organization and World Bank, 2011) and the Sphere Project (2011) provide guidance and effective DRR practices for persons with disabilities, there is little empirical research supporting these recommendations (Stough, 2015). Furthermore, since persons with disabilities represent a diverse group, efforts should be made to create specialized DRR strategies and disability-related supports, rather than adopting a blanket-approach (The Sphere Project, 2011).

Similarly, the literature clearly establishes that women are disproportionately impacted by disasters due to gender-based vulnerability and exposure to risk (Sharma et al., 2015). Generally,

women are more likely to suffer fatalities (UNDP, 2012), and more likely to be displaced to unfamiliar locations and receive fewer resources for recovery (Peek & Fothergill, 2008). These disaster impacts can be attributed to pre-existing societal structures and gender-specific roles. For instance, following the aftermath of Hurricane Katrina (2005), women were faced with additional responsibilities of providing care, emotional and economic support, health promotion and protection for their children (Peek & Fothergrill, 2008). There is a need to further examine differential disaster impacts between men and women, with reliable and consistent data (Cutter, 2017). Furthermore, it is important to develop gender-sensitive DRR strategies that include women from planning to implementation (UNISDR, 2011).

In the context of DRR, the capability approach (CA) and asset-based approach are frameworks that can foster inclusive, *all-of-society* strategies (O’Sullivan et al., 2017). Amartya Sen’s CA (2000) is a human-centered approach to the evaluation of individual and collective well-being, policy design and social reform (Kremakova, 2013). In this approach, capability is defined as a “person’s ability to do valuable acts to reach valuable states of being” (Sen, 1993, p. 30). This approach is sensitive to human diversity, and understands that humans can reflect on and express what they value for themselves and for others. As such, it is concerned with equalizing capabilities rather than outcomes (Walker & Unterhalter, 2007).

Developed by Morgan and Ziglio (2007), the asset-based approach to public health investigates assets that enable the creation of health, rather than the prevention of disease. In doing so, this approach places emphasis on the positive capability of individuals within a community to recognize problems and activate solutions. The asset-based approach encourages full participation of communities in the health development process (Morgan & Ziglio, 2007). An important strategy to foster participation is asset mapping. It is the process of building an

inventory of the strengths of a community, and can foster empowerment and renewal among individuals (McKnight, 1995).

A key component of DRR is community engagement and social participation (Witvorapong et al., 2015); the sustainability of disaster management plans is highly dependent on partnership, participation and ownership of local communities (Shaw, 2012). The process of conscientisation refers to the need for communities to engage in critical reflection, dialogue and mobilized action to promote social justice (Freire, 1974); this can be facilitated through participatory research projects that enable co-creation of knowledge by individuals who are experts on their own lived experiences (Graham, 2013).

The overarching purpose of this study was to investigate perceptions of capability among female stroke survivors, in the context of DRR. Strokes are the leading cause of long-term adult disability in most developed countries (Gibson & Atwood, 2016). A report released by the government of Canada in 2015 indicated that while stroke prevalence rises sharply after the age of 55, 1 in 4 Canadians who have suffered a stroke are under the age of 65 (Public Health Agency of Canada, 2015).

Cerebral ischemic strokes are caused by an interruption to the blood flow to the brain due to the presence of a thrombus or embolism. Risk factors include high blood pressure, smoking, obesity, diabetes, high blood cholesterol and atrial fibrillation (Public Health Agency of Canada, 2015). Symptoms include speech/language disturbances, lack of mobility, visual impairments, problems with coordination, paralysis, etc. (Lisabeth et al., 2009). Among stroke survivors, it is estimated that 70% of individuals experience compromised work capacity and 30% require assistance with self-care (Gibson & Atwood, 2016).

Stroke presents a unique set of risk factors, symptoms and consequences in women. According to the National Stroke Association (2018), it is the third leading cause of death in women and every year, 55 000 more women suffer strokes than men. A report published by the Heart and Stroke Foundation of Canada (2018) indicates that compared to men, women are 35% more likely to die within a year of experiencing a stroke and 24% more likely to die within five years. Unique risk factors for stroke in women include taking birth control pills, being pregnant and using hormone replacement therapy to relieve menopausal symptoms (National Stroke Association, 2018). Pregnant women are three times more likely to experience a stroke than non-pregnant women. Furthermore, 25% of strokes in women occur between ages 50 and 69 years (Heart and Stroke Foundation of Canada, 2018).

Women are more likely to live alone when they have the stroke, live in a long-term health care facilities and undergo an arduous recovery process. Post-stroke, women are less likely to participate in rehabilitation than men (46% vs 54%) (Heart and Stroke Foundation of Canada (2018). Stroke was the chosen focus for this research due to its high prevalence, as well as its diverse and unique health and disability outcomes.

In this study, participants were involved in a 5-month Photovoice initiative, through which they shared their lived experiences with fellow female stroke survivors. This study was participatory in nature, encouraging survivors to decide the direction and content of the stories they shared. While the intention was to contribute to the limited body of research on this topic, an additional objective was to provide an opportunity for the voices of female stroke survivors to be heard and for them to be agents of change. As such, this study was designed to foster co-creation of knowledge about capability from the perspectives of female stroke survivors, and facilitate social participation in community resilience and DRR (McLeroy et al., 1988).

1.2 Research Question and Objectives

In this study we explored perceptions of capability among female stroke survivors in the context of DRR through the following research question and study objectives:

- 1) What does capability mean to female stroke survivors, in the context of disaster risk reduction?

Objective 1: To examine the role of asset literacy in the social construction of capability and lived experiences of female stroke survivors

Objective 2: To create an opportunity for female stroke survivors to share their lived experiences, enhance collective asset literacy among members of the stroke and DRR communities, and support social participation.

1.3 Thesis Overview

This thesis is organized as follows: Chapter 2 is a literature review that provides context to this study through an overview of key concepts and terms. Chapter 3 describes and justifies research methods. In Chapter 4 study results are presented, followed by the discussion in Chapter 5 and conclusion in Chapter 6, which highlights implications of this study and future avenues for research. The final sections of this thesis contain a list of references and appendices, with the ethics certificate, recruitment notice, consent form, social media posts, introduction meeting agenda, coding grid and a list of resources for persons with disabilities in Ottawa.

CHAPTER 2: LITERATURE REVIEW

This chapter explores current literature to provide context and rationale for this study. The first section investigates DRR from a social vulnerability perspective, focusing on gender and disability as variables. The second section examines the theoretical underpinnings of this research: The Capability Approach and the Asset-Based Approach. The final portion explores applications of the asset-based approach to DRR and stroke survivors.

2.1 Disaster Risk Reduction: Key Terms

As defined by the UNISDR (2015), DRR is the policy aim to prevent, reduce and manage disaster risk, and to increase resilience and foster sustainable development. For the purposes of this project, disasters were defined as “a serious disruption of the functioning of a community or a society involving widespread human, material, economic or environmental losses and impacts” (UNISDR, 2009, p. 9). The concept of community resilience is also integral to the DRR discussion; this refers to a community’s capacity to resist and recover from a disturbance (Castleden et al., 2011).

2.2 Social Vulnerability and Disaster Risk

Historically, disasters have been perceived as random events that indiscriminately impact populations (Peek & Stough, 2010). However, in the mid-1970s, social scientists began adopting a social vulnerability lens; this conceptualizes disaster impacts as the products of social, political and economic factors that influence risk exposure and capacity to prepare for, respond to and recover from adverse events. Disaster risk is distributed in ways that highlight pre-existing social inequalities (Wisner, 2004). Research shows that children, women, seniors, racial and ethnic

minorities, those living in poverty and persons with disabilities are at disproportionate risk during disasters (Cutter et al., 2003). Due to socio-historical and economic reasons, they often lack access to important economic and social resources, and have limited autonomy and power (Morrow, 1999). The social vulnerability lens supports identification of groups at disproportionate risk, but there is a need to further explore the complex intersections between these demographics (Peek & Stough, 2010; Phillips & Morrow, 2007).

2.2.1 Disability and Disaster Risk

In recent years, researchers have also examined disability through a social lens, where it is viewed as the product of interactions between social factors and individual capacities (Kelman & Stough, 2015). Society plays an influential role in the social construction of disability, and in establishing and perpetuating inequality. When society does not plan for the needs of persons with disabilities, barriers are created and independence is limited. The social vulnerability approach focuses on the supports that persons with disabilities require to live independently and how they wish. To meet this goal, disability theorists examine concepts such as equity, inclusion, accessibility, stigma and accommodation (Kelman & Stough, 2015). The intersectionality between disability and disasters reveal how structural aspects of society can be relevant in both domains (Kelman & Stough, 2015).

Research indicates that persons with disabilities live in circumstances that do not allow them to prepare for, respond to and cope with disasters. Lower rates of employment and home ownership, as well as higher chances of having significant medical needs are among the many factors that contribute to increased disaster risk (Stough et al., 2010). Research also shows that persons living with disabilities are more dependent on pre-disaster accommodations, such as in-

home care, that may not be available to them during and after disasters (Stough et al., 2010). Furthermore, those living with disabilities are more likely to live in mobile homes and as a result, experience more damage to their homes during disasters (Van Willigen et al., 2002). Accessing post-disaster services may also present challenges; it often requires skills that are not accessible to individuals with particular deficits. For example, cognitive disabilities may impact completion of paper work, or the capacity to initiate contact with service agencies (Stough et al., 2010).

A large focus of existing studies on DRR for persons with disabilities is evacuation and emergency preparedness (Twigg et al., 2011). Research shows that households with persons with disabilities are less likely to have evacuation plans (Usher-Pines et al., 2009). Furthermore, persons with disabilities require more time and resources to complete a safe evacuation (Christensen et al., 2007). For example, they may need to take their personal care equipment during evacuation; medical support such as ventilators and dialysis equipment are often difficult to transport. They may also require assistance with transportation, mobility and communication during evacuation (Kelman & Stough, 2015). In addition, persons with disabilities are often hindered by their own built environment to evacuate efficiently (Christensen et al., 2007). Thus, evacuations of these households can be delayed (Van Willigen et al, 2002); this delay is increased when families refuse to leave behind members who do not have accessible modes of transportation (Elder et al., 2007). It is important that strategies to promote emergency preparedness consider the unique needs of persons with disabilities, and that barriers are removed and proper supports are made available (Levac et al., 2012).

There is a need to reorient societal perceptions of disability and encourage disability-inclusive disaster planning. An article released by the UNISDR indicates that the main reason why a disproportionate number of persons with disabilities suffer during disasters is because

their needs are neglected and they are not included in disaster planning (UNISDR, 2013). When those with disabilities are not included in the planning process, their needs are not met and they can suffer serious consequences. As such, persons with disabilities should be included in governmental disaster preparedness activities (O’Sullivan et al., 2013; O’Sullivan et al., 2014; Tracey et al., 2017).

One approach to disability-inclusive DRR strategies is incorporating sensitivity training to planning. The need for sensitivity training is highlighted in a study by Murray et al. (2009), where results revealed that university faculty members who were not given disability-focused training were less sensitive towards their students with disabilities. Insensitivity towards those with disabilities arises when people do not understand or recognize the nuance of disability; as a result, people can be seen as helpless and dependent on the strengths of others (Godan et al., 2008). Other strategies include training persons with disabilities to be weather alert and know which actions will lead them to the safest account. Similarly, caregivers should be trained on when and how to help persons with disabilities. This training should be extended to disaster organizations as well (Kelman & Stough, 2015).

2.2.2 Women and Disaster Risk

Similar to the study of disability, a social vulnerability lens must be adopted when examining women in the context of disasters. The gendered nature of disasters and the societal constructs that impact women is well-documented in the literature. Pre-existing lower social statuses and gender-specific roles for women may be exaggerated during and can carry over after disasters. Existing gaps in education, property ownership, access to resources, capacity to make

decisions and domestic responsibilities are all factors that can exacerbate gender-specific disaster impacts (Juran, 2012).

Gendered economic inequality is a pervasive social issue among women in both developed and developing countries (Cutter, 2017). A report released by the United Nations in 2015 indicates that women continue to serve as primary caregivers, and are responsible for unpaid household and child care tasks (United Nations, 2015). In many parts of the world, women remain dependent on their spouses and often lack independent financial security (Cutter, 2017). For those employed full-time, the gender pay gap persists; although this is narrowing in developed countries, women continue to earn 70-90% of the pay men receive, despite similar levels of experience (World Economic Forum, 2015). As a result, women generally have higher rates of poverty than men, and are more likely to live in high-risk residences such as trailer homes or near hazardous neighborhood environments. In addition, they tend to have lower access to health care and proper nutrition (Enarson, 2012). Gender disadvantages in livelihoods and living conditions are magnified during and after disasters (López et al., 2014).

Violence against women and girls is another form of gender inequality that is amplified post-disaster. Existing research reports increased levels of intimate partner violence (IPV) during and after disasters. For example, a study conducted in 1999 by Enarson revealed that domestic violence centers in Canada and the United States located in disaster-affected areas experienced higher service demands. This can be attributed to several causes. Studies suggest that post-disaster stressors such as housing and financial disruptions and unemployment can disrupt relationships, leading to increased rates of IPV (Enarson, 1999; Lowe et al., 2012). Gender-based violence can prevent women from adapting to and recovering from disasters (Cutter, 2017).

The gendered nature of disaster impacts highlights the need to include women in the DRR discussion. During the 2015 World Conference on Disaster Risk Reduction (WCDRR), the importance of viewing women as participants and leaders in DRR strategies was emphasized by the WCDRR Women's Major Group (WEDO, 2015). Women can contribute an important understanding of social networks and community resources that can benefit disaster management plans. Gender-specific post-disaster response is an opportunity to empower women and promote community resilience (UNDP, 2012). As such, there is a need to include women in the DRR discussion at both grass roots and governmental levels. Furthermore, gender-specific data collection is necessary to ensure the needs of women are met (Lewis, 2016).

In 2011, the UNISDR released a 20-point checklist that provides guidelines on how governments can ensure DRR strategies are gender sensitive and inclusive of women. This checklist highlights the need to incorporate gender-sensitive DRR strategies in technical, political, social, developmental and humanitarian processes. Among the recommendations, the UNISDR suggests the need for gender-sensitive risk assessments and DRR indicators, gender analysis of existing policies, investment in advocacy initiatives, creating opportunities for leadership among women, and encouraging women to engage in community planning activities to support DRR.

2.3 Capability Approach and Asset-Based Approach

Recommendations for disability and gender-sensitive DRR strategies highlight the existence of societal barriers that increase disaster risk, and the need to adopt engaging, inclusive practices that meet individual needs. This section examines two human-centered paradigms for

health and well-being that support resilience through empowerment, and focus on positive capacity.

The Capability Approach (CA) is a theoretical framework that was developed by economist and philosopher Amartya Sen (2000) and further extended by Nussbaum (2000). Broadly, CA asserts that society should foster environments that widen opportunities for people to achieve what they value in life (Tiwari, 2017; Clark, 2006). Thus, it places humans at the center of development discourse and focuses on the diverse capabilities of people to convert resources into achievements or outcomes (Clark, 2006). This approach has become increasingly popular in social sciences domains, including international justice, human rights as well as policy research, evaluation and practice (Kremakova, 2013). The core concepts of CA are capabilities and functionings.

