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Emergency preparedness – The perceptions and experiences of people with disabilities

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ABSTRACT

Background: A population well-prepared for mass emergencies will respond better in real-time crisis and will be less exposed to the negative effects caused by the event. Our aim was to learn about the ways in which people with disabilities perceive emergencies and to understand their needs in preparing for these situations.

Methods: Sixteen semistructured in-depth interviews were held with 17 people with disabilities (motor, sensory or mental) (One interview was with a pair who chose to be interviewed together). The analysis was conducted using the phenomenological approach.

Results: Participants had not made any particular preparation for managing emergencies. Their approach was fatalistic, given their strong dependence on people and machines. They expressed their general distrust of the authorities' ability to address their needs in an emergency. Even individuals with the same disability presented a variety of needs.

Conclusions: To properly address the vulnerability of people with disabilities in emergencies, professionals need a better understanding of their individual way of life in routine times and to find ways to empower them to become involved in their own emergency preparedness. The needs of people with disabilities should be considered in terms of space and time, as well as by categories of disability.

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Introduction

Emergency situations take a high toll both in terms of human lives and in economic repercussions. Mass emergencies include a wide range of events, whether caused by human beings (e.g., mass accidents, terror attacks, wars, etc.) or by nature (storms, earthquakes, etc., which are sometimes referred to as *disasters*). A state of emergency is declared in the aftermath of a mass emergency or a disaster, when there is an imbalance between resources and abilities, on the one hand, and the needs of the local population, on the other hand [1].

A population well-prepared for mass emergencies will respond better at the time of a real crisis and will be less exposed to the negative effects caused by the event [2]. Studies have found that preparedness of the population at the community and family level (e.g., preparing shelters) helps increase resilience in real-time [3–5]. Although it is virtually impossible to actually prepare for a mass disaster, efficient foresight can significantly reduce the number of casualties in human life and resources, the severity of injuries and, in some situations, it can even prevent casualties [1]. To be sufficiently prepared to operate efficiently in cases of mass disaster, it is necessary to consider the risks and the population's exposure to such risks and to anticipate the types of injuries that can occur. Such comprehensive preparation includes identifying population groups at higher risk and devising intervention and prevention programs accordingly [6]. According to McEntire [7], the concept of preparedness implies that specific efforts are made to identify potential hazards so as to decrease the number of

variables that can lead to disasters, while at the same time increasing the ability of individuals, organizations, and nations to prevent, prepare for, and react to them effectively. Fifolt et al. [8] mentioned that in addition to active operations, such as writing training plans, it is important to recognize that there is room for flexibility and improvisation.

Israel is considered one of the leading countries in terms of preparedness for mass emergencies [1]. Notwithstanding, Bodas et al. [9] found that only one half of the population in Israel responded positively and complied with at least 50% of the authorities' recommendations on how to prepare households for emergency situations. In yet another study, researchers showed that the Israeli public has a unique perception of emergencies, one that features a pattern of denial, along with a view of emergencies as routine occurrences, which makes it difficult for the authorities to prepare the civil population [10].

In recent years, there has been an increased focus in academic research on the behavior and preparedness of people with disabilities for emergencies [11, 12]. Often this increased attention comes in the aftermath of particular events, such as 9/11, Hurricane Katrina, or the recent volcanic eruption in Japan [13]. Thus, for example, Uscher-Pines, et al. [14] surveyed 501 families in Pennsylvania, USA, and found that households with people with disabilities did not devote time to prepare their family members with disabilities for emergencies. Despite the fact that this population is more vulnerable and despite the resulting efforts of both governmental and nongovernmental agencies to address the needs of this segment of the population, the study's findings

indicated that no special preparation had been initiated in order to plan proper behavior in an emergency, nor had they taken steps to stock up on items that this population needs.

Smith and Notaro [15] conducted a wide-ranging survey among 188, 288 respondents with disabilities, from six different US states regarding their preparedness for emergency situations. Their findings indicated that persons with disabilities were significantly more likely to state that they were not prepared at all for an emergency. They also found that persons with disabilities were not prepared to evacuate in an emergency situation and were also less likely than people without disabilities to have a three-day supply of water, a working battery-operated radio, or a working flashlight, as is the standard requirement. During a mass emergency, not only were people with disabilities significantly less prepared than were people without disabilities, but they also used different communication modes to contact others (landline vs. cell phone, respectively) and to collect information from the authorities (television vs. radio, respectively). The researchers concluded that increased efforts must be made to empower persons with disabilities to become involved in their own emergency preparedness; at the same time, strategies for emergency preparedness must be considerate of these high-risk populations. Bricout and Baker [16] noted that one of the first lessons learned following Hurricane Katrina regarding people with disabilities was the important and significant role played by interpersonal and technologically-based social networks, in terms of conveying information and coordinating resources quickly and efficiently. However, Shankar [17] raised the question regarding the degree to which people with disabilities are part of such networks. Tomio, Sato, and Mizumura [18] considered the specific case of people with chronic diseases who have severe disabilities related to their illness, as in the case of patients with rheumatoid arthritis. They concluded that participants were not sufficiently prepared for emergency situations and recommended that policymakers seriously consider ways to address the unique needs of this segment of the population and their preparedness for emergency and disaster situations.

In general, the ability of people with disabilities to cope during a mass emergency situation is a complex issue, which is affected by several factors, including personal strengths, the type and severity of the disability, and of course, the locale's and the residential facility's degree of accessibility and preparedness for emergency situations [19].