Capabilities are the freedoms or opportunities for a person to attain achievements that she/he/they value (Clark, 2006). In other words, it refers to what a person can do or become with available resources; this varies depending on personal, social and environmental factors, and not solely on the amount of resources available. Functionings are the outcomes that can be obtained through capabilities. Examples include being healthy, having an education, being able to be involved in the community, etc. (Tiwari, 2017). The Human Development and Capability Association (2005) uses an example of a person riding a bicycle to explain the relationships between these concepts. In this case, the bicycle is the resource, the ability to ride a bike is the capability and the resulting mobility is the functioning. By placing emphasis on capabilities rather than functionings, this approach focuses on establishing equality in choices, freedoms and decision-making (Trani et al., 2011).

The Asset-Based Model for Health (Morgan & Ziglio, 2007) compliments the CA as it highlights the positive capability of humans to identify problems and activate solutions. This model draws on the Theory of Salutogenesis (Antonovsky, 1987), which examines positive patterns for health rather than negative outcomes. The asset-based approach focuses on identifying assets that foster creation of health - these are protective factors that build resilience and inhibit high-risk behaviours (Morgan & Ziglio, 2007). In applying this lens, people become aware of their resources and capabilities, and feel more empowered to take responsibility for their own development (Nel, 2015). Asset-mapping is the process of building an inventory of strengths and resources of a community (Kretzmann & McKnight, 1993). This allows investigators and policy makers to work with existing capabilities of individuals and communities (Morgan & Ziglio, 2007).

According to Morgan & Ziglio (2007), at an individual level, health and development assets can include: Social and cultural competence, a commitment to learning, positive values, positive self-esteem and a sense of purpose. At a community level this can include: Supportive networks, intergenerational solidarity, community cohesion, religious tolerance, etc. At an institutional level, health assets can encompass: Employment security, opportunities to volunteer, safe housing, political democracy, resources that promote physical, mental and social health, social justice, etc.

2.3.1 Agency, Resilience and Inclusive Community Engagement

Both the CA and asset-based approach lend support for empowerment and inclusive community engagement (O'Sullivan et al., 2017), and draw from similar concepts. The concept of *resilience* is central to both approaches. Resilience was identified as a health asset by Morgan

& Ziglio (2007). According to the CA, a focus on capability to achieve valued states of being can serve as a positive basis for building resilience because it allows for inclusion of the social and physical environment. Rather than focusing on deficits, it draws attention to how external social structures can build individual and community resilience by creating a supportive social environment (Stephens et al., 2014).

The concept of *agency* is also important – it refers to the ability and responsibility for people to shape their own lives to meet goals they deem valuable. It is a key component of human well-being as it allows humans to further advance their well-being in a way they believe worthwhile (Alkire, 2002). The CA views individuals as active participants in their own development (Ulterhalter, 2007). According to Sen (2000), to be actively involved in shaping one's own life and to reflect on this ability is critical in facilitating positive social change. As such, agency is needed to drive collective action and democratic participation. Asset-mapping is an example of a process that supports active participation, where communities jointly identify and activate resources. In doing so, they develop independence to shape their own well-being (Morgan & Ziglio, 2007). Recognizing agency allows for classification of individuals based on their choices, beliefs and priorities, instead of characteristics such as gender or disability status (Trani et al., 2011).

2.3.2 Applying an Asset-Based Approach to DRR

The Framework for Critical Social Infrastructure to Promote Population Health and Resilience (O'Sullivan et al., 2013) sheds light on the complexity of community resilience. It recommends building on existing assets within a community to promote resilience, and highlights connectedness, collaboration and situational awareness as assets that support adaptive

capacity to respond to change. This framework provided the theoretical basis for the EnRiCH (Enhancing Resilience and Capacity for Health) Project (O’Sullivan et al., 2013), which used an asset-mapping exercise to identify resources within four different communities that can enhance resilience and preparedness among groups at disproportionate risk during disasters. In this study, the need to recognize the asset profiles of individuals within a community was highlighted. Through having the opportunity to engage in an asset-mapping exercise, participants were able to enhance and activate several assets within their profiles, and the community benefited from their expertise.

The concept of *asset literacy*, which is a type of awareness, is a way to understand the social learning that takes place during asset-mapping (O’Sullivan et al., 2014). The theoretical underpinnings of asset literacy are the Social Cognitive Theory (Bandura, 1986) and self-efficacy (Bandura, 1997). Social Cognitive Theory postulates that the foundation for human behavior is the reciprocal influences of the environment and past behaviours (Bandura, 1986). Self-efficacy is a type of perceived capability; it refers to a person’s belief in their capability to accomplish a task. It determines whether a person will initiate an action and is associated with perseverance when faced with obstacles (Bandura, 1997). Awareness of personal assets is an important factor influencing whether a person feels capable to respond to and recover from a disaster (Hrostowski & Rehner, 2012).

Asset literacy is comprised of four components. First is the ability to identify which assets are available within an individual (micro level), an organization (meso level) and a community (macro level). The second entails recognizing how assets can enhance function and capability – this can include how an asset can contribute to disaster prevention, preparedness, response and recovery within a community. The third component is understanding how to access

and mobilize assets across the different levels. Finally, the fourth component of asset literacy refers to having the self-efficacy and motivation necessary to activate available assets, and develop assets that are not currently available; this can contribute to social innovation (O'Sullivan et al., 2014).

Asset literacy contributes to the adaptive capacity of a community through collaborative practices, innovative activation of assets to meet changing demands, and empowering individuals and organizations within a community (O'Sullivan et al., 2014). Projects that aim to enhance asset literacy align with the community-based participatory research principle of building on the existing strengths of a community (Israel, 2005). Collective asset literacy can be enhanced through group consultations that establish common ground across different sectors within a community (O'Sullivan et al., 2014).

2.4 Stroke Survivors, Asset Literacy and Social Participation

A study conducted by O'Sullivan et al. (2017) explored the lived experiences of female stroke survivors and mapped household assets that could be used to promote resilience during a disaster. Four classes of assets were identified: 1) social, 2) physical, 3) energy and 4) personal characteristics. It is recognized that asset-mapping is the first step towards enhancing asset literacy. However, as part of this process, it is also important recognize the value of different assets, and how to access them. Finally, O'Sullivan et al. (2017) indicate that an all-of-society approach to DRR that includes stroke survivors requires an understanding of what people are capable of, the assets that support their resilience and the types of supports that can support independence. The current research study attempts to contribute to this knowledge while taking the next step in engagement, which is to foster social participation.

CHAPTER 3: METHODOLOGY

This chapter explains and justifies the study methodology by describing the research design and case setting, as well as the data collection, analysis and dissemination processes.

3.1 Research Design

The overarching purpose of this study was to explore perceptions of capability among female stroke survivors in the context of DRR, with a focus on asset literacy. Ultimately, the study aimed to provide opportunities for female stroke survivors to share their lived experiences with one another, and to enhance collective asset literacy among members of the stroke and DRR communities. In order to meet these study objectives, a qualitative approach was adopted (Israel, 2012).

A qualitative approach was chosen for several reasons. Firstly, as there is little empirical research focusing on stroke survivors and their perceptions of capability in the context of DRR, an exploratory approach was necessary. Secondly, the disaster experiences of persons living with disabilities and the interplay between capability, resilience and the asset-based approach is complex and nuanced – a qualitative method facilitated understanding of the complexity of this problem (Creswell, 2016). Finally, this study aimed to share the lived experiences of a population considered to be at disproportionate risk during disasters; a qualitative method is appropriate because it allows researchers to lift the voice of silent groups with non-traditional tools (Creswell, 2016).

An important objective of this study was to facilitate social participation in an activity that can support disaster resilience. A community-based participatory research (CBPR) approach was adopted because its focus is to build on the resources and strengths within a community by

facilitating collaborative partnerships, and fostering co-learning and capacity among participants. In doing so, this approach builds mutual respect, trust, equal decision-making and empowerment among all individuals in the research process (Israel, 2012).

The method we used for this study is called Photovoice (Wang & Burris, 1997). The following section provides an overview of this method and the rationale for its use.

3.1.1 The Photovoice Method

Photovoice (Wang & Burris, 1997) is a participatory research method in which participants can represent and enhance their communities through photography and dialogue. The Photovoice method aims to: 1) Enable individuals to record and reflect on their communities' strengths and concerns, 2) facilitate dialogue about important community issues and 3) reach important stakeholders. In this method, participants are asked to take images in response to specific photo assignments. These images are brought back to the group where participants share and discuss them together. The final step in a Photovoice project is to engage stakeholders in the community and provide an opportunity for participants to discuss their photos and ideas with people who have influence on this issue in the community (Wang & Burris, 1997).

As a method, Photovoice is based on literature on empowerment education, feminist theory and document photography. Wallerstein & Bernstein (1988) introduced the concept of empowerment education based on pedagogy methods by Freire. Empowerment education supports individuals in their efforts to identify problems, critically assess social and historical roots to problems and envision a healthier society, by developing strategies to overcome

obstacles. Empowerment education favours community participation and allows individuals to develop confidence in their capacity to influence their personal and social circles.

Feminist theories recognize that in research, women's voices are not often heard (Ackerly & True, 2010). Other groups in society face similar discriminations. Photovoice is an important method to address this because the camera is an inclusive tool for communication. Most individuals can learn how to use a camera, and photography as a tool for communication can also evade language barrier issues (Wang & Burris, 1997). Finally, documentary photography recognizes photographs as the social conscience presented in visual imagery (Weissman, 1996). Photovoice also addresses issues of power in photographic representations presented in media; this method returns ownership to the community as they can choose how they are represented (Wang & Burris, 1997).

The Photovoice method has many strengths as a participatory research tool. Firstly, it links needs assessment with community participation, bypassing the tendency of researchers to neglect what the community thinks is important. The Photovoice method values the knowledge put forth by the individuals as the vital source of expertise, and facilitates sampling of different social and behavioural settings to which researchers are not privy. This method is also adaptable; its flexibility allows for projects that meet specific participatory goals for communities with distinct health concerns (Wang & Burris, 1997). For example, a recent study by Yi-Frazier et al. (2015) used Instagram® as a modified application of the Photovoice method to gather information on the lived experiences of adolescents with Type 1 Diabetes. Finally, the Photovoice method also builds capacity for action by enabling individuals to connect with and influence their larger social environment (McLeroy et al., 1988).

There are some limitations to the Photovoice method. Due to the participatory nature of this study and its social implications, participants may fear how their images represent themselves and their communities. As such, the personal judgement of the participants could impact the images they choose to take (Wang & Burris, 1997). This can be managed through ongoing discussions about the possible social changes the research may elicit and encouraging participants to only present pictures they are comfortable sharing. Furthermore, to ensure stories are accurately represented, study participants can be involved as co-researchers in data analysis (Maratos et al., 2016).

3.2 Case Setting

The city of Ottawa is the capital and fourth largest city in Canada, with a population of close to one million people. It covers a land area of 2796 km² and is larger than the cities of Vancouver, Calgary, Edmonton, Toronto and Montréal combined. Ottawa has the second highest family income among major Canadian cities (\$102 000), with average housing costs of \$394 000 (based on data from 2016) (City of Ottawa, 2017a). Ottawa is the only officially bilingual city in Canada, where French and English serve as the two official languages. Ottawa has an unemployment rate of 6.3%, and has the largest technology and federal employment nodes in Canada (City of Ottawa, 2017a).

The 2011 National Health Survey reported that people living with disabilities comprised 13.2% of Ottawa's population. One-third of this population was over the age of 65 and 25% of people living with disabilities were immigrants, although only 2.3% were recent immigrants. Furthermore, a higher percentage of women had disabilities than men (54.7% vs. 45.3%) (City of Ottawa, 2017a). In 2006, the City of Ottawa made a commitment to incorporate an Equity and

Inclusion Lens in its city management. By applying this lens, the city hoped to 1) create solutions by incorporating diverse perspectives, 2) take positive steps towards removing systemic barriers and promote inclusion, 3) create a positive and respectful work environment and 4) increase client satisfaction (City of Ottawa, 2017b).

3.3 Data Collection

3.3.1 Recruitment

Ethics approval for this research was obtained from the University of Ottawa Research Ethics Board on June 15th, 2017 (see Appendix A – Ethics Certificate). Initial participant recruitment took place from June 2017 to October 2017. Snowball strategies were used for the recruitment of participants, with broad inclusion criteria to maximize participation: 1) Female stroke survivors aged 18 years or older, 2) able to communicate in English, and 3) willing to participate in 6 photovoice sessions over a 5-month period. The initial recruitment protocol entailed the distribution of a recruitment notice (see Appendix B) and consent form (see Appendix D) to members of The EnRiCH International Collaboration; a network comprised of national and international community partners and researchers who are interested in enhancing population health through inclusive, resilience-oriented activities. Recipients of these documents were asked to then forward the e-mail to members of their networks who may be interested in participating. Interested participants were asked to contact Dr. O’Sullivan or Ms. Ananthamoorthy (NA) for more information. Three female participants were recruited through this initial process.

To broaden recruitment, ethics was amended on November 13th, 2017 to include male stroke survivors, and to allow participants to participate by bringing in pictures rather than using

a camera. We also expanded the recruitment channels to recruit via external community organizations and social media platforms (See Appendix C – Social Media Posts). Community organizations were contacted via e-mail and phone. The notice was also posted on Facebook® and Twitter®. One additional participant was recruited via the second round. Participants were asked complete and return consent forms prior to beginning the project. The following flow chart presents a summary of the recruitment process:

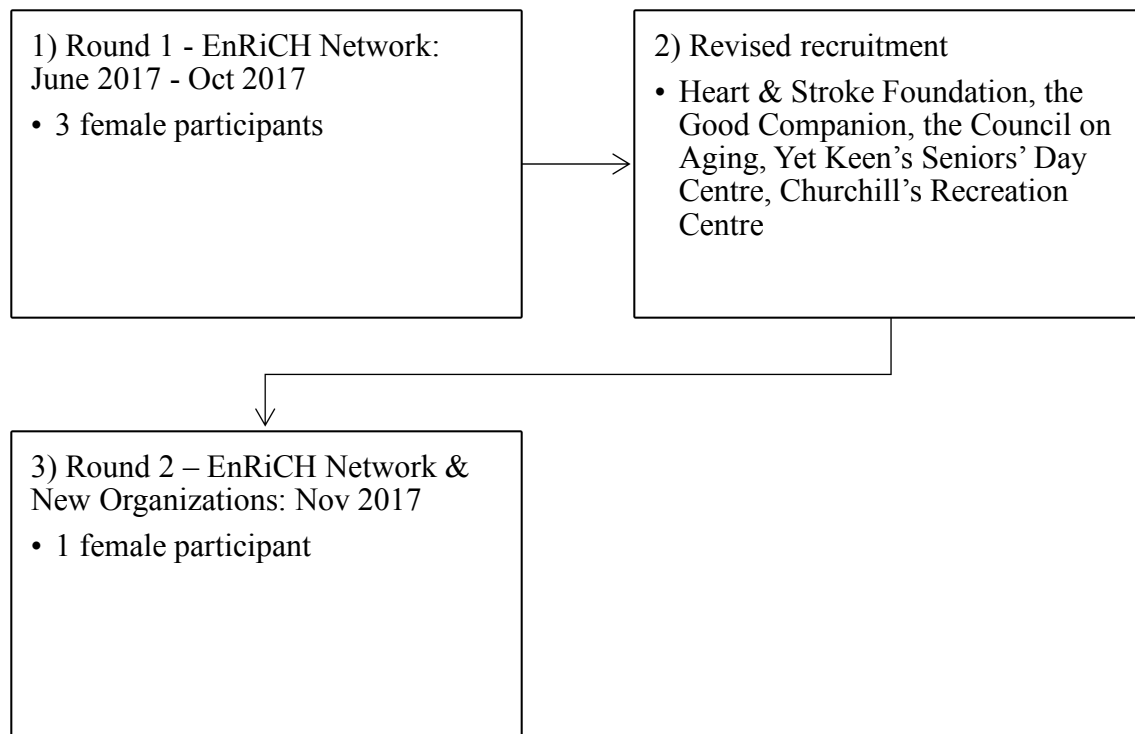


Figure 1. Recruitment Process

3.3.2 Data Source

Study data was obtained through six Photovoice sessions that were held every three weeks, from December 2017 – April 2018. Each session was approximately 90 minutes in length and was audio-recorded. The discussion was facilitated by myself (NA) and my thesis supervisor, Dr.

O'Sullivan. The data collection protocol for this Photovoice initiative was based on the methods used by Wang & Burris (1997) and Maratos et al. (2016):

- 1) Orientation Session: This orientation session served as an introduction to the study (see Appendix E – Introductory Meeting Agenda). Participants were introduced to the Photovoice process, camera mechanics, issues related to privacy and the ethics of photographing in public. To create a safe environment, participants were reminded of the importance of being respectful and keeping the discussion within the group. Then, participants were presented with the research question and discussion questions pertaining to capability, assets and DRR. The first photo assignment was explained and participants were encouraged to take three to five photos for the following meeting.
- 2) Focus Group Sessions: Each session consisted of three parts. First, participants were presented with preliminary thematic analyses of their discussions from the previous session. The themes were developed based on memos taken by NA. This step was important because each photo assignment was based on discussions from the previous session. As such, the preliminary analyses were used to remind the participants of what they had discussed during the previous focus group, and to ensure the research team had accurately captured the essence of the discussion in themes. Next, participants were given the opportunity to share their photographs using the Photovoice acronym SHOWED: 1) What do you **SEE** here? 2) What is really **HAPPENING** here? 3) How does this relate to **OUR** lives? 4) **WHY** does this problem, concern or strength exist? 5) How could this image **EDUCATE** community stakeholders or policy makers? 6) What can we **DO** about it? (Schaffer, 1986). Other participants were then given the opportunity to contribute to the discussion by providing their

own insights. At the end of each meeting, using a consensus process, participants selected the photo assignment for the subsequent session.

- 3) Photo Exhibit: The final portion of this study is the dissemination of results. Typically, participants identify members of their communities with whom they would like to share their work, and they plan and organize an exhibit featuring their photos. A meeting was held on April 6th, 2018 to plan next steps. Participants were presented with a second set of themes based on the preliminary analyses. These themes were refined in collaboration with the participants, ensuring accuracy in depicting their lived experiences. The remainder of the meeting was spent choosing photographs that best represented the participants' stories. Plans for the exhibition are underway and will be elaborated in Section 3.5.

The following figure shows a visual representation of the study protocol (Wang & Burris, 1997; Maratos et al. 2016):

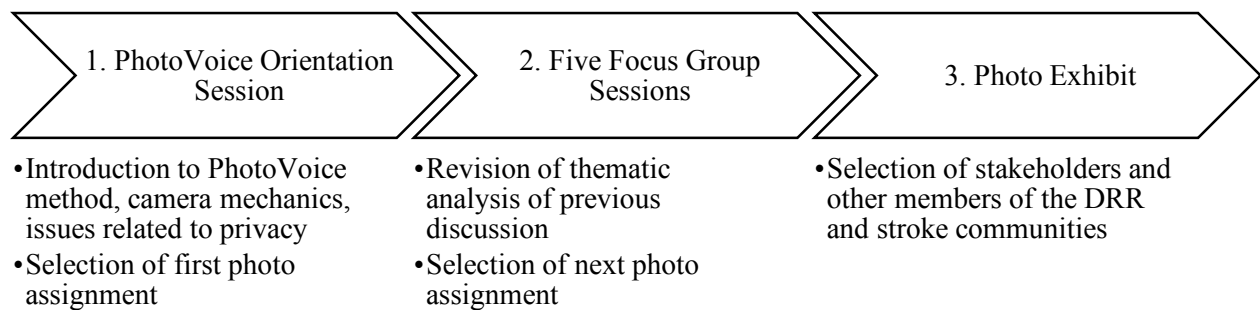


Figure 2. Study Protocol

3.4 Data Analysis

Prior to analysis, audio-recordings were transcribed verbatim by a research assistant at the EnRiCH research lab and checked by NA to ensure accuracy. Data analysis was conducted in collaboration with study participants and was a two-pronged process:

- 1) Preliminary Analysis: A preliminary set of themes were developed that focused on each photo assignment. After every focus group, NA read through the transcript and created a memo, which was used to develop the themes. These themes were brought back to group during the subsequent meeting to ensure accuracy and served as a framework for the following photo assignment.
- 2) Second Phase of Analysis: A second set of themes were developed after the completion of all photo assignments and prior to the planning meeting. These themes were developed through content analysis and were built on the preliminary framework confirmed by the participants. These themes were brought back to the group during the planning meeting and were further refined until consensus was reached. This part of the analysis consisted of developing a coding grid, coding the transcriptions and identifying the emergent themes. Qualitative content analysis is a systematic and flexible method for describing the meaning of qualitative data (Mayring, 2000; Schreier, 2014). This form of analysis allows the researcher to reduce the amount of material and focus on selected aspects of the meaning, specifically those that have relevance to the research question (Shreier, 2014).

An inductive approach was used to create the coding grid and identify emergent themes (Creswell, 2016). Coding is a process through which researchers can sort and categorize qualitative data in a systematic way (Saldaña, 2009). For the first cycle of coding, a team of two

researchers (NA and another research assistant) read the transcripts from the Introduction Session, Meeting #1, Meeting#2, Meeting #3 and Meeting #4 independently and assigned descriptive codes to summarize and gain a broad understanding of the data (Saldaña, 2009). Next, the research team convened to compare codes; duplicate codes were removed and similar codes were condensed into categories. A detailed coding grid was created (see Appendix F), with definitions and inclusion criteria developed based on the initial descriptive codes from the first cycle of coding as well as the preliminary themes. Then, the research team met with my thesis supervisor to discuss the coding grid. Dr. O’Sullivan was present at each Photovoice session, therefore she was able to assist with refining the grid and confirm its accuracy. Following this meeting, the research team tested the coding grids with the transcript from the Introduction Session and Meeting #1. Upon further discussion, the coding grid was refined to better fit the data and align with the preliminary themes that were developed with feedback from the participants.

Transcripts and images were uploaded into Microsoft Word® and coded by Ms. Ananthamoorthy. Memos were taken after coding each transcript and were used, along with the coded transcripts, to develop themes that build on the session themes confirmed by the participants. To ensure rigour, the second set of themes were brought back to the research team and the participants for further refinement.

3.5 Dissemination of Results

An important component of the Photovoice method is the opportunity for participants to share the study results and their images with audiences they deem appropriate. During this study, participants expressed interest in sharing their images with researchers, stakeholders and other

members of the stroke, disability and DRR communities. Preliminary study results were presented at the annual meeting of The EnRiCH International Collaboration held at the University of Ottawa on April 8th, 2018. Three Photovoice participants were among the 30 attendees at the meeting.

As this thesis is being written, we are in the midst of planning a digital photo exhibit which will be available online through The EnRiCH website.

3.6 Strategies to Ensure Trustworthiness

To ensure quality of the research produced, researchers must consider the trustworthiness of their work. The term trustworthiness poses the question: “Can the findings be trusted?”. Trustworthiness is comprised of four criteria: 1) Credibility, 2) confirmability, 3) transferability and 4) dependability (Lincoln & Guba, 1985).

Credibility and confirmability refers to the truth of the interpretation and representation of data (Polit & Beck, 2012). In this study, credibility and confirmability were ensured through continuous member checks with the participants (Cope, 2014). Transferability is whether findings can be applied to other settings (Houghten et al., 2013; Polit & Beck, 2012). We have provided a detailed description of the research methods and case setting; transferability judgement allows others to decide whether the study findings are applicable in their settings (Cope, 2014). A study is dependable if the results can be reproduced in similar conditions (Polit & Beck, 2012; Tobin & Begley, 2004). We established dependability through a detailed audit trail, which provides a transparent and comprehensive description of the research steps taken from the onset of this project to the reported findings (Cope, 2014).

Given the CBPR approach of this research, it was imperative to be aware of researcher biases and assumptions throughout the study (Lincoln & Guba, 1985). A key aspect of preparation for this study was understanding the concept of cultural humility, which is an important tool in CBPR. Cultural humility refers to a commitment to ongoing self-reflection and self-critique on existing power imbalances, as well as intentional and unintentional prejudices (Tervalon & Murray-Garcia, 1998). This was achieved through examining literature on power imbalances in facilitation prior to data collection. Self-reflection occurred during the recruitment process and when creating memos after each focus group.

CHAPTER 4: RESULTS

A total of ($n=4$) participants were involved in this project. All participants were considered young stroke survivors (<65 years of age), having experienced their strokes from ages 39 – 56. Current participant ages range from 48 – 68 years.

The Photovoice method is a fluid and iterative process; discussions from one session help to refine and contribute to previously explored and future themes. This chapter presents study results in chronological order, as they emerged from the focus groups. Broadly, the study results pertained to two overarching concepts: 1) Stroke recovery and 2) DRR. Figure 3 below provides an overview of the sessions (on the left) and emergent themes (on the right); the results are explained below in detail, by theme. The results are colour-coded as follows: 1) Stroke recovery = red, 2) DRR = blue and 3) stroke recovery and DRR = purple.

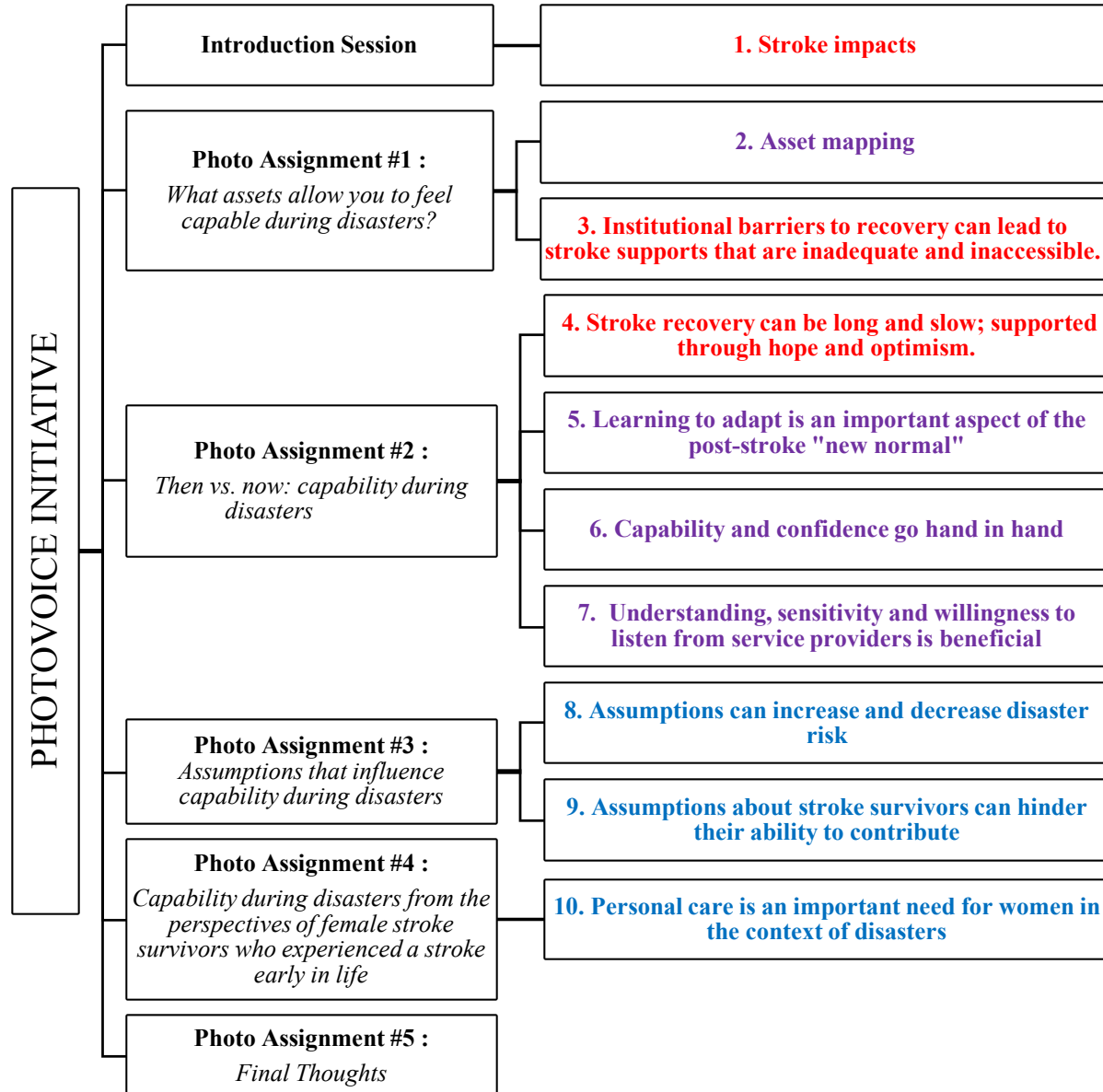


Figure 3. Overview of study results

4.1 Introduction Session

The first Photovoice meeting was an opportunity for introductions and for participants to share their stroke journeys. Substantial discussion centered around the short- and long-term impacts of stroke; this provided context to the assets and themes that were later identified through the photo assignments. Stroke impacts were categorized as such: 1) Physical impacts, 2) cognitive impacts, 3) emotional impacts and 4) impacts on social networks. The following sections describe the stroke impacts and their relevance to recovery. For the purposes of this study, stroke recovery was defined as the process to return to normal or a *new normal*. A *new normal* is a state in which survivors have adapted to their new realities and although they may have not completely regained prior capacities, they have regained new versions of capacity through recovery.

4.1.1 Physical Impacts

Physical impacts were discussed frequently in the Photovoice sessions, and are consistent with those documented in the literature. A wide range of physical impacts were detailed, including: 1) Paralysis, 2) loss of strength and fine motor skills, 3) reduced mobility 4) having less energy, 5) speech deficits, 6) altered proprioception, and 7) overuse of unaffected body parts.