Based on what is already known about the general population's reaction in the aftermath of emergencies, it can be expected that people with disabilities might be at higher risk for developing posttraumatic stress symptoms, as found in a study conducted in Israel [20]. It may be assumed that they have access to fewer financial resources (in terms of education, employment, and socioeconomic status), social resources (personal and professional networks), and emotional-psychological resources (e.g., self-esteem and optimism), which are essential for coping with emergencies and disasters [21]. Consequently, the unique physical and mental needs that people with disabilities have in their daily routine require special attention in times of emergency [15, 22].

Emergency preparedness of people with disabilities in Israel

In Israel, there are 1, 603, 500 people with disabilities, constituting approximately 20% of the country's population [23]. Approximately 25% (1, 344, 600 individuals) of the entire adult population in Israel (i.e., with disabilities, and without disabilities, of ages 20 and over) are people with disabilities; approximately 10% (535, 500 individuals)

of the entire adult population in Israel are people with a severe disability, and approximately 15% (809, 200 individuals) of the entire adult population in the country are people with a mild disability. These numbers refer to a wide range of disabilities, including physical-motor, physical-sensory, mental, and cognitive-developmental disabilities. This population is both socially and economically weakened and, hence, exceptionally vulnerable in crisis situations [24].

In recent years, special legislation has been established in an attempt to enable people with disabilities to integrate equally into Israeli society [25]. In 1998, the Equal Rights Act for People with Disabilities was passed and since then detailed regulations have been issued regarding accessibility standards that meet the needs of this particular population in emergencies. In 2016, regulations were added regarding measures intended to maximize the safety of the civil population, which explicitly required that public shelters be adapted to the needs of people with disabilities, by ensuring an accessible path to the shelter, and fitting the shelter with the specially-adapted amenities, as required [19].

The authorities in charge of home-front security issued guidelines about how to prepare to meet the needs of people with disabilities during emergencies [26]. These guidelines, which can be found online, provide details regarding the preparedness of both the public and private spaces, with a focus on issues related to mobility, orientation, and communication needs of people with disabilities. There is also an emphasis on the need to prepare and drill the security staff in the relevant facilities on how to assist people with disabilities during mass emergencies.

Peled [27] conducted a study among people with physical disabilities (ages 20–65) residing in the southern region of the country, where the population lives under a constant threat of missile attacks, terror attacks, and war. Findings of the study emphasized not only the physical needs of people with disabilities (access to and adaption of amenities in shelters, as well as supplies of food and medications), but also their social and psychological needs (e.g., the need to maintain contact with family members, social networks, and sources of emotional support). Another study conducted in Israel focused on people with cognitive and developmental disabilities from the southern region of the country who live independently in the community and who were subject to repeated missile attacks over a prolonged period of time. Findings of that study revealed a correlation between the distance and amount of exposure to missile fallings and the severity of the participants' posttraumatic stress disorder symptoms, which included significant functional difficulties [28]. A qualitative study conducted among people with disabilities residing both in the northern and the southern regions of Israel, where there is a constant security threat, revealed that in emergency situations, participants found it difficult to use personal devices, such as eyeglasses and hearing aids (e.g., when wearing a mask in case of chemical warfare) or wheelchairs [21]. In addition, participants of the study noted a lack of accessible information in real-time, a fact that increased their anxiety and fear. Participants also raised the issue of caring for others; for example, people with disabilities who have children were afraid they would not be able to care for the children appropriately while caring for themselves in an emergency situation. Other participants, especially those who rely on the assistance of guide dogs, expressed their anxiety at the thought of being separated from their guide dog in an emergency, a situation that would entail not only physical but also emotional difficulty. It should be noted that the main interest of the studies mentioned herein was emergency situations related to national security, such as wartime, or a terror attack, but only little

Table 1. Demographic characteristics of participants.

Pseudonym	Gender (w/m)	Age	Disability (1-Mental; 2-Partial paralysis; 3- CP; 4- Quadriplegia, 5-Visual impairment; 6-Auditory impairment)	Education Level	Personal Status 1- Single; 2- Married or with partner; 3-Divorced	Employment + Employed – Unemployed * Retired
1.Edna	w	41	1	MA student	2	–
2.Miriam	w	47	1	High school	1	–
3.Yossi	m	45	2- Upper torso	Practical engineer	1	–
4.Moshe	m	49	3	High school	2	+
5.Almog	m	82	6	Elementary school	2	+ (Family business)
6.Orr	w	27	1	BA student	1	+
7.Chen	w	36	1	Practical engineer	2 (+ 4 children)	+
8.Susan	w	67	4 –On a ventilator	High school	2	*
9.Menny	m	71	4	High school	2	–
10.Ronit	w	64	4	High school	1	*
11.Ronen	m	67	4	High school	3	*
12.Jonathan	m	45	4 –On a ventilator	High school	1	–
13.Muhammad	m	25	5	MA student	1	+
14.Omer	m	52	2- Lower torso wheelchair-bound	MA	2 (+3 children)	+
15.Ilan	m	44	5	PhD	2 (+2 children)	+
16.Nuriya	w	34	3 - Lower torso wheelchair-bound	MA	1	+
17.Nathaniel	m	27	5	BA	2 (+1 child)	+

attention has been directed to examine the preparedness of this population for coping in the event of a natural disaster.