All participants experienced varying degrees of paralysis. The resulting consequences included loss of strength, fine motor skills and mobility. This was a great source of frustration, as they were unable to complete day-to-day tasks and needed assistance from outside sources. As young stroke survivors, these women were also caregivers in their families and were responsible for their children. The sudden loss of independence prevented them from fulfilling their

responsibilities, and at times, changed their roles within their families. Within the group, the level of support received varied based on family connectedness, financial situations and the quality of services provided. However, all participants ultimately experienced lifestyle changes. For example, one participant expressed her frustration with cooking post-stroke; as a single parent, she was forced to change the kinds of meals she provided for her children:

“I could not cut up vegetables with my right hand. I could not pick anything up and if I picked up anything that was hot, it would spasm and it would fall...But it also meant I couldn't go shopping either. Because I couldn't make the meals anymore from scratch, I then had to go and buy the food, which costs a whole lot more money and it's not the best food for us to be eating” (Participant 1)

Another change in lifestyle was the inability to drive. Participants were no longer comfortable using a car and were reliant on others to transport their children:

“Before driving, it was natural. But after...I didn't really feel comfortable. So I said I don't know if I'll ever drive again.” (Participant 4)

“My kids were small and we needed to bring them to school. So, my mom would actually fill in and come to pick them up to bring them to school. And my husband would get them at the end of the day ... My husband at the time.” (Participant 2).

Reduced energy was also identified as a physical impact that hindered daily living. Participants expressed that they had lost stamina throughout the day:

“Then around 7 o'clock at night, I couldn't believe how heavy my head was. Like how much you use your muscles. I couldn't believe it. It's like a bowling ball, trying to keep my head up.” (Participant 2)

Other physical impacts included inability to produce speech, loss of proprioception and overuse of unaffected body parts. The latter refers to the overuse of limbs that were not impacted by the stroke.

An important consequence of physical stroke impacts was an inability to accomplish personal self-care tasks. Participants identified self-care as a critical need. In particular, because most of these women were pre-menopausal at the time of their stroke, they experienced

difficulties coping with their menstrual cycles post-stroke. The loss of independence and dignity was noteworthy during these discussions:

“I could not move at that point.... But I was young. I was 48 and had my period. So imagine... And I had these young guys, like young nurses... fresh out of school and they're like 20 something taking care of an older lady but now they have to come to me and help me with my tampon. Can you believe it?” (Participant 3)

In addition to lifestyle modifications, participants described changes to life plans due to physical stroke impacts. For example, one participant was unable to vacation after her stroke due to her lack of mobility:

“Now it's still because since the stroke about 7 years, I only went once to Florida... you have to walk a long way to the airport... I said, oh my gawd if I had to go with my daughter because if I needed someone to push me... [otherwise] I wouldn't manage” (Participant 4)

The recovery process entailed regaining physical capacities, such that survivors could regain autonomy and return to their roles as caregivers in their families.

4.1.2 Cognitive Impacts

Many cognitive stroke impacts were described by the participants, including: 1) loss of memory, 2) reduced initiative and 3) issues with speech and reading. The most common forms of memory loss were issues with recall, such as remembering passwords or spellings. The term *survival mode* was used to describe brief moments where participants forgot about their surroundings and responsibilities, and they entered into flight or fight. This was particularly prominent immediately post-stroke when participants were recovering at the hospital, as highlighted below:

“It took me 3 weeks before I even realized. I told my husband... I have to see the children. How are the children? Three weeks it took me! Before I realized, well, I knew I had children but the actual need, desire or... it took me a long time” (Participant 3)

Survival mode was a shared and understood experience. The women were empathetic because they were aware of the immediate trauma of experiencing a stroke and agreed that to take care of their families, it was imperative to take care of themselves first: *“It’s not selfish cause it’s like if you can’t survive, it doesn’t matter about the kids, cause you’re not there. You know?”*

(Participant 2)

Another cognitive impact was reduced initiative; participants could internalize and act upon instructions but were not able to initiate action. Other impacts included decreased reading levels and limitations in producing coherent speech. Similar to physical stroke impacts, cognitive impacts (the inability to recall important details, initiate action and communicate clearly) affected the participants’ daily living – particularly their capacity to be independent. It also affected life plans, such as the decision whether to go back to work or school:

“I was also trying to get a job as well because I had, what, another 10 years, I could beef up my CPP. And then after the stroke, it took two and half years to finish [school]. And by that time, I’m nearly 60 and I thought ...what’s the point. So, basically I finished it because I wanted to finish it. Not necessarily to get a job. I mean, got that far, two-thirds of it done, I thought, I have got to finish it.” (Participant 1)

The process to recover entailed regaining cognitive capacities, such that survivors could live independently.

4.1.3 Emotional Impacts

Emotional impacts were consequences of physical and cognitive impacts of stroke. These included: 1) Loss of confidence, 2) anxiety and 3) heightened emotions. Loss of confidence is noteworthy due to its relevance to capability and self-efficacy. When participants lost physical and cognitive capacities, they lost confidence in their ability to cope with adverse situations (loss of self-efficacy). Loss of confidence was identified as an obstacle to recovery, and was described as a type of awkwardness or a feeling of insecurity because day-to-day tasks did not feel natural:

“It’s that awkwardness feeling... It doesn’t feel comfortable... there’s this feeling of insecurity, of how secure these items are in your hand.” (Participant 2)

Fear of having another stroke was described as a source of anxiety. As young survivors, the cause of stroke was often unknown, which contributed greatly to this fear:

“In my case, when I had my stroke, they didn’t know what caused the stroke, so that doesn’t leave you feeling good because you’re leaving the hospital and they say well, we don’t know what really caused it but chances are it won’t happen again. Really?... In that period of time when you don’t know what caused it, you don’t know how you can prevent it from happening again. Even though it just might be a false sense of security if you know what caused it to help prevent it. But still, you’d have less anxiety because once we found out what likely contributed to it, what likely caused it and fixed that, you know, I never had that level of anxiety again..., but without knowing, it’s like okay, am I just a ticking time bomb?” (Participant 2)

In a later meeting, a participant compared this anxiety to the feeling of vertigo when looking up at a building. She brought a photo (Figure 4) taken from the perspective of looking up at the building to depict this feeling:

"You know when you’re down on the ground and you’re looking way up, you feel this feeling of dizziness...well that’s kind of what I would feel.” (Participant 1)

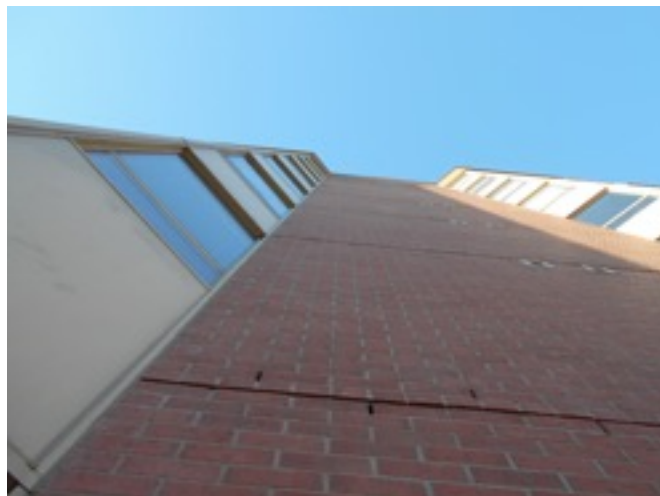


Figure 4. Vertigo

Other emotional impacts included changes in emotional processing and heightened emotions. One participant described this change as impactful because it caused others to perceive her as vulnerable and incapable during adverse events: *“I think that’s the one thing I noticed post-stroke is I’m more emotional now... easy to trigger.”* (Participant 2).

Recovery from emotional impacts required regaining physical and cognitive capacities. It also entailed finding assets to cope with the survivors’ *new normal*. For one woman, this involved prioritizing her mental health. For example, because she felt anxious when driving her son, she decided to give herself more time to complete this task. In doing so, she accepted that she could not always be punctual:

“Yeah, well I gave up trying to be on time. I said okay, I’ll get there when I get there. And also I had two young children, so I took my time every time, everywhere, I took my time. I had to.” (Participant 1)

4.1.4 Impacts on Social Networks

Impacts on social networks referred to family trauma and strain on relationships. Common consequences included divorce, difficulty in fulfilling family responsibilities and the need to seek assistance from external sources. Often, these were by-products of the physical, cognitive and emotional impacts of stroke. It was clear the women valued their place in their families – and when the physical, cognitive and emotional impacts of stroke changed their roles within their families, their relationships were affected as well.

Stroke impact on social networks was also framed positively. As young stroke survivors, these women felt that they were given the chance to build new, positive connections with members of the stroke communities in Ottawa. They also viewed it as an opportunity for the stroke survivors to give back through involvement in stroke research and stroke survivor groups:

“I’m involved in the Ottawa Brain and Mind Institute. I think that’s a fabulous group...and it’s just trying to find... it’s not just more awareness of what’s out there research-wise, but it’s also trying to bridge the gap between the research community and the stroke recovery community itself.... It’s a nice group, consortium of people, like I said, it’s not just the researchers and doctors, but you have the therapists that are part of the group as well. As well as stroke recovery victims. So I’m enjoying it.” (Participant 2)

In summary, while participants described a wide range of stroke impacts, they also identified opportunities to cope, adapt and recover using assets within their environments and within themselves.

4.2 Photo Assignment #1: *What assets allow you to feel capable during disasters?*

The first photo assignment was an asset-mapping exercise, in which assets for DRR were defined as resources that could allow participants to prepare for, respond to and cope with disasters. Participants used images to identify many assets – some were important for DRR, some for stroke recovery, and many overlapped. The overlap between DRR and stroke recovery assets highlight an important relationship between stroke recovery and capability during disasters. Participants indicated that some assets for stroke recovery allowed them to gain or regain assets for DRR. Other assets supported adaptive capacity, which could enhance disaster resilience. Assets were categorized into four classes, based on O’Sullivan et al. (2017), Moser & Statterthwaite (2008) and Hobfoll (2001). They are as follows: 1) physical assets, 2) energy assets, 3) social assets and 4) personal characteristics as assets.

4.2.1 Physical Assets

Physical assets are structural and/or tangible and support autonomy and independent living, which could ultimately build disaster resilience. We explored these types of assets at

community and individual levels, including broader environments that could support independence and active participation in the community.

Physical attributes of buildings that are disability-inclusive were identified as important because they grant access to services and opportunities for social participation. Becoming more aware of these buildings was highlighted as a post-stroke adaptation: “*I’ve had experience with that. When I’m going into the building, I know which buildings...a handicapped person cannot go into.*” (Participant 1). *Transportation* is another community-level physical asset that supports autonomy because mobility is critical for independent living. Participants understood the value of services such as public busses and Paratranspo (specialty transportation) in both daily living and emergency situations, as one participant noted in a later assignment:

“Before, I was on Paratranspo, I could not drive, so that was my Paratranspo ID card. In case of emergency, I would have to rely on Paratranspo I guess, to roll me around.”
(Participant 3)



Figure 5. Paratranspo

Inclusive characteristics of public transportation, such as ramps and priority seating were also appreciated. *Physical characteristics of the environment*, such as roads that are cleaned and

salted during snow storms, can decrease disaster risk for those with disabilities. One participant recounted a fall where she had slipped and was unable to get up from the snowbank herself.

At an individual-level, *assistive devices* such as canes, walkers and beside supports were imperative for regaining mobility. Participants recognized that these devices also decrease risk in emergency situations and poor weather conditions:

“That’s why I carry [a cane]. Especially in the winter. You never know what’s going to happen and I’ve got osteoporosis, so I do not want to fall.” (Participant 1).

Finally, *assets for disaster preparedness* such as first aid kits and non-perishable foods are important in reducing disaster risk. One participant identified her cottage as a potential safe haven during disasters because it is self-sufficient and equipped with things that her family would need during a disaster:

“This is a family cottage. It is self-sufficient. We have water, there’s a generator that is solar powered. Anyways, there’s fire, there’s your fishing, there’s hunting. There’s everything. So should there be a massive disaster, we can run away to the cottage and run our own, you know, continue to live with everything.” (Participant 3)



Figure 6. Cottage

The following table provides a summary of the physical assets; the checkmarks indicate whether the assets pertain to stroke recovery, DRR or both.

Table 1. Physical assets for stroke recovery and DRR

Asset	Stroke Recovery	DRR
Universally-accessible environment	√	√
Universally-accessible transportation	√	√
Assistive devices	√	√
Assets for disaster preparedness		√

4.2.2. Energy Assets

According to Hobfoll (2001), energy assets allow procurement of other kinds of resources. *Money* is important because it can be used to acquire goods and services that are assets for stroke recovery and DRR. In stroke recovery, many services are provided via the Ontario Health Insurance Plan (OHIP) but when additional supports are needed, they must be paid out-of-pocket. As one woman explained: “*The rehab was all on my own dime...I paid for my own rehab.*” (Participant 2). Those with limited money were required to adapt their recovery plans because they were unable to acquire the supports they initially wanted. For example, one participant described her home renovations as such:

“Unfortunately, it always comes down to money. And when they have limited amount of money...I remember when we were doing our renovations in the house, we came up with some really grandiose ideas, and the contractor would say, sure you can do anything, as long as you have enough [money]... so it’s true. You can do anything you want as long as you have enough.” (Participant 1)

For the participants, *time* represented opportunity. As young stroke survivors, they were able to contribute to their communities and build connections with other stroke survivors. Ultimately, they believe these social networks could enhance community and disaster resilience. In a later assignment, a participant used two images to explain this concept. The first image

referred to in the following quotation was an online page for a stroke survivors group. It is not shown here because it identified members of a private group.

“So, I think my capabilities are around my assets...So what I have here is my involvement with the stroke community of survivors, which is a website. My pictures go hand-in-hand. And the second one is a clock to interpret time. So... as an asset I guess I have time ...to offer in case there's a disaster ...to the stroke community. So I have time on my hands because it's been earlier in life, I'm not in an adult world because of my situation, so I have time to devote to the stroke community in case of disaster.” (Participant 3)



Figure 7. Time

Knowledge was regarded as an asset for both stroke recovery and DRR. In stroke recovery, knowledge of the health care system is needed to find services and supports. Participants stated that knowledge is easier to acquire with assistance from a supportive professional. As one participant explained: *“It depends if you have a good doctor...that will help you push through the system.”* (Participant 2).

In the context of DRR, participants viewed *media* and *media awareness* as knowledge assets that could reduce disaster risk. Media can provide up-to-date and instantaneous information on emergency situations and keep citizens informed about how to respond. One participant stated:

“I just so happened to see as well, over the holidays, I got an emergency alert on the TV. So should there be a disaster, the media seems to be, they will send a message of some kind.” (Participant 3).