In summary, there is a paucity of in-depth studies about the experiences of people with disabilities during mass emergencies and disasters [29–31], and there is a need to involve people with disabilities in the various research stages when designing programs for emergency preparedness of this segment of the population [19, 21, 32, 33]. Hence, the goal of the current study was to understand the personal experiences of individuals with disabilities in emergency situations, so as to enhance our understanding of their perceptions of emergencies, their unique needs in an emergency event, the accessibility and appropriateness of information resources, the existing services that cater to their needs, and their social support networks.

The theoretical framework of the study

Our article employs the approach of disability geography: by examining the multiple and diverse spatial aspects of the lives of people with disabilities, we intended to identify spatial patterns and processes [34], as expressed by Hansen and Philo [35]:

Individual impairments *do* matter, and must be foregrounded, but always in relation to the kinds of spaces that non-disabled people have created – and the sorts of time-space organization of activities required by ableist society – which differentially, but rarely in a helpful manner, impact upon most cohorts of disabled people. (p. 494).

Hence individual circumstances, experiences, and narratives must be included in the theoretical and practical discussion about people with disabilities [36].

The disability geography approach was developed as a criticism of the social model of disability [37]. Despite the positive gains made by shifting the perspective from the medical to the social model, the latter was criticized as being disembodied [38, 39] and, consequently, the impaired body and the specificity of its physical differences was completely ignored by studies [35]. There was a call led by researchers and activists to bring “our bodies and ourselves back in” [40] and to look critically at the dynamics of human appearance and how it is shaped by dominant visions of the idealized body shape, size, and tone [41]. Bodies are viewed as “*things lived in*, the immediate vehicles for a person’s emotional, cognised and perhaps voiced encounter with the world” [35, p. 495]. However, this approach was introduced with great hesitation, noting that addressing the materiality of

the impaired body might be interpreted as an invitation to return to the medical model [42]. Some examples illustrate the approach and its relevance to the fields of disability and rehabilitation [See 43–46].

To conclude, Hansen and Philo [35] advocate implementing an approach that examines the intersection of disability and space, one that recognizes how humans of all kinds go about doing things in the world, i.e., managing the time, space, and speed as part of the realities of daily living.

Materials and methods

Participants

The study included 17 participants with various types of disabilities (motor, sensory, or mental disabilities). To meet the inclusion criteria, participants had to be at least 18 years old, have a disability, and be able to express themselves adequately in Hebrew. Accordingly, the exclusion criteria were as follows: age under 18, an intellectual-developmental disability, or autism spectrum disorder.

The sample was varied in terms of gender (see Table 1); however, the majority of the participants were Jewish (of secular and observant backgrounds) and one was a Muslim. Approximately half of the participants were married or with a partner, several had children, and approximately half of them had an academic degree (BA or higher). Three of the participants had a congenital disability; as for the others, the disability was a result of illness (12) or accident (2).

Participants were recruited using a convenience-sample method. We first approached people we knew, as well as people who we met coincidentally (on the street or in the mall, etc.). After a brief introduction, we were granted permission to call them by phone at a later date, to give a more detailed presentation of the research study and arrange a meeting. Then, additional participants were recruited using the “snowball method,” whereby participants led us to other potential participants.

Data collection

A qualitative approach was chosen as the methodology for the current study. We used semistructured in-depth interviews. We developed an interview guide (see Table 2) following the main research question: How do individuals with disabilities prepare themselves for disaster and emergency situations. Notwithstanding, interviewees

Table 2. Semistructured interview: Main questions.

1. What is the disability you face?
2. Is your disability congenital or acquired?
3. Tell me about your routine (work/family/leisure)
4. In what ways does your disability affect your everyday life?
5. In what situations do you feel dependent on those around you?
6. What does a mass emergency entail for you?
7. Have you ever been in an emergency situation?
 - What did you feel? What did you do?
 - What made it easier for you to cope? What made it difficult for you?
 - Did others help you in that event? In what way?
8. What are your unique needs during emergencies?
9. Did you get any preparation, like a lecture on how to manage in emergency situations?
 - Have you practiced ways of acting in an emergency?
 - Do you know the emergency guidelines?
 - Have you been contacted by the authorities (municipality/HMO/community center) regarding your preparation for emergency situation?
10. On the issue of preparing people with disabilities for emergencies, what do you propose to emphasize? Based on your experience, what are the important points to consider when helping prepare people with disabilities for emergency situations?

Table 3. Themes and Subthemes.

Themes	Subthemes
1. Attitudes towards emergencies and preparation for emergencies	1.1 Emergency as an existential condition 1.2 Indifference and fear in relation to emergency preparedness
2. Practices in emergency situations	2.1 Familiarity with emergency guidelines 2.2 Maintaining a balance between dependence and independence in times of emergency 2.3 Experiences with the welfare department and the medical staff in times of emergencies 2.4 Concerns regarding real-time emergencies 2.5 Suggestions for the future about the possible ways to prepare people with disabilities for emergency situations

were welcome to raise other issues or to ignore issues addressed in our questions – the choice was theirs.

Data were collected between February 2017 and August 2017. A total of 16 interviews were conducted with 17 participants. One interview was with a pair of interviewees who chose to be interviewed together. The interviews were conducted in the homes of the interviewees or at their workplace, according to their preference. One of the interviews was conducted over the phone. Interviews lasted between 30 and 120 min. All interviews were recorded and fully transcribed. Additionally, during and after each interview, field notes were recorded by the researchers in a journal [47]. These included the researchers' impressions after concluding the interview, regarding, for example, the interviewee's living conditions and way of life, and reflections about the atmosphere during the meeting and the interview. We also included reflective commentary that we conducted during the research.

Ethical considerations

By signing an informed consent form, all participants indicated their willingness to participate in this study, have the interviews recorded, and the findings published. The interviewees were given the contact details of the researchers, in case they had additional questions. The study was approved by the ethics committee of the academic institute with which Author 1 is affiliated. In the presentation of the findings, only pseudonyms are used, so as to protect the identity and ensure the anonymity of participants.

Data analysis

The analysis was conducted using the phenomenological approach. Paul Ricoeur referred to phenomenological research as “the descriptive study of the essential features of experience taken as a whole” [48, p. 1214]. It aims to learn about the way in which participants experienced an event or a phenomenon, the way they perceive it, and the way they present it [49]. We chose the phenomenological approach because it aims to create meaning through the experience of moving through space and across time [50].

The interview transcripts were coded by hand and analyzed by both authors, according to the following stages. The first step was to read and re-read the interview transcripts until a good grasp of the material was obtained. Then, we followed the steps for a thematic analysis [51]. We found that thematic analysis was the best suitable to our analysis because it allowed us to follow the way by which our participants make sense of or interpret the phenomena of our study in their daily life and at the same time it gave us an order of understanding that involves generating categories through which to interpret and describe the phenomenon under investigation [52]: (1) From each transcript, we retrieved meaningful chunks (words, phrases, sentences and clusters of related sentences), each of which was represented by a category name or brief descriptor (*code*) relevant to the framework of participants' utterances. (2) The codes were organized into groups. We eliminated those codes that expressed similar ideas and arranged them into major themes, while unique codes that were introduced by only some of the interviewees were assigned to separate themes. Accordingly, we produced subthemes to facilitate the analysis of important thematic interrelationships. Relevant quotes were placed under the different subthemes to keep and clarify interviewees' authentic meanings. The above-mentioned steps (1 and 2) were conducted both midway through the interviews (after the eighth interview) and again at a later stage (after the 14th interview). Each researcher conducted the two-step analysis separately; we then shared the findings with each other and reached an agreement regarding the thematic categories. (3) After each interim analysis, in addition to following the interview guidelines, we shared some of the recent insights with the next interviewees and asked for their opinions. Their responses helped clarify thematic categories, which led to the formulation of additional questions, intended to enhance our understanding. For example, after the eighth interview, we expanded the question: In your opinion, what is an emergency? And after the 14th interview, we asked the participants why –in their opinion– people with disabilities responded indifferently to the issue of emergency preparedness and disaster. We decided to stop after the 16th interview, when we recognized that we had reached a point of saturation. The final analysis was conducted after all of the interviews had taken place. The thematic categories were clearly defined and agreed on by both authors. The method described served to validate the final analysis of the findings [53]. To ensure trustworthiness of analysis, we also shared our analysis with an additional participant who had more than two decades of experience working with children and adults with visual impairments. Finally, we utilized our own experience, given that one of us is coping with a disability [54] and the other has expertise in the management of emergency situations.

Results

Below we present our findings (themes and subthemes are shown in Table 3). Our emphasis is on the interaction between disability,

time, and space. We will show that in our participants' experiences, spaces are adapted to the abilities of a "normal" or "standard" human body, which is without disability, thereby endangering people with disabilities in emergencies. At the same time, the body and impairment have a great significance in terms of time and space in the participants' experience, especially in times of emergency and disaster.

Theme 1 attitudes towards emergencies and preparation for emergencies

Emergency as an existential condition: "I am always in a state of emergency"

The interviewees explained that in many ways in everyday life they live in a state of emergency.

Edna said: "For me, I am always in a state of emergency," and explained that her daily existence consists of an ongoing struggle that requires a great deal of resources and effort, so that it seems a privilege to worry about an emergency situation that might occur in the future: "If I don't have a meal ready, then I'll worry about that first, and only then will I go on to worry about what to do in case of an emergency." The example was a way for Edna to say that for her, everyday life requires coping with existential challenges, and therefore being prepared for an emergency is a secondary priority.

Nathaniel expressed a similar view and defined an emergency as follows: "... A situation in which I cannot cope alone, in which I need the help of others. Perhaps a situation that is life-threatening or is unfamiliar." Much like Edna, he explained that his everyday life is wrought with challenges that constitute a kind of risk, as in the example he gave, saying that if he gets off the bus at the wrong stop, he needs assistance from others to find his way. Otherwise, it could be a threatening situation for him. Also Ilan expressed ideas similar to those of Edna and Nathaniel. Nonetheless, in his opinion, not every daily challenge, even if it is complicated and dangerous, constitutes an emergency:

When I go out onto the street today, I enter a state of hyper-alertness, let's say, more than you typically do... a kind of constant tension... But would I say that it's comparable to a war situation or if the house were to catch fire? I'd say there's still quite a large gap.

Indifference and fear in relation to emergency preparedness: "whatever happens – happens"

The interviewees presented a perception of indifference when we asked about their preparedness for emergency situations such as an earthquake. They said that they had never considered what needed to be done in preparation, or what they would do in an emergency situation. Ronit said, "It's not something I think about, because if I did, it would have a negative effect. There's no need to think all the time about fear and things like that." She later mentioned that in her apartment building there is no shelter for wartime emergencies nor is there a fortified room in her apartment. Nevertheless, she stated, "I'm not afraid." In the course of the interview, we also discovered that the neighborhood shelter is not accessible to her, because there are stairs that lead into it. In light of this fact we posed the question "What will you do in an emergency situation?" She responded "I don't think about it at all... So I say, 'whatever happens – happens.'" Susan's attitude was similar: "It doesn't worry me. When there is an earthquake... then I'll think about it." Similar to Ronit, other interviewees demonstrated apparent indifference, as in the example of Moshe, who said, "I'll do whatever everybody else does."