Media awareness was defined as the recognition of media as a source of information. This included understanding how to access social media platforms (i.e. Facebook®, Twitter®, Instagram®). For the purposes of this photo assignment, one participant searched the City of Ottawa website for information on disaster preparedness for persons with disabilities. Other participants had not visited the website before; however, there was a general awareness of its existence and an expectation that this information would be readily available during disasters:

“If... we still had the internet. Yeah, I would go and say ok, what do they suggest? Like it depends on the emergency ... there was, in fact, when there was flooding on the Quebec side, not that long ago in May, they had on the City of Ottawa (website) where to go to help and what to do. If you have water in your basement, what should you do? Like put sandbag in the corners and whatever. So it was on their site.” (Participant 3)

“Yeah, I agree with you. I don’t think it’s something that we readily go to on an everyday basis... But when disaster strikes, I think it’s one of those go-to things. You’re gonna say, oh what’s the City of Ottawa doing... I didn’t know it was 2 screen shots long. But I knew some kind of emergency list was there... and I think generally people would expect it to be there. And if it’s not there, whoa, we’d hear about it after the disaster’s dealt with.” (Participant 2)

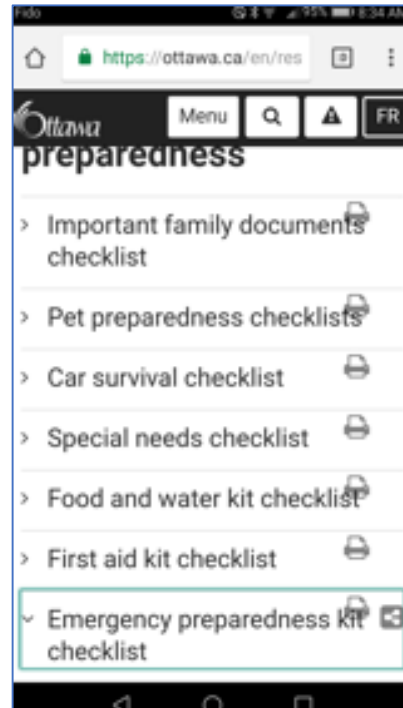


Figure 8. Media

Physical and cognitive rehabilitation were critical stroke recovery assets because they allowed participants to regain *tangible skills* or capacities that had been impacted due to the stroke. Rehabilitation was sought through professional sources as well as cheap, at-home alternatives:

“I attribute a lot of my recovery... to physiotherapy... The physiotherapist would come in and... she would use things around the house. My kids were small so we had these little building blocks. Typical wooden block things. And so, in the hour time she was there all I would do with my left hand is stack the blocks and then stack them and then at the end she would get me to...walk down my hall, like back and forth maybe once or twice”
(Participant 2)

“So little things like playing with paper clips and hooking the paper clips to make a chain, but doing that with your left hand... Those are like, you’re not going out and buying dumbbells or whatever it is. Super duper equipment. And it’s just paper clips.”
(Participant 2)

A wide range of *tangible skills* were described, including physical capacities such as strength, fine motor skills and mobility, as well as cognitive capacities such as speech and ability to recall. These skills enhanced survivors' ability to return to being independent and active members of their communities. Evidently, the nature of such tangible skills evolved based on the stage of stroke recovery and the kinds of supports available. Participants recognized that physical and cognitive capacities could promote disaster resilience and reduce disaster risk. The following reflections show how strength and fine motor skills could be useful during disasters:

"I wanted something to show strength. [After the stroke]... I didn't have a lot of strength... so I thought again in emergency situation if there was something to move, I might not be capable of all that. I wouldn't say I couldn't open a door, but if the door was jammed or something and you had to use some level of force – I would not have been capable in doing that. So, it makes the situation a little more precarious in an emergency." (Participant 2)



Figure 9. Strength

"I try working with my hands (through baking)... because that's one time there's an emergency and a friend of mine was talking, I mean like, she came home and she was trying to make some salad and she realized a can opener is electrical." (Participant 4)



Figure 10. Fine motor skills

Finally, *resources that support self-care* (i.e. make-up, shampoo, fashionable shoes and clothing) were identified as energy assets because they enhance sense of well-being, which ultimately promotes adaptive capacity and resilience. This was regarded as beneficial because it supports independent living and potentially, the ability to cope with disasters. The following table provides a summary of identified energy assets:

Table 2. Energy assets for stroke recovery and DRR

Asset	Stroke Recovery	DRR
Money	√	
Time	√	√
Knowledge	√	√
Rehabilitation	√	
Tangible skills		√
Resources that supports self-care	√	√

4.2.3 Social Assets

Social networks provide both practical and emotional benefits to stroke survivors. In this discussion, the term *community* was used to broadly describe an array of social networks

including family, stroke survivor groups, stroke research groups, rehabilitation centres and special interest clubs. This is consistent with definitions of *community* in the literature (Linell, 2013). Social networks supported the participants in stroke recovery through tangible means while also fostering opportunities for growth, and feelings of belonging and security. One participant described community as such:

“I think that in some situations family could be replaced by community, depending on the situation, right? Not everyone has family close to them. Whether it’s physically or emotionally close to them... They might have a very strong community. Friends, people in the community. So I think family could be replaced with community too in the same aspects of that emotional support, that belonging aspect. Not feeling left out.”
(Participant 2)

Family was the primary source of support for most participants, as spouses and parents assisted with daily tasks and took on more responsibilities. Family also provided a sense of stability because it was viewed as unconditional support:

“That was one of the things that were important to me, especially with the stroke recovery and everything. Because that’s my foundation and you know, no matter, like you can’t choose your family, right? You can’t choose your siblings. But no matter what differences you may have, you’re there for each other” (Participant 2)

Family was recognized as a support that could be extended to disaster situations as well: *“For sure you have to count on family. Like... you have to count on each other to deal with whatever emergency is happening.”* (Participant 3).

The importance of extending their networks to build larger support systems and increase opportunities to socialize was also emphasized. For those with small social circles, networking ensured that during emergencies, someone is looking out for them:

“When my son passed away, we didn’t go out in the evening because we had to look after him and so I suddenly realized I don’t really know that many people around here. So, I went bowling, I joined a writing group, I rejoined the church, everything I had to not do because of my son. I got back on it. But, I had to make myself do that because I don’t have a problem being by myself but I realized, oh if something happened to me, nobody would know.” (Participant 1)

Post-stroke, participants joined a wide range of social networks – some were stroke-related, while others involved hobbies such as dancing or practicing a new language. Stroke-related networks included research communities, stroke survivor groups and centers for rehabilitation. The benefits of such groups were twofold. First, they were opportunities for social participation and to give back. Second, they allowed survivors to interact with individuals who understood stroke. Finally, participants viewed involvement in hobby groups as continued opportunities for growth and recovery. The following table provides a summary of social assets:

Table 3. Social assets for stroke recovery and DRR

Asset	Stroke Recovery	DRR
Social Networks	√	√
Social Participation	√	

4.2.4 Personal Characteristics as Assets

Participants cited *personal motivations*, such as taking care of children or returning to school, as reasons to persevere through recovery. *Hope and belief* were identified as important assets in stroke recovery because they allowed survivors to trust the stroke recovery process and believe there is always opportunity to progress. Hope allowed survivors to persevere through recovery, ultimately building resilience. One woman used lanterns as a symbol of hope:

“Hope was important to me because you know, when you go through something that’s so life changing, you could lose faith and belief in yourself... but the one thing that keeps you going is hope... Ok, it was a difficult day today, maybe tomorrow’s not gonna be so bad. Or today wasn’t as bad as yesterday. You know? So you have that kind of hope to build your resilience.” (Participant 2)



Figure 11. Hope

Reflection, planning and adaptation refer to stroke survivors' ability to critically consider their personality traits, limitations, responsibilities to their families, and environments when developing strategies to cope with their post-stroke realities; these assets promote adaptive capacity and resilience for everyday and during disasters. For the Photovoice discussion, one participant used an image of long, limber trees to depict the idea of 'bending but not breaking' during storms as a metaphor for her resilience. She stressed the importance of planning for disasters and knowing her boundaries because she was caregiving for her son, who also had a disability.

"So those trees have been there for a very long time. For me, that's resilience. Cause they survived the... ice storm. I thought, that shows trees that bend and yet go straight, continue to grow and stay up. The asset is that I can suddenly start, I can, despite of the disaster and a minute of panic, I can then start planning. What am I going to do about it? And I've planned before but plans, who knows? But after a disaster, I can then, look at it and go, ok, is my plan still ok? Do I need to have a new one? ...I've discovered basically how far I can go, more or less. How much could I help?" (Participant 1)

"I've had a lot of thought thinking about this (potential disasters) because one of my children is in a wheelchair. A power chair. You don't pick those up and move them. So I've had to think. What would I do if there was a fire in my place? How would I get him out? So we had a plan for that. And so the resilience is that I have a plan." (Participant 1)



Figure 12. Resilience

In the context of this study, *confidence* was described as a belief in one's capabilities (similar to self-efficacy). For all participants, confidence allowed them to function independently post-stroke. They identified two sources for confidence. As participants regained capacities through recovery, confidence came from within. It also came through support from external sources such as doctors and family members. The following table lists identified personal characteristics as assets:

Table 4. Personal characteristics as assets for stroke recovery and DRR

Asset	Stroke Recovery	DRR
Personal motivation	√	
Hope and belief	√	
Reflection, planning and adaptation	√	√
Confidence	√	√

4.2.5 Review of Assets

Participants used this photo assignment to compile an inventory of assets that support stroke recovery and/or DRR. Broadly, these assets could serve one or more of the following purposes: 1) Support independence and active participation in the community, 2) enhance disaster preparedness and response and/or 3) provide general emotional support. Finally, in addition to identifying assets, participants also identified barriers to stroke recovery and access to supports. These barriers are explained in the following section.

4.2.6 Institutional barriers can lead to stroke supports that are inadequate and inaccessible.

For the participants, systemic problems that rendered supports inaccessible and inadequate were a source of frustration. Inadequate supports were defined as supports that did not meet needs or expectations. Issues with supports hindered and lengthened stroke recovery. The most frequently referenced institutional barrier was lack of communication - or miscommunication - between service providers; this resulted in lack of continuity between services. The stroke survivors found themselves constantly re-explaining their situation and being re-evaluated by service providers during recovery. As described by one participant:

“The information doesn’t get relayed from one health facility to the other. Because if you were capable of doing all that stuff when you’re at the (hospital), and they start you 10 paces back when you go to (another hospital), like oh come on. Like clearly, something’s not being conveyed. I appreciate that in the health care sector it’s under-funded and under-resourced. I appreciate that... But still this is about quality of life and betterment.”
(Participant 2)

A common experience was confusion regarding whether their drivers’ license had been suspended after the stroke. This uncertainty was detrimental because their license granted mobility and independence. When they went to re-instate their license, there was uncertainty regarding the procedure:

“I thought it was my license, they tell me no, the test you did was with the rehabilitation center. It was to decide if you can drive. But now you have to go through the ministry. Start all over again. Going to the exam and start all over – I mean even with over 20, 25 years of experience driving.” (Participant 4).

Another form of institutional barrier were one-size-fits-all policies put in place by services that did not account for the nuance and complexity of stroke. One participant expressed frustration with her hospital stay because she felt the policies were not necessary for her condition and hindered her independence:

“For 20 min, 25 min, half an hour before someone can come. And I could just sleep. Because they give me the new wheel chair. I could just sleep on the bed. I didn’t, no, no. I have to sit on my bed to wait. It was a policy. I have to wait and even like, they have some schedule for bath. I mean you’re, you’re allowed to get one bath a week. I mean, I said I would like to do my bath. Maybe not... I mean when I feel I need a bath, I’d like to get a shower. I feel the need. So it’s only once a week you have a shower, so I have to wait for the schedule. If after they train me, so I was able to take the shower whenever I wanted to. Not according to the schedule.” (Participant 4).

Other forms of institutional barriers that prevented participants from accessing services included distance, cost and a health care system that was difficult to navigate. Ultimately, when services did not meet their needs, they felt abandoned. One participant used an image of dying trees that had been neglected as a metaphor for this feeling:

“After the stroke, after we did all the...when I finished the therapy and everything like that, I did not feel that was enough and so I had feelings of abandonment. Now that [referring to the tree in the photo]...was cut up when one of the trees was dying. They cut it off and they just left it there. And that to me is ...abandonment.” (Participant 1)



Figure 13. Abandonment

This sheds light on how patient advocacy can support stroke recovery. Participants often had different understandings of the services available to them, and as a result, had different levels of access to supports. Having an ally who understands and is connected to the health care system, makes it easier to find appropriate resources: *“I was lucky...it just happened and my doctor was kind of pissed off at this situation and she somehow navigated me and pushed me”* (Participant 3).

4.3 Photo Assignment #2: Then vs. now: Capability during disasters

The asset mapping exercise and the overlap between assets revealed an important relationship between stroke recovery and capability during disasters. Participants recognized some identified assets for DRR were universal – ie. not stroke-specific – and could be useful to most individuals. They indicated their selection of DRR assets was linked to their stage in stroke recovery. The purpose of Photo Assignment #2 was to further explore this concept by examining how participants perceived their capability during different points in their recovery. The

following themes shed light on their recovery journeys and possible connections to capability during disasters.

4.3.1 The stroke recovery process can be long and slow; supported through hope and optimism.

Hope and optimism were the underpinnings of discussions on recovery. Hope was framed as an asset in Photo Assignment #1 because it fosters resilience. Hope was described as stemming from a persistent belief in the recovery process; although the journey can feel stagnant, the body and mind is always recovering:

“I mean people who think they aren’t getting better, actually are slowly getting better. Because they’re not actually working at it, it doesn’t get, it doesn’t fix quickly, but their brain still works on it.” (Participant 1)

“As far as recovery, I’m a true believer that you’re always recovering... it validates in my mind that... your brain, you know the old thinking was that you plateau. And yeah, you don’t recover as quickly but you’re not really ever plateauing. It’s just, you’re still recovering, but slowly but surely.” (Participant 2)

Throughout this discussion, participants reflected on their progress and expressed gratitude for the little achievements they had attained along the way. The impact of recovery on themselves and their families served as validation for having hope. Two participants were single parents, therefore their recovery impacted their capacity as caregivers. One participant described her children’s reaction to her driving as follows and emphasized the importance of driving in emergency situations:

“I remember distinctly when I was able to drive again and I had the kids in the car and the kids were so happy. ‘Mom, you can drive again!’ It’s like mom’s back. So, that was a big thing.” (Participant 2)

“In an emergency situation, it was like, I wouldn’t be able to get everyone in the car, get to safety kind of thing. Then, now I can, I’m capable of doing that.” (Participant 2)



Figure 14. Regaining ability to drive

The women's belief in the process was evidenced by their willingness to seek new ways to recover:

"I was willing to try everything that could be helpful for me. I already tried acupuncture. But I talked to my doctor, he said yeah. We can try that. I don't know if there's benefit or not but I did try it. As long as it won't impact my heart health, physical health and even emotional health." (Participant 4)

4.3.2 Learning to adapt is an important aspect of the post-stroke 'new normal'

When describing their recovery journeys, the participants acknowledged it was not always possible to return to normal. Instead, they had all strived to reach a *new normal* that accommodated the stroke and its impacts.

Two themes of physical adaptations were discussed. Firstly, some adaptations required the use of assistive devices. Resources such as canes or walkers could support mobility. This was identified as especially important during adverse weather conditions – assistive devices were often used as precautionary tools:

"That's why I carry it (a cane). Especially in the winter. You never know what's going to happen and I've got osteoporosis. So I do not want to fall." (Participant 1)

“As soon as I’m outside, I will always use it. I don’t take any chance because... one of the stroke survivors said... she didn’t use the cane and she fell all the time. Take your cane.” (Participant 4).