However, there were also participants that openly expressed concerns and fears in relation to preparations for situations of emergency, noting that preparing would only serve to clarify to them their vulnerability at times of emergency. For example, Edna expressed her fears that because of her mental condition, which leaves her highly sensitive and anxious, to the point that even in an emergency drill, her condition would worsen: "... I've never received guidance on what to do in emergency situations... Even if it's only a drill, when I hear the siren, I get hyper-anxious."

Miriam mentioned that even in her daily routine she experiences fears, worries, and anxieties, and thinking about an emergency situation would surely increase her level of anxiety. Therefore, she emphasized that while undoubtedly it is important to prepare for emergency situations, for example, to know where the nearest shelter is located, "the greatest concern is to reduce the fears and anxieties... At least for people with disabilities... That has to be part of the preparation."

In response to the question of whether their aide is prepared to manage their care in a state of emergency, both Susan and Menny explained that although they have had the same aide for the past 20 years, he is not especially prepared for an emergency situation. Menny said that during the Gulf War, the aide who had been assisting him and Susan left the country and returned to his homeland right away, because he was afraid of the falling missiles (in Israel, healthcare aides are typically foreign workers who do not speak Hebrew). Thus, Susan's sister was left to cope alone without anyone else to provide the much-needed assistance. Moreover, Menny requested that the interviewers avoid asking his current aide (who was present in the room, but as he did not speak Hebrew, he could not follow the conversation) about his ability to assist Menny and Susan in an emergency situation: "If you ask him about it, he might get extremely frightened and it's hard to know how he might react," said Menny.

Theme 2 practices in emergency situations

Familiarity with emergency guidelines: "I've never received guidance on what to do in emergency situations"

Our interviewees were not familiar with any of the existing guidelines, either for people with their specific disability, for people with disabilities in general, or even those for the general population. Thus, for example, Almog said, "I don't think there's any website or Internet information on how people with disabilities can manage in emergency situations; there's a lot that can be done to help and ease the situation for people with disabilities during emergencies." This lack of information existed even though such guidelines can easily be accessed on the Internet.

Students in the school system in Israel regularly practice how to behave in situations of emergency, although both Muhammad and Chen said that in their respective experiences, this is not a routine practice in schools of the Arab sector or of the Jewish-Orthodox sector. However, as adults, the interviewees noted that they had not received any guidance on the issue (e.g., at the workplace or at the local community center), nor had they received specific formal guidance on the conduct of people with disabilities in emergency situations. The only interviewee who had been exposed to such guidelines was employed by the local authorities: "We participated in some kind of course given by the council on earthquakes."

Interviewees indicated that proper preparation would certainly be helpful, as expressed by Jonathan: "I never heard a lecture on this subject; a lecture could alleviate worries and anxieties," and by Almog, who stated,

I think Homeland Security should be more involved in these things, as it is their responsibility to protect all of Israel's citizens and to provide solutions for people with disabilities during a state of emergency. ... Or they should inform the local authorities on how to cope with these things.

Miriam noted that during the Gulf War, she had relied on guidelines provided by the Ministry of Homeland Security: "At that time, I had read a book about chemical warfare that included guidelines for emergencies ... I had prepared my family ... Each of us had prepared his own kit." Nathaniel thought it was important to receive guidance on the subject of emergency preparedness: "If the fire department, for example, comes out with a new project to guide people with disabilities ... I'll go wherever it is held and will participate. I think it's crucial. The same is true about providing first aid."

When we asked more specific questions, for example, if they had bothered to prepare a water supply or an emergency kit, as instructed by the Office of Homeland Security, the interviewees responded that they did not know about the kit, as Almog said: "No, we don't have water in the shelter ... No, I don't have any emergency kit." As regards their medications, most of them routinely have a supply for at least one month; however, this is not a matter of forethought in case of an emergency, but rather a habit of convenience (the HMO makes it possible to purchase a three-month supply of prescribed medications).

Maintaining a balance between dependence and independence in times of emergency: "I am completely dependent on those around me"

Participants with quadriplegia described themselves as completely dependent on machines and on other people to take care of their vital needs, such as breathing and eating. Such dependence is a major factor in an emergency, according to Ronit: "The most frightening thing is this electric wheelchair. If I don't have the electric wheelchair, that's traumatic for me ... Because then I am not mobile." Jonathan explained that there is a respirator that is always attached to his wheelchair and its battery needs to be recharged regularly, but the most important thing is to have someone on hand who knows how to extract the secretions from his trachea, otherwise he will suffocate. Susan, who has a feeding tube attached directly to her stomach and whose breathing depends on a machine and an oxygen tank, said the following:

I depend on my aide ... am completely dependent on my oxygen tank, which lasts for about an hour or an hour-and-a-half, depending on my breathing rate. ... At home, I have a machine that produces oxygen.

Participants describe how important it is for them to be independent in their daily lives. On the other hand, getting help from others is in many cases essential to their existence. They explain the delicate balance between dependence and independence, especially in emergencies, when willingness to seek help can be critical.

Jonathan, who is totally aware of his dependence on others, emphasizes that for him there is a certain degree of independence that gives him a feeling of control and therefore is important to him even in times of emergency. He said that even in an emergency he prefers to navigate the electric wheelchair on his own (which he operates with the one finger that still functions), "because from my point of view, I am much less stressed when I can control the wheelchair myself." Jonathan explained that it is very important that whoever comes to help him must be familiar with him and his special needs. For example, if he is seated in the wheelchair in a cross-legged position and someone attempts to

move him, there is the risk of causing irreversible damage to his knees. Hence, it is crucial that the person who is helping him know that it is important to first bring his legs down and only then attempt to move him. Susan made a similar comment, noting that because of her spinal problems, she cannot be moved from a stretcher by holding the sheet underneath her, as is typically done; rather, she must be transferred gradually and carefully. Both emphasized the importance of the encounter and personal acquaintance with them even before a state of emergency occurs.

Nathaniel explained about his willingness to receive help even though he considers himself independent. This change was the outcome of an emotional process that he has undergone over the past few years: "In the past, only five or six years ago, I was very, [in a] ... kind of in denial, thinking that I could manage on my own. But now I am much more willing to receive help. I ask for help and allow others to guide me, and this is especially relevant for emergency situations."

Last, referring to emergency situations, the participants mentioned during the interview their social network, mostly friends—with or without disabilities—and relatives. For example, Menny told how Susan's sister helped them after their aide left. Ronit lives with a roommate who also has a disability. While we were interviewing Ronit, two young people, a man and a woman, came to visit her. At the end of the interview, they all went for a walk. Yossi lives next door to his sister and her family.

Experiences with the welfare department and the medical staff in times of emergencies: "there is no connection between the community and the person with the disability"

We found that our interviewees maintained no contact on a regular basis with someone from the welfare department or from the local community where they reside, and all of them stated that no one had contacted them on the topic of preparing for an emergency. Edna said, "Social Security is a system that transfers money once a month and then summons you to appear before their committee once a year, to ensure that you still deserve the financial assistance ... I don't know, perhaps there are special services [for emergency situations]? ..."

We asked the interviewees regarding their contact with the medical staff in routine times, as a way of inferring whether they might rely on them in case of an emergency. Their answers varied according to the type and severity of the impairment. Thus, for example, participants who use a ventilator reported that the HMO has listed them as entitled to maintain direct contact with a physician about their disease or impairment. The same was stated by interviewees with other chronic medical conditions. Susan said

The HMO has a special department for people that rely on a ventilator, with their own staff of specialists and someone is sent to check on me, if I catch a cold, for example. In addition, I am cared for by a lung specialist and a specialist who handles tube-feeding and they come once a week or every 10 days to check on me. I also have their direct phone number which I can use 24 h a day if I should need.

However, respondents with other disabilities, such as visual impairment, explained that they—like everyone else (without special needs)—appeal to formal frameworks for support (e.g., a social worker contacted through the Department of Welfare or a general practitioner through the HMO) when the need arises, as Ilan said: "You want to know who my social worker is? There is no such thing ... The physician? An impairment is not a disease. When you are sick, you are in constant contact with the physician ... But what can a physician do about my visual impairment?"

Interviewees described the medical and welfare authorities in the community, which are supposed to provide the services needed in times of emergency, as uninvolved in their lives and needs. Thus, for example, Miriam told us that during the Gulf War, she experienced increased anxiety, and had no one to turn to in the community. "My friend, who also has a mental disability, and I felt our level of anxiety increase significantly, so we went to the hospital emergency room."

Interviewees raised the subject of distrusting social security, the medical system, or the welfare services as well as the professionals, after having spent years appealing against decisions made by the official institutions, trying to obtain the rights and benefits to which they are entitled. In this context, Edna said the following: "When I was with the HMO's social worker, it was simply disheartening; there was nothing she could do to help me or to move my case along." Orr said, "You have to be wary of people with power."

Given this sense of distrust, it is not clear to what extent people with disabilities would be willing to abide by the instructions and guidance or accept the services offered to them by the authorities in times of emergency and distress. Menny commented, "If there were an earthquake right now, or missiles falling, would they offer any services? We will only find out in real-time, in the moment of truth." Ilan emphasized that he viewed the current study as significant:

This study should call attention to this failure, to the fact that there is no connection between the community and the person with the disability... You know, if a person with a disability resides in a peripheral area, there's no one who keeps in touch to find out how he's doing, whether he is alive or dead....

Nuriya had a similar comment: "It's important that you're doing this study... Maybe something will come from this academic knowledge, or at least it will increase awareness...."

Concerns regarding real-time emergencies: "the disability interferes with the ability to react spontaneously"

Participants' expressed their doubts whether being prepared would even matter in a time of emergency. They addressed different issues. Omer commented that "the disability interferes with the ability to react spontaneously", thus making a point about how difficult it is for people in his condition to respond to unexpected events. Nuriya commented specifically on the dimension of time which can be critical in times of emergency: "There's no chance; I mean, no matter what I do, I won't get there [to the shelter] on time." Ilan referred to the dimension of space when he said: "However, what happens if the person is not at home or in a familiar environment when the emergency occurs? How will this person find his or her way and know where to go?" And later on, "When I come to a new place, I am completely lost."