The second form of adaptation involved changing how they used their bodies. One participant described buying a pair of left-handed scissors because she could no longer use her right hand. Another participant described adapting her car so that she could drive with her left foot:

“I have to [drive] with the left foot... I realized that it wasn’t well adjust[ed]... my brother is a mechanic but he’s not certified ...so he went back to them [the mechanic] to ask them to fix it” (Participant 4)



Figure 15. Adaptations to car

This form of adaption was sometimes referred to as a type of re-learning. One participant described her experience re-learning how to peel potatoes:

“Well, the thing was, if you held on too tight, it like, literally the potatoes would jump out of my hand. Like you’ll lose control. You’ll lose control of it and then you have this peeler in one hand and it’s like okay that was almost my hand. And I have seven more to do... And the therapist actually said well what you’re supposed to do is loosen the grip. You’re holding on too tight. The harder you hold on or the tighter you hold, the less control you actually have, which is counter intuitive. You’d think I need to hold onto this little sucker.” (Participant 2).

Furthermore, the notion of adapting mindsets was explored. One participant described how she needed to swallow her pride when using assistive devices:

“Yeah because as soon as [I’m] outside, I will always use it. I don’t take any chance because... one of the stroke survivors said you have to swallow your pride. Because she used to be the same, she didn’t use the cane and she fell all the time. And she said swallow your pride. Take your cane.” (Participant 4).

Participants also described adaptations to their daily living. For those experiencing cognitive impacts, this involved changing their passwords to more simple combinations. For those who were responsible for their children, this involved reallocating their responsibilities to other family members. One participant removed items from her house that were no longer of use, such as high-heeled shoes.

Finally, stroke recovery is a dynamic process that must constantly be adapted. The participants described taking small steps to reach different comfort levels:

“[It is] part of [reaching a] comfort level. So it’s like, so start with the cutting some butter with bread knife kind of thing where you know that the risk is low. You know work your way up.” (Participant 2).

4.3.3 Capability and confidence go hand-in-hand

In this study, capability was described as being able to do and being able to contribute. Participants indicated that capability was dependent on the severity of stroke and the stage of recovery. As they regained capacities through recovery, they felt more confident. The following examples describe this relationship; one participant acknowledged that an ability she considers an asset in daily living and in disasters (climbing stairs) may not be available to all stroke survivors:

“Making a contribution. What are the contributions we can make? Now, again, that’s dependent on the severity of the stroke... [and] the stage of stroke recovery.” (Participant 2)

“My pictures are showing... a person who can walk up and down the stairs and can go to the nearest hospital and do all those things. But that’s not most [stroke survivors].” (Participant 1)



Figure 16. Mobility/Ability to use staircase

The participants explored the relationship between confidence and capability. Confidence was viewed as an asset because it supports adaptive capacity and independent living. Confidence is enhanced when survivors regain capacities through recovery: *“Capability and confidence go hand in hand. As you progress, when you’re more capable, you become more confident”* (Participant 2).

Participants described their first post-stroke experiences with everyday tasks as awkward and un-natural and they often required support from external sources. As such, regaining capacities through recovery promoted empowerment and self-assurance. This was evident in this explanation of one participant’s account of her journey to gain mobility in winter conditions; as she became more independent, she gained more confidence:

“It reminds me even of a winter conditions. Like, the first couple of years, even though I could walk probably like you, I would not be able to go on ice, like forget it. But now, you know, I can like tip toe on ice like a normal person, but before, no way. I cannot, I had to wear these big strap things on my shoes and my husband had to hold onto me like. So yeah, so in an emergency situation, not being able to go outside in the winter, because of...yeah. So this year, I’m like ‘Woo, look at me!... That level of confidence. Like, in an emergency situation, you feel that much more self-empowered in a sense... [you’re] a little more assured of yourself. It’s an assurance” (Participant 2)

4.3.4 Understanding, sensitivity and willingness to listen from service providers is beneficial

A major focus of our discussions on stroke recovery were the interactions participants had had with service providers. Generally, participants indicated there is a lack of understanding because service providers are not aware of the complex and unique needs of stroke survivors. When service providers adopt a one-size-fits-all approach, they make assumptions about needs. One participant explained this as such: *“I think there is this underlying discrimination of you’re not capable of knowing what you need”* (Participant 2)

When supporting a stroke survivor, a collaborative approach is necessary to find solutions that are sensitive to their priorities and allow them to take control of their recovery. All participants experienced a loss associated with feeling like they had few choices; particularly when service providers interfered with their lifestyles. For example, one participant was frustrated with her doctor when he told her where to put her bedside support without trying to understand her lifestyle. For this participant, the placement of her support was imperative as it could enhance her mobility in both her day-to-day living as well as in emergencies.

“They suggest I do it on the other side because it would be much easier for me... I find it more difficult if I want to...watching something late at night and I have my tablet and yeah, it’s become quite difficult. So sometimes I have to put it on...but it...just like you have your way and I mean, what is, do what you feel more comfortable, and sometimes a person says why don’t you do that, and I said, no because that’s out of my way”
(Participant 4)



Figure 17. Bedside support

Assumptions regarding her capability were also evident when she described her experiences with Child Services:

“I felt like good because I was able to give [my daughter a] bath. I felt good. Because everything, I was able to do by myself without putting her life in danger. And she could just go to the bathtub and my older daughter, sometimes she would do things. Everything that I try to do, because I feel good about myself, yeah I can do that. I can do that. But they were telling me why you have to do that, you shouldn’t do that, you shouldn’t do that, and I didn’t know why CS was involved. And yeah, other things I had to go through because... but everything I did so everything I feel good, yeah, I can do that, I can go to the stairs, yeah, I feel good about myself and they tell me, you shouldn’t do that.”
(Participant 4)

This example underscores an important issue among female stroke survivors, where they feel they are making a contribution to their children and families by fulfilling their caregiving roles. The participants emphasized the need for making a contribution and for having a voice in decisions regarding their lifestyles and recovery process.

Sensitivity training for service providers was identified as important because it ensures service providers are more aware of the unique needs and struggles faced by stroke survivors.

One participant suggested:

“But in the summer time, and I remember this a couple of years ago, where the city talks, you know, it must have been around the budget time for the city, but somebody was telling them about how, you know, this is not an accessible city. And they were actually kind of challenging city councilors to take a wheelchair and just go around in the city one day in a wheelchair and you will see how challenging it is. You know, you think you’re doing...think of things with the curbs, half the curbs are still too high to get up and stuff like this... you know in the city, you know, you use that same argument and it’s like okay, but now we have a ramp, but the thing is so blatantly, it’s fixed but suddenly it’s not fixed because maybe the ramp...you know there’s still some kind of a challenge to get onto the ramp. But once you’re on the ramp, great” (Participant 2)

The need for sensitivity training was emphasized in the following story. One day, a participant was waiting for a bus after a snowy day. She was unable to access the bus stop due to her issues with mobility, but the bus driver was not aware of this and nearly drove away. In situations similar to this, awareness is important because it allows service providers to reach groups that are overlooked:

“This morning like, I was taking the bus and I was waiting for the bus, and the driver just passed through the stop, like I was supposed to be with someone else, and the other guy he went and after that why stop halfway for the bus, so I have to wait for someone to help me get onto the bus, even when I was walking, there’s a pathway, I mean, the city didn’t clean everything, didn’t put salt on the ice, and a woman saw me, and of course she came to help me, just one two step, just a step to get there, so she wasn’t... I mean unfortunately people don’t think about [it]” (Participant 4).

It is important for service providers to listen to stroke survivors; in doing so, they can support community resilience and allow them to adopt a lifestyle that they value.

4.4 Photo Assignment #3: *Assumptions that influence capability during disasters*

The previous assignment revealed the impacts of assumptions on stroke survivors. The third assignment examined how assumptions of stroke survivors influence capability during disasters.

Public perceptions of stroke survivors were important to the discussion around assumptions and capability. The participants revealed they are generally not perceived as stroke survivors by the public. They believe this is due to two reasons. Firstly, because they experienced strokes before the age of 64, they are not considered typical survivors. Secondly, they made reference to stroke as an *invisible disability*. At first glance, these four women do not display any visual indications of their disabilities, due to their age and stage in stroke recovery. This perception quickly changes when the survivors show signs of deficits. As they explained, whether or not they are perceived as stroke survivors, assumptions could have important implications on their ability to prepare for, respond to and cope with disasters. Agency is a key term in the discussion of perceptions and assumptions. When limiting assumptions are placed on stroke survivors and their capabilities, they typically lose agency, or the power to make decisions.

4.4.1: *Assumptions can increase and decrease disaster risk*

General assumptions could increase disaster risk when stroke survivors are not perceived as persons with disabilities. When a disability is invisible, an individual may not receive the support they require. One participant experiences this in her daily life:

“I find that assumptions are worse now for me now that I look like I am capable, people assume, oh she could that she could that, but I can’t. Like, you know, I had difficulties with certain things...but people don’t think I have difficulties but I do. So they assume I’m okay but I’m not.” (Participant 3)

In the context of disasters, failure to provide adequate support could increase risk for both the survivor and those around her. Two examples of this concept were discussed during this focus group. One survivor reflected that although she looks physically capable, she is uncomfortable using staircases and she would require assistance in a disaster situation if she had to descend the stairs quickly. Another participant used an image of a phone to represent her impairments in speech. She reflected that this could increase her vulnerability and impede her ability to ask for assistance during disasters.

“So one of my pictures was the stairs, and I was trying to do it such a way so I can get more depth perception. So if it were an emergency reason or for whatever reason, had to go down a whole flight of stairs, then I’d definitely need assistance because I’m going to fall or I’m going to be super slow and backing up the line behind me. And that adds on to your anxiety... So, if I was in emergency, I would be able to walk without assistance but [if I was someone who] couldn’t speak. And then I come to the stairs and I stop, you know that kind of thing for my own safety I stop. How can tell somebody that I need assistance here.” (Participant 2)



Figure 18. Using staircases during emergencies

“At the early stages of my rehab, I could not speak clearly enough or loudly enough to make myself understood properly. [This} could make me vulnerable in times of disasters” (Participant 3)



Figure 19. Importance of speech in disasters

Assumptions about capability can also reduce disaster risk. For example, visual representations of disability (i.e. a cane or a walker) can be useful in these situations because others will assume the individual requires assistance.

4.4.2 Assumptions about stroke survivors can hinder their ability to contribute

In the context of disasters, capability was defined as the ability to contribute. Often, there is a disconnect between how a stroke survivor is perceived and their true capacities. Deficits tend to mask any other skills or assets the stroke survivor may possess. The following examples explain this concept:

“I think there are perceptions once you see a deficit in somebody, you automatically put limitations on them. And so that’s why, it depends on who you’re asking ... Because if it’s somebody who’s showing clear deficits, I think people automatically have perceptions, that okay, well, they probably can’t do what this person who’s not showing any deficits can do.” (Participant 2)

“I guess this works more for physical appearance... even though [they] might look physically impaired, they’re still capable to help out.” (Participant 2)

Another participant experienced heightened emotions following her stroke, and explained that this could misrepresent her cognitive and emotional capability:

“That whole emotional aspect was so different back then, when you had, or after having the stroke. So I could only think that if it were an emergency situation, I think I might be capable, but I’d be crying... And again, the perception would be that oh... they can’t handle anything. They’re freaking out.” (Participant 2)



Figure 20. Emotional capability

Similarly, another participant reflecting on her limited speech following her stroke, stated that her loss of speech could be perceived as a loss of cognitive capacity. As such, others may assume she is not able to understand and carry out instructions:

“Once I got to a shelter for instance, I actually could help people because I did have enough strength, I could walk around, I could carry stuff back and forth, I could...well even though I couldn’t talk, I could still do stuff. But, in the beginning, they’d have to consider me to be a liability” (Participant 1)

4.5 Photo Assignment #4: *Capability during disasters from the perspectives of female stroke survivors who experienced a stroke early in life*

4.5.1 Personal care is an important need in the context of disasters

The women in this study identified personal care items as an important need; however, it could be neglected in disaster situations if not considered a priority. The participants referred to

personal care items, such as soaps, shampoos, makeup, as *little pieces of comfort* that can contribute to overall well-being in disaster situations. Sanitary products such as pads or tampons were also included in these discussions.

“Some nice soap or some nice hand cream or you know, just to wash your hair you know, like in a disaster situation, you may be going through 4 or 5 days of not being able to bathe or you know wash yourself and just you know, you want to wash your hair and you just feel so much better, like putting on that lipstick and just feeling alive again.”
(Participant 2)



Figure 21. Personal care items

It was recognized that overall well-being could enhance coping and disaster resilience. As such, participants recommended including female sanitary products and other self-care items in emergency preparedness kits:

“You can make up your own survival kits. I mean, there are people who do this all the time. Really don’t need to, but this should be in it. The pad should be in with that thing.”
(Participant 1)

4.6 Photo Assignment #5: Final Thoughts

The last photo assignment was an opportunity for participants to share final thoughts and emphasize important messages. Ultimately, the participants shared a message of positivity and

strength; they were proud of their journeys and viewed themselves as capable, contributing members of their communities who would like to be included in social planning:

“My summary picture is a glass of water that’s half full or half empty because it’s summarizing perspectives ... first of all, water because water can take any shape or form kind of idea. If you have a leak, it gets everywhere and it’s kind of like the stroke can take any shape or form. Everyone’s stroke is different and hence the symbolism of the water. Then the whole glass, typically glass half full half empty, was about perspective and in that if your stroke symptoms ... effects are visible, then already, people have perspectives on what your capabilities are. And if your stroke effects, like for many of us, aren’t visible, then there is that perception that you are 100% fine. The last part of this, really the message I want to get through, is that we’re all capable. Like in emergency situations, we can all contribute so don’t just write us off” (Participant 2)



Figure 22. Glass half full

4.7 Application to Asset Literacy

Table 5 below examines the study results through the four components of asset literacy (O’Sullivan et al., 2014). To varying degrees, participants could identify assets, understand their value and how to mobilize them. This was dependent on their information sources, which included other members of the stroke community, their health care providers, past experiences and own research. The final component of asset literacy is having the self-efficacy and

motivation to activate assets. Generally, this was dependent on two sets of factors. Participants identified many extrinsic factors, such as having enough money, proximity to services or having positive social networks, that enabled them to activate assets. Intrinsically, participants described personal characteristics and personal motivations that allowed them to access assets. Most notably, self-efficacy is reliant on the stage in the stroke recovery journey. Through regaining tangible skills (i.e. strength and fine motor skills), recovery fostered confidence and self-assurance. Participants indicated that this would allow them to activate other assets for recovery and could allow them to activate assets for DRR. Our application of the asset literacy lens to the study results is presented in Table 5 below.