The ability to evacuate during an emergency was a major concern that was raised repeatedly during the interviews. The question arose whether and how the instructions issued to the general public on how to evacuate a danger zone could be applied and adapted to address people with disabilities. Participants noted that in their case, the situation is complicated by difficulties related to mobility, especially in the public sphere. Jonathan reflected on his experience of complications and discomfort when an entire ward of people with life-threatening disabilities had to be evacuated during wartime. Some of the individuals needed a ventilator attached 24 h a day, seven days a week, or depended on other people or equipment:

"They moved us from one department to another. I remember one night I was moved three times from one place to another. Then I was in the shelter for people on a ventilator".

Nuriya voiced her criticism, saying that it is often assumed that people with disabilities are constantly at home, which, as she explained, is not necessarily the case. "I'm very independent... I do not have a full-time aide, nor do I need one. I spend most of my time outside the house." She went on to add that as a result of this general assumption, the needs of people with disabilities during an emergency are not addressed in the public sphere.

It's as if they're trying to somehow reduce the sphere of activity of the person with disability; they think he's worthless, is constantly at home... But I do get around and for me, there is no proper protection. What happens if I'm somewhere outside and suddenly, a warning siren is heard? I wouldn't know what to do. As it is, everybody would be running and -where am I supposed to go?

As an example, Nuriya told about her experience during the Israel-Gaza conflict in 2014. Working with youths at risk, she was unable to join the other volunteers to survey the streets and steer young people to safety. "It wasn't because I was afraid, but because I didn't know where the accessible shelters are located throughout the city."

The last issue related to the need to evacuate during an emergency was whether people with disabilities should be kept in a group for their own security or should be separated. The guidelines indicated by the Homeland Security authorities was that in certain situations, such as a terror attack or an earthquake, people should make an effort to spread out as much as possible, to reduce the risk. However, the participants explained that even in routine situations - and all the more so in an emergency, they try to be in the company of another person they know so that they can watch out for and support each other. Edna mentioned that during the Gulf War, she was in the company of another friend who similarly was coping with a mental disability. Nathaniel explained, "Alone I simply won't manage; I won't know how..."

Suggestions for the future about the possible ways to prepare people with disabilities for emergency situations: "it should be nonthreatening, personal"

Interviewees were asked about possible ways to prepare for emergency situations or actions that could be relevant to their need during an emergency. In this context, Susan, as well as Menny, mentioned that they have a vehicle with a special disability permit and perhaps that vehicle could be equipped with a loud-speaker or flashing lights, and the authorities could be given their license plates, so as to give them right-of-way in an emergency.

Interviewees described the difficulty of using public shelters and noted the need to find alternative solutions for them. For example, interviewees who need assistance related to intimate care noted that in a public shelter they do not have the space or the privacy they require. Omer stated, "I need some private space... with all the intimate care that I require, sleeping in a public place such as a shelter is simply irrelevant." Miriam told us that she is emotionally attached to her dog and would not leave it behind in an emergency, as it is also a source of comfort for her in times of crisis: "I have to tell you that I even argued with the people in the shelter about the fact that the dog comes with me. I cannot leave her outside."

Jonathan emphasized that it is important that the Homeland Security authorities responsible for evacuating the public familiarize themselves ahead of time with the particulars of each case, "so that when they see us in a state of emergency, it is not our first encounter." "They might be frightened or shocked; they have

to meet us in advance. We need people to learn about our needs and not just talk about them,” said Menny, and Susan noted, “... they will need to keep an open mind.”

Edna emphasized the need to provide assistance with a personal touch, especially in an emergency. “Personal assistance – not over the phone, not on TV and not... Sometimes we are disconnected from media and devices. Some of us never turn on a television and are not on Facebook. It has to be personal.” Nathaniel concluded that people with disabilities should be given preferential treatment in times of emergency: “I think that the people who are personally in charge of the public’s safety and evacuation should first take care of people with disabilities, and not rely on the public authorities to handle this, because we need a different approach.”

Discussion

The aim of our study was to learn about the ways in which people with disabilities perceive emergencies and to understand their needs in preparing for these situations. The interviewees emphasized their vulnerability in emergency situations and the need for specific preparation for people with different disabilities, to enable them to cope with such a situation when the time comes. However, despite attributing importance to receiving emergency guidelines, participants expressed their doubts whether being prepared would even matter in an emergency situation. One of the most surprising findings was the attitude of some of the interviewees regarding the issue of preparedness for emergency situations, which we characterized as “after me, the deluge,” especially in regard to natural disasters. They were not familiar with the guidelines provided on the website of the Department of Homeland Security. In fact, as they attested, they had not devoted much time or effort to the issue at all and assumed that when the moment came, they would manage.

Our findings strengthen what has been found in other studies [14, 15, 18], namely, that in the matter of the preparedness of adults with disabilities, there is no centralized organization or authority charged with providing hands-on preparation and/or assistance in an actual emergency. Rather, people with disabilities are left to fend for themselves. In addition, it appears that the existing directives for people with disabilities are very general and did not come to their attention.

The experiences described by the interviewees exemplify the interaction between body, time, and space, as described by Hansen and Philo [35]. Their embodied reality of disability is as crucial in daily life as it is in emergencies. Despite the fact that the study participants had a variety of different disabilities and correspondingly, a variety of experiences and needs, maneuvering in the public sphere was a common difficulty. For example, even if accessible shelters were available in the public arena, in an emergency, a person with a disability might not be within reachable distance of the type of shelter needed. Similarly, the preparedness of people with a visual impairment depends on their particular location at the time of the emergency event, and even being in a familiar environment is not enough to manage independently, because of the different conditions during an emergency. In other words, to safely reach a shelter in the short amount of time available during an emergency requires the ability to move quickly. Additionally, there may be physical obstacles, created by the disaster or placed by the authorities, which cannot be anticipated by people with a visual impairment.