Table 5. Application of Asset Literacy

Component of Asset Literacy	Pertinence to Results
1) Identifying assets	Stroke survivors identified four kinds of assets (social, physical, energy and personal characteristics) that supported stroke recovery, DRR or both. Participants' sources of information to identify assets are the following: 1) their own experiences, 2), their own research, 3) the experiences of other members of their stroke survivor networks and 4) information from health care providers.
2) Recognizing the value of assets	The main perceived value was autonomy. This was deemed important in both stroke recovery and DRR. Autonomy allowed participants to live how they wished and make decisions they valued. Specific assets such as physical assistive devices and tangible skills were identified as beneficial during disasters because they could allow survivors to respond independently. Participants also understood how energy assets could enable them to access other assets. For example, mobility was gained through physiotherapy*. <i>*Note: Participants identified physiotherapy as both an energy and social asset.</i>
3) Understanding how to mobilize assets	Understanding how to mobilize assets came from the same sources that allowed participants to identify assets. First, they relied on their health care providers for information and assistance with navigating the health care system. When health care professionals were not willing to listen, or did not advocate for patient needs, the participants did not receive sufficient information on how to access services. Second, participants received information from members of their stroke networks. Third, participants showed initiative and the willingness to seek information through the internet. Finally, participants could gather information from previous experiences. For example, participants knew from past adverse experiences that social networks are assets that can be activated if needed.
4) Having the self-efficacy and motivation to access the assets	Firstly, the self-efficacy needed to access assets was driven by both intrinsic and extrinsic factors. In stroke recovery, intrinsic factors included the participants' hope and belief in the process; they believed that there is always opportunity to recover and continued to seek new ways to support this process. Motivations were personal; for example, participants wished to return to their role as caregivers within the family or to return to work/school. Furthermore, the confidence established through stroke recovery allowed participants to access other assets. Participants indicated that this could be beneficial in disaster situations. For example, confidence in their mobility could allow them to use staircases during evacuations. Extrinsically, participants indicated many factors influencing motivation, including money, proximity to resources and availability of positive social supports.

CHAPTER 5: DISCUSSION

The overall purpose of this research was to explore the perceptions of capability among female stroke in the context of DRR. To address this, the following research question and study objectives were presented:

- 1) What does capability mean to female stroke survivors, in the context of disaster risk reduction?

Objective 1: To examine the role of asset literacy in the social construction of capability and lived experiences of female stroke survivors

Objective 2: To create an opportunity for female stroke survivors to share their lived experiences, enhance collective asset literacy among members of the stroke and DRR communities, and support social participation.

5.1 Perceptions of Capability and Autonomy

In this study, participants described capability as the ability to do and the ability to contribute. Capability was viewed as a dynamic concept that involves the ability to function as an *individual*, as well as the ability to be an *active participant* in the wider community. To the participants, being an individual was a multi-faceted concept and entailed living autonomously, living based on their priorities and values, as well as fulfilling their social roles. Being active participants involved establishing social networks, and creating social capital and giving back, especially to other stroke survivors and persons with disabilities. As such, the women in this study valued their autonomy and the feeling of being meaningful contributors to the community.

Participants' perceptions of their capability during disasters was rooted in the context of their stroke recovery journeys. Often, after experiencing a stroke, daily functioning involves

adapting to the challenges of living with an acquired disability (O'Sullivan et al., 2009). Stroke survivors can feel restricted by limited mobility, cognitive impairments, fatigue, depression symptoms, and a lack of social connectedness and self-efficacy for engagement (Chau et al., 2009; Kubina et al., 2013; Mayo et al., 2013). This can lead to changes in social lives, an inability to accomplish day-to-day tasks (Mayo et al., 2002) and an overall sense of a loss of independence (Obembe & Eng, 2016; Mayo et al., 2002). In this study, participants described a similar set of stroke impacts (i.e. physical, cognitive, emotional and on social networks). Ultimately, the survivors faced a loss of autonomy due to diminished physical, cognitive and emotional capacities, and struggled to resume their roles within their families.

For these survivors, recovery entailed using assets to gain tangible skills that promote autonomy (i.e. strength, speech, ability to recall). Autonomy was important to regain a sense of normalcy but it was also used to build social capital through stroke groups, and to give back to other survivors through active participation in their communities. The participants recognized the importance of autonomy to DRR; it could allow them to prepare for and respond to disasters in a way that is valuable to them, meets their needs and priorities, and supports their role as caregivers.

The value of autonomy to DRR is confirmed by the literature and the need to develop DRR strategies that enhance autonomy for persons with disabilities is highlighted (Phibbs et al., 2014). Individual disaster resilience is enhanced when people are empowered to be independent and active participants in life (O'Sullivan et al., 2014). As such, inclusion of persons with disabilities in disaster planning should be examined through a lens of independent living, rather than a medical model lens (Casey-Lockyer & Myers, 2016). Autonomy can be supported

through knowledge, skills, motivation and supportive environment (O'Sullivan et al., 2014; Liu & Fu, 2011).

The Social Vulnerability Lens sheds light on the importance of fostering autonomy in DRR through a supportive environment. This approach indicates that society plays a role in the social construction of disability (Kelman & Stough, 2015); often, persons with disabilities have the capacity to function independently but are limited by their surrounding societal structures and attitudes (Maratos et al., 2016). When society does not plan for the needs of persons with disabilities, inequality is established and perpetuated (Kelman & Stough, 2015). Disability standards during disasters should not be separated from disability standards for society at large. If society creates an environment that supports independence for persons with disability in their daily lives, an increase in general activity (Zhang et al., 2017) and in autonomy during disasters will inherently be supported (Twigg et al., 2011).

The concept of self-efficacy is also vital to understanding the relationships between stroke recovery, autonomy and capability during disasters. Self-efficacy refers to a *perceived capability*, or a person's belief that they can succeed at accomplishing a task (Bandura, 1978). General self-efficacy correlates with self-esteem (Judge et al., 2002); it is needed to cope with existing vulnerabilities and support the ability to overcome future obstacles (Goodman et al., 2016). In this study, participants used the term confidence synonymously with self-efficacy. When evaluating their perceptions of capability during disasters, all participants indicated that it was dependent on the stage of recovery. The notion of *capability and confidence go hand-in-hand* was an important theme in this study. As participants regained capacities through recovery, they also gained confidence and autonomy. As a result, they felt they were more capable of dealing with a disaster.

Research shows that self-efficacy and adaptive capacity are foundational pieces of disaster resilience (O’Sullivan et al., 2014). The adaptive capacity of individuals to cope relies on their circumstances, personal characteristics and ability to make use of opportunities (Marshall et al., 2010). In our research, participants identified confidence as a personal trait that enhanced their general resilience, and could support adaptive capacity during disasters. This is consistent with a study by O’Sullivan et al. (2017), in which self-efficacy was indicated as an asset for DRR because it fosters a sense of competence and allows people to overcome obstacles when faced with adversities. Self-efficacy was also identified as an aspect of asset literacy because it is needed to move from awareness of assets to activating assets (O’Sullivan et al., 2017).

5.2 Asset Literacy and Social Participation

In this study, participants were involved in an asset-mapping exercise, where they were asked to list assets that support capability during disasters. The way in which assets were framed confirm the importance of recovery to the perceptions of capability among stroke survivors in the context of DRR. Participants listed many assets – some could serve as both DRR and stroke recovery assets, and some stroke recovery assets could give rise to DRR assets. Assets that support general resilience, such as personal characteristics, personal motivations and social supports, are useful to both recovery and DRR. Furthermore, stroke assets enabled participants to regain tangible skills; tangible skills were then identified as potential assets for DRR. Ultimately, all assets served the following overarching purposes: 1) Promoting independence and active participation in the community, 2) fostering disaster preparedness and response and/or 3)

providing emotional support. Examining how participants described assets revealed how asset literacy can shape perceptions of capability during disasters.

O’Sullivan et al. (2014) described asset literacy as a type of awareness; it involves understanding available assets, their potential contribution and the means to access them, and having the self-efficacy to activate them. The way in which individuals interpret and integrate information pertaining to the self and the external environment can help to build self-efficacy (Bandura, 1997). For the stroke survivors, understanding the assets that were available to them and the assets that they could access were important in gauging what they could be capable of during disasters. This awareness of assets came from various information sources – some were personal, such as the participants’ own experiences or their own research, but some were external and included members of their social networks such as other stroke survivors and health care professionals. This highlights the importance of social participation (i.e. establishing social networks and gaining social capital) in building asset literacy, and in ultimately building disaster resilience.

Social participation is an important dimension of DRR because it increases social connectedness, facilitates information exchange and increases motivation for action (Witvoropong et al., 2015). It is strongly correlated with DRR behavior, such as following disaster-related news, preparing emergency supplies and creating emergency plans (Witvoropong et al., 2015). The concepts of *social networks* and *social capital* are vital to understanding social participation and its relevance to DRR.

Social networks serve a variety of functions including sharing expertise and knowledge (Crabbé & Robin, 2006) as well as supporting practices that may decrease disaster risk (Ford et al., 2006). Well-connected individuals benefit from social ties in terms of disaster preparedness

and response (Witvoropong et al., 2015). Social capital are community- or individual-level attributes embedded in social networks (Lin, 2008; Waverijn et al., 2017), and is related to trust and social cohesion in the community (Witvoropong et al., 2015). Overall, studies show that having increased individual- and community-level social capital is positively associated with disaster prevention, preparedness, response and recovery (Reininger et al., 2013; Aldrich, 2011; Bihari & Ryan, 2012).

The participants' perceptions of capability in life and in DRR draws from general principles of social participation, as presented in the literature. The International Classification of Functioning (WHO, 2001) broadly defines social participation as "a person's involvement in a life situation" (p.213). The Disability Creation Process Model describes social participation as a combination of performing daily living tasks autonomously, and assuming roles within their socio-cultural contexts (Fougeyrollas, 1995).

Social participation and engaging in meaningful activities have been identified as both a quality of care and quality of life indicators for stroke survivors (Berges et al., 2012; Mayo et al., 2015). Thus, the return to the quality of life and degree of participation in the community prior to the onset of stroke are identified as important recovery outcomes (Mayo et al., 2015; Obembe & Eng, 2016; Noreau et al., 2004), and can contribute to general well-being and health (Tse et al., 2013; Young et al., 2001). Restricted social participation can lead to social isolation (Gouda & Okamoto, 2012; Hinojosa et al., 2011).

When participants joined this study, they viewed it as an opportunity for social participation – to give back, but also to continue to learn and develop. The asset-mapping exercise was an important exercise for knowledge exchange; participants were able to share and compare their recovery journeys and the assets they found valuable. It was also an opportunity

for them to enhance their own asset literacy by widening their awareness of recovery and DRR assets. The final aspect of asset literacy is having the self-efficacy and motivation to activate assets (O’Sullivan et al., 2014). For the participants, stroke recovery was important to reaching this step because it allowed them to build self-efficacy – when they were confident in their capabilities, they felt more empowered to seek other assets and become involved in new opportunities. Research indicates that even when there are opportunities for participation available, it is a challenge to engage survivors (Mayo et al., 2015); this study shows how asset literacy and social participation can support one another, and foster self-efficacy and resilience among stroke survivors.

5.3 Inclusion of Women and Persons with Disabilities in DRR

A by-product of the asset-mapping exercise were discussions pertaining to obstacles to accessing assets. Broadly, participants described a lack of understanding of stroke survivor needs, and assumptions regarding how services and supports should be delivered. To address these shortcomings, participants recommended sensitivity training for service providers and increasing opportunities for stroke survivors to share their unique concerns. This is consistent with previous research on the lived experiences of stroke survivors (Maratos et al., 2016).

Disasters and the circumstances that surround them can often result in inequity in services and access to services (Stough, 2015). It is important to understand the specific needs of persons with disabilities (Gill et al., 2008) and to not only investigate what resources are provided, but also how they are provided (Stough, 2015). First-hand narratives from persons with disabilities are important opportunities for inclusion and are sources of information that ensure independent and productive living (Bourke et al., 2017). There is a need to include the voices of

persons with disabilities and increase avenues through which they can be involved in general and individualized disaster planning (Ronoh et al., 2017). Including persons with disabilities in DRR planning better prepares agencies and service providers to tailor resources and disaster training to meet individual needs, create appropriate messages to motivate and engage, establish more partnerships, and strengthen communication between disaster planners and those at disproportionate risk (Kruger et al., 2018). Building social connections is important in fostering inclusion because it provides a sense of belonging, reassurance and support, and allows persons with disabilities to feel they are a part of a larger community (Bourke et al., 2017). In doing so, underlying institutional weaknesses can be addressed (Twigg et al., 2011).

The gender variable was also discussed through the asset-mapping exercise. The women in this study indicated that they have unique concerns and priorities compared to men in daily living, and in potential disaster situations. For example, it was often reported that there was a lack of sensitivity when health care professionals handled their sanitary needs post-stroke. This is consistent with the literature: Females in pre-puberty, puberty, pregnancy and lactating periods require special medical and psychological care. However, during disaster planning and responses, sanitary and privacy needs of women are often neglected (Enarson & Chakrabarti, 2009). The women also indicated that personal care items (i.e. soaps, make-up, shampoo) were important to them and could be important to them during disasters because they enhance general well-being. The specific needs of women highlight the importance of including them in the DRR discussion.

Walby (2005) recommends a *gendered approach* to integrating women in DRR; this entails including and listening to women during the planning processes, and incorporating their perspectives. Ultimately, disaster risk must be reduced by through gender equality, and most

critically, before disasters (Bradshaw, 2015). A recent study conducted by Forbes-Genade & van Niekerk (2018) revealed how activating female capacities can drive inclusive involvement and enhance community resilience. When women and girls are heard, it encourages cooperation and engagement among stakeholders and community members. Validating the importance of women and girls in DRR and creating opportunities for female-led DRR initiatives can reduce disaster risk (Forbes-Genade & van Niekerk, 2018).

Ultimately, it is important to adopt an intersectional approach to inclusion – that examines different dimensions (i.e. gender-based) to disability (Baranyi & Louis, 2016). This is supported by the Sendai Framework (UNISDR, 2015), which encourages a gender- and disability-inclusive lens to DRR. This study shows how opportunities for social participation (such as a Photovoice initiative or an asset-mapping exercise), can foster inclusion in the DRR discussion, by allowing women and stroke survivors to gain knowledge but also to share their expertise with others and take control of their own risk reduction.

5.4 Study Limitations

This study has several limitations that must be acknowledged. Firstly, this study had a small sample size ($n = 4$); typical focus groups are comprised of 6-12 individuals (Guest et al., 2013). Smaller focus groups are acceptable when participants are highly involved in the process, and the topic is complex and emotional (Guest et al., 2013), which was the case for this study. Although this study meets those criteria, the study data is drawn from a narrow pool of sources. Participants were recruited through members of the EnRiCH collaboration and stroke groups from Ottawa. This suggests that the participants were already well-connected to their communities and willing to engage in opportunities for social participation.

Secondly, the study location may have influenced recruitment. Focus group meetings were held at the University of Ottawa – this location may not have been convenient for those who rely on public transportation. For example, one participant who expressed interest in becoming involved in this project withdrew due to substantial travel times.

CHAPTER 6: CONCLUSION

6.1 Contribution of Research

This current research sought to understand perceptions of capability among female stroke survivors in the context of DRR. In doing so, it builds on existing knowledge on autonomy, self-efficacy and social participation, and their relevance to DRR. This study identifies autonomy as a valued recovery outcome; being able to function independently, resume previously held roles and contribute to the wider community are all capacities that can enhance perceived capability in the context of disasters. Regaining tangible skills through stroke recovery is needed to establish self-efficacy and become independent – as such, supporting stroke survivors in DRR must involve supporting them through recovery as well, and creating an environment in which they can make decisions and live in a way that is valuable to them.

Social participation and asset literacy can support one another, and are viewed as important in building disaster resilience. Building social networks and social capital are opportunities to increase awareness of individual- and community-level assets for stroke recovery and DRR, and motivation to access new assets. Social participation promotes inclusion of women and persons with disability in the DRR discussion by allowing them to share their expertise, and needs and concerns. Activities such as asset-mapping exercises or Photovoice initiatives are examples of creative tools that can foster social participation and place focus on the positive capabilities of those that are considered at disproportionate risk.