Most of the participants in our study were dependent upon others –people, machines, and pets– to a greater or lesser extent,

and in some cases even for their basic life functions. This dependence also compromises their ability to move from one place to another in routine times, a mission that becomes even more complex and gains an added time-related urgency in an emergency event, thus making them more vulnerable than the general population.

It is perhaps due to these circumstances that our interviewees preferred to simply ignore the risk of unpreparedness and adopt a fatalistic attitude, i.e., they believed that their chances of finding and reaching a safe place in a limited time were slim at best, even if they could be adequately prepared. Hence, as demonstrated in other studies [14, 15, 29], the participants in the current study did not take steps to prepare for an emergency situation and it seems that those who are in need of assistance and support in routine times are even less prepared to cope in emergency situations. This conclusion is also in line with the pattern of “routine and denial” that was found to characterize the attitude of the general population in Israel [9].

Another possible explanation for the attitude of the interviewees can be found in some of the explanations the participants provided, namely that coping with the challenges posed by daily tasks makes everyday life feel like a state of emergency, even in times of routine. Finkelstein and Marcus [55] consider this carefully in their discussion about people living with Duchenne. Whether for eating and breathing, personal hygiene, or moving from one place to another: all of these functions and actions require –to some extent– advance preparation, assistance, caution, and daily supervision. It is important to note that the interviewees typically lead an active life, do not cower from daily challenges, leave the house on a daily basis, and participate in the public sphere, whether attending university, or workplaces, traveling to shopping malls, and so forth. Nevertheless, as they explained, their physical situation involves complexity daily organization and planning, as well as attention to many details. Therefore, worrying about how they will manage in future emergencies is not a high priority on their agenda. The combined emotions that led participants to express fear, fatalism, as well as nonchalance, could be understood as a strong indication of the need to provide them with emotional and mental preparation, in addition to the practical preparations at the system level.

There is yet another possible explanation for the denial and nonchalance exhibited by the interviewees, which merits investigation in future studies. This explanation has to do with what is referred to in disability studies as the “*supercrip*” image [56]. Namely, this term refers to individuals with disabilities who successfully complete a personal endeavor, such as a sports achievement, thus exceeding the expectations of people with disabilities. At first sight, the *supercrip* image is a positive one and can serve as a source of encouragement and motivation for others. At the same time, people with disabilities have voiced their criticism about this image, as it represents the social values of ableism and leads to the mistaken assumption that a disability is a personal problem, which can be successfully handled as long as the individual is sufficiently motivated. This perception ignores the social barriers with which people with disabilities must cope on a daily basis.

The interviewees in our study often expressed their pride that despite their disability, they have been able to lead a “normal life” (i.e., hold a job, travel abroad, maintain an active social life, etc.). This can create the image of a *supercrip*, which minimizes the many challenges and difficulties with which they must cope incessantly. This sociocultural attitude can also make it difficult for people with disabilities to admit to themselves that they need help

from others and, in a reciprocal manner, might deter people around them from offering help, for fear of insulting them.

An important aspect revealed in interviews was the complete disconnect between people with disabilities and the authorities (the welfare department, the municipality, the community management, etc.), which should be involved in helping people with disabilities prepare for emergency situations and in real-time. The same was true about the relationship between people with disabilities and community-based medical staff (mainly family physicians who in Israel are usually the patients' primary healthcare providers). Some of the participants openly expressed their distrust in the willingness or the ability of these establishments to provide assistance in the event of a public emergency, and others even expressed surprised when we raised this possibility. However, it became apparent that the majority of participants rely on close social networks that include family and friends and assume that these will be available also in an emergency situation. The research of Kapucu and Hu [57] suggests that friendship networks, i.e., informal networks which do not involve formal collaboration actions, are important for encouraging organizations to be involved in disaster preparedness networks. Within friendship networks, organizational representatives know other public, nonprofit, and private organizations working in the field of emergency management. Furthermore, this could benefit the authorities in developing effective plans for times of emergency and disaster.

Finally, another issue, which in the course of the interviews was treated like "the elephant in the room," was that of needs related to personal hygiene and everyday care, be it managing a colostomy bag, a feeding tube, or a ventilator. The participants did not raise this issue, although most likely, it is a major daily concern for them and those who addressed the issue often did so indirectly. Consequently, it was difficult to learn about these particular needs, so as to be able to address them in emergency situations. As indicated [21], the issue should be studied and investigated, because these are often vital functions. If they are not addressed in preparing for emergency situations, people with disabilities will be unable to use public shelters and other services, even if they are able to reach and access them on time.

Conclusions

The conclusions drawn from our study, which aligns with the approach of Hansen and Philo [35], lead to an understanding that emergency preparedness of people with disabilities requires gathering detailed information about the individual's daily life, experiences, practices, habits, and needs. Their embodied way of managing time, space, and speed in the realities of daily living need to be taken into account in the planning of the timing and spaces in the context of preparing for emergencies. Another aspect that the study revealed is that people with disabilities already have an array of means and strategies which they employ in their everyday routines. These too should be mapped, so as to harness