6.2 Opportunities for Future Research

Due to unique combination of topics being addressed and the participatory nature of the study objectives, an exploratory approach was adopted. Moving forward, it would be valuable to

confirm these results through different approaches (i.e. traditional focus groups, surveys or structured interviews) to glean more specific insight on the relationships between capability, stroke recovery and asset literacy. Using a different study design that does not require in-person meetings or a large time commitment may open the research to a larger, more diverse population. For example, it would be valuable to investigate the relationships between autonomy and social participation for survivors who are in the early stages of their recovery and experiencing aphasia. A second study exploring participant perceptions of being involved in a Photovoice initiative could provide more insight on the value of this form of research, and the potential impact it has on social participation in DRR. Finally, an in-depth gender analysis is needed to further understand the differential impact of stroke on women, specifically focusing on their responsibilities as caregivers and their roles within society.

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APPENDECIES**Appendix A: Ethics Certificate**

File Number: H03-17-14

Date (mm/dd/yyyy): 06/15/2017



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice
Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Tracey	O'Sullivan	Health Sciences / Others	Supervisor
Nilani	Ananthamoorthy	Health Sciences / Others	Student Researcher

File Number: H03-17-14**Type of Project:** Master's Thesis

Title: Perceptions of Capability Among Female Stroke Survivors in the Context of Disaster Prevention, Preparedness, Response and Recovery

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
06/15/2017	06/14/2018	Approval

Special Conditions / Comments:
N/A

Appendix B: Recruitment Notice**Stroke Survivors Photovoice Initiative**

uOttawa

Université d'Ottawa
Faculté des sciences de
la santé

École interdisciplinaire
des sciences de la santé

University of Ottawa
Faculty of Health
Sciences

Interdisciplinary
School of Health
Sciences

Our EnRiCH research team at the University of Ottawa is conducting a research project exploring the perceptions of capability among stroke survivors in the context of emergency management.

Why?**It is an opportunity for stroke survivors to:**

- 1) Share their lived experiences and generate discussion with other stroke survivors
- 2) Identify important assets in their lives that support emergency preparedness
- 3) Create a digital gallery of photographs and narratives to share with the wider community

What is Photovoice?

Photovoice is an action research method to engage participants in research that directly affects them and is important to their well-being.

A Photovoice group (about 6-10 people) meets once per month over a 6-month period. Each month, the members of the group will be asked to take photos that are meaningful to them – or bring photos they have found – to discuss with the group. After 6 months, the group will host an exhibit to display a sample of the photos and invite the community to discuss the topic.

For the exhibition, people from all over the community are invited to attend. Invitations are sent to people who have decision-making power around the issues related to the project. It is a gathering for members of the group to engage in discussion with people in different roles in the community – to share their ideas and experiences.

How can people get involved?

We would appreciate your help in forwarding this notice to anyone who might be interested in participating. For more information, please contact **Tracey O'Sullivan or Nilani Ananthamoorthy at 613-562-5800 (x7254).**

Thank you!

Tracey O'Sullivan
Faculty of Health Sciences,
University of Ottawa
25 University Pvt, Ottawa, ON, K1N 6X1

Appendix C: Social Media Posts**Facebook® Post:**

Hello everyone! The EnRiCH lab at the University of Ottawa is currently recruiting **stroke survivors** to participate in a **Photovoice Project** – this a collaborative initiative where participants are asked to discuss their perceptions of capability and vulnerability using photos that they have taken or selected. If you are interested or have any questions, please take a look at the attached recruitment notice!

Twitter® Post:

Recruiting for a Stroke Survivor Photovoice Project – an initiative where participants discuss their perceptions of capability and vulnerability using photos that they have selected. Check out attached notice!

Appendix D: Consent Form

uOttawa

Participant Consent Form

Title of the Research Project: Perceptions of Capability Among Stroke Survivors in the Context of Disaster Management and Emergency Preparedness

Principal Investigator:

Nilani Ananthamoorthy
Faculty of Health Sciences, University of Ottawa
200 Lees Ave., room E155E
Phone: 613-562-5800 x 7254

Thesis Supervisor:

Dr. Tracey O'Sullivan
Faculty of Health Sciences, University of Ottawa
25 University Pvt.
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tosullivan@uottawa.ca

Our EnRiCH research team at the University of Ottawa is conducting a research project exploring the perceptions of capability among stroke survivors in the context of emergency management.

Why?

It is an opportunity for stroke survivors to:

- 4) Share their lived experiences and generate discussion with other stroke survivors
- 5) Identify important assets in their lives that support emergency preparedness
- 6) Create a digital gallery of photographs and narratives to share with the wider community

What is Photovoice?

Photovoice is a qualitative method used in action research to engage participants in co-creating rich data about a topic that is important for their community (Wang & Burris, 1994). Participants are involved in each aspect of the research: a) outlining the objectives, b) determining what the photo assignments will be, c) taking the photos (or bringing in previously-taken photos or photos from the internet) and discussing them with the group, d) identifying emergent themes, and e) hosting a photo exhibition to present the photos and the themes to the community, policy audiences, decision-makers, and other stakeholders who are influential regarding the topic (Wang & Burris, 1997; Lopez, 2013).

A Photovoice group (about 6-10 people) meets once per month over a 6-month period. Each month, the members of the group take photos that are meaningful to them – or bring photos they have found – to discuss with the group. After 6 months, the group will host an exhibit to display a sample of the photos and invite the community to discuss the topic.

For the exhibition, people from all over the community are invited to attend. Invitations are sent to people who have decision-making power around the issues related to the project. It is a gathering for members of the group to engage in discussion with people in different roles in the community – to share their ideas and experiences. The exhibition is an important aspect of Photovoice because it provides an opportunity for the voices of the participants to be heard through the sharing of the photos and the narratives, which explain the photos and their relevance.

Participation:

As a participant in this study, I am being asked to participate in a 6-month Photovoice initiative (5 sessions and the exhibition).

The Photovoice sessions will be held once per month starting in November and will be approximately 75 minutes each. The first session is an orientation session where the group will talk about the project, discuss the process and ethics of community photography, distribute and discuss how to use the cameras. The group will then decide on a photo assignment to do over the next month. Photo assignment topics may include your lived experiences after surviving a stroke, what capability and resilience means to you, and assets within your community or yourself that foster capability and resilience. These topics will be examined in the context of emergency preparedness and disaster management.

Participants will be asked to take/select 5-6 photos each month and to bring them back to discuss at the next session. A similar process will be followed each month.

Benefits:

My participation in this study will contribute to knowledge about the perceptions of capability among stroke survivors. It will also be an opportunity to network with other people in the community and share my lived experiences.

Confidentiality and Anonymity:

The nature of the group discussions in Photovoice make it difficult to ensure confidentiality. And given the nature of this project, some participants may want their name to be displayed with their photos / comments.

While the members of the group will be asked to respect the confidentiality of the members in the project, it is not possible to guarantee that this will be followed. Also –

given that photos will be used to explain concepts related to the project and displayed in the exhibition – this also will make it difficult to ensure confidentiality or anonymity.

However – participants have the right to decide how their photos and explanations can be used in presenting the findings from this study. For example, participants can provide consent for using the photos in presentations, theses, publications, and/or the photo exhibition. If the group decides to do a digital gallery of the exhibition, the participants can decide if they would like to have their photos uploaded as part of the digital gallery as well.

The group discussions will be audio-recorded to ensure the transcripts are accurate representations of the conversation. In the transcripts, all identifying information (eg. names) will be removed. This information will only be accessed by the researchers and research assistants working under Professor O’Sullivan’s supervision for this project.

I understand that my responses included in the transcripts for the group discussions will be used for the purposes of this project, and possibly for the basis of secondary studies related to this topic, including student thesis projects. To protect my confidentiality, I have been assured that in written reports, presentations, and publications, my name will be disguised – unless I wish to have my name associated with my responses and photos. Any students or research assistants working with the data will sign a privacy and confidentiality form.

Conservation of data:

The data collected (photos, digital recordings of the group discussions, and transcripts of the recordings) will be kept in a secure manner. They will be stored on a computer with a secure password. Only Nilani Ananthamoorthy (lead researcher), Prof. O’Sullivan (thesis supervisor) and the student researchers working under Prof. O’Sullivan’s supervision will have access to the data. The data will be conserved for 10 years.

Risks:

Some people may find it stressful to discuss issues related to disasters in their community or view images related to disasters in their community. I understand I may refuse to answer any questions I do not wish to answer, and I have the right to withdraw from the study at any time. I understand that Photovoice sessions are similar to traditional focus groups and if I choose to withdraw from the study, it will not be possible to withdraw my data from the focus group transcripts.

Quotations:

I understand that participants in this project may be quoted in the research study reports, presentations and publications, but no names or identifying information will be used (unless participants express that they want to be identified).

I understand that it is my choice whether or not to be quoted and whether the pictures I generate for this project will be displayed. I can change this permission at any time.

(please initial beside your choice)

- *I agree to be quoted from the group discussions but all personally identifying information shall be removed or altered and contents of the quotation shall not be revelatory of my identity* _____.
- *I do not wish to be quoted from the group discussions* _____.
- *I would like my name to appear with my comments about the photos* _____.
- *I agree that the photos I generate for this project may be used for*
 - *presentations, thesis documents, and publications* _____.
 - *the photo exhibition* _____.
 - *the digital photo gallery (which will be displayed online)* _____.

Signatures:

My participation is voluntary and there is no financial compensation provided for my participation in this study. I understand I am free to withdraw from the study at any time. My signature on this form indicates I understand the information regarding my participation in the research project and agree to participate.

Participants are invited to contact the principal investigator (Nilani Ananthamoorthy) at 613-562-5800 x7254 for more information.

Note: If you have any questions concerning your rights as a participant in this research, please contact The Protocol Officer for Ethics in Research at the University of Ottawa at the following address, phone number or email:

Mailing address: Protocol Officer for Ethics in Research
Research Grants and Ethics Services
University of Ottawa
Tabaret Hall (154)
Ottawa, ON K1N 6N5

Phone: 613-562-5387 Email: ethics@uottawa.ca

Participant name (please print): _____

Participant signature: _____

Date: _____

Researcher signature (please print): _____

Researcher signature: _____ Date: _____

Please sign and date this letter and return to Nilani Ananthamoorthy before the first focus group session.

Alternatively you may mail it to:

Dr. Tracey O'Sullivan
Interdisciplinary School of Health Sciences
University of Ottawa
25 University Pvt.
Ottawa, ON., K1N 6N5.

Participants should save a copy of the consent form to keep for their personal records.
Thank you for your interest and contribution to this project.

Appendix E: Introductory Meeting Agenda**PhotoVoice Introductory Session Agenda****Pre-meeting set-up:**

1. Set up food
2. Write out research question on the board
3. Put out name cards, cameras, set up recorders

10:00 – 10:15: Introductions

1. Ask participants to grab snacks
2. Ask those who haven't signed consent forms to do so
3. Round table introductions

10:15 – 10:45: Explain Study

1. **What is the purpose of our study?** We are trying to find out how stroke survivors perceive their own capability during disasters and emergencies. We want to know resources (assets) you have in your life that impact your capability.
2. **How are we doing this? (PhotoVoice Study)** A PhotoVoice project is a project where we use photos that you take to generate discussion about the research topic. Every month we will have a different photo assignment and each month you will bring in different photos to talk about. A lot of this driven by you! We will decide what the photo assignment is together and it will be decided based on our discussions. At the end, we are going to plan a photo exhibit, where we can share your pictures with others – we'll design the exhibit based on who you'd like to share it with and what kind of audiences you want to reach.
3. **Show the example of the PhotoVoice project regarding food insecurity in Nunavut**
4. **Explain how to use camera:** If you are going to take a picture with a person, you will need their consent. You do not have to take a picture of anything you don't feel comfortable sharing.
5. **Any questions?**

10:45 – 11:20: Discussion & First PhotoVoice Assignment

1. **What does capability mean to you? What does it mean to you in the context of disasters/emergencies?**
2. **What assets/resources do you have that allow you to feel capable during disasters/emergencies?**
3. **What does community mean to you?**

11:20 – 11:30: Decide on new meeting time

Appendix F: Coding Grid

1. **Stroke-Related Impacts:** Any changes in the stroke survivor's life that is directly or indirectly related to their stroke
 - a. **Emotional:** Can include (but is not limited to): feelings of abandonment, feelings of discomfort, feeling judged, having to "swallow pride", decreases in confidence/assurance, feeling like a burden, loss of self-efficacy, etc. → don't assume emotional impact (make sure they mention it)
 - b. **Physical:** Can include (but is not limited to): loss of function, loss of energy, loss of strength, loss of mobility, challenges using computers, speech, etc.
 - c. **Cognitive/Mental:** Can include (but is not limited to): loss of memory, entering "survival mode"
 - d. **Environment:** Can include (but is not limited to): changes to living space
 - e. **Social Networks & Social Interactions**
2. **Recovery:** Recovery is defined as: 1) regaining what the stroke survivor had lost due to the stroke, 2) returning to "normal" or "better than normal" (i.e. building back better) after the stroke or 3) the journey to move past stroke-related trauma and establish a "new normal"
 - a. **Emotions related to recovery:** Can include (but is not limited to): hope, optimism, gratitude, faith, belief, perseverance, happiness about "little achievements", wishing for a "better tomorrow"
 - b. **Adaptations Post-Stroke:** Anything related to adapting to the post-stroke "new normal", changes/adaptations that have been made by the stroke survivors or others around the stroke survivors to support their "new normal"

Ex. Adapted supports, new ways of carrying out day-to-day tasks

 - c. **Mental/Cognitive Recovery**
 - d. **Physical Recovery**
 - e. **Assets for Recovery:** Can include but is not limited to: services, personal goals, patient engagement, etc. This can also include advantages of social networks/institutions.
 - f. **Obstacles in Recovery:** Refer to the previously mentioned definition of recovery
 - i. **Institutional Barriers:** Can include but is not limited to any systemic, administrative, governmental, bureaucratic obstacles → anything wrong with the "system"
 - ii. **Barriers to Accessibility:** Any barriers that render tools for recovery inaccessible (i.e. money, distance, etc.)
 - iii. **Inadequacy of supports:** Anything related to dissatisfaction with supports or when individual, specific needs are not met through a support. i.e. due to a lack of communication with health care providers
3. **Disaster Risk Reduction/Emergency Preparedness**
 - a. **Assets**
 - b. **Obstacles**
4. **Assumptions:** Assumptions is defined as: any belief, supposition, presumption or expectation placed on individuals that are based on preconceptions/misconceptions of

stroke and/or a lack of understanding. Can be related to having an “invisible condition”, the dichotomy between physical and mental well-being, physical representations of limitations, etc.

- a. **Related to capability:** Capability is defined by the participants as “being able to do” or “feeling able to do”
 - b. **Related to being a young stroke survivor**
 - c. **Related to being a female stroke survivor**
5. **Then vs. Now:** Comparisons to physical/mental/emotional states pre-stroke/post-stroke to present day
6. **Agency:** Can include anything related to power, choice, control, patient advocacy, dignity, respect etc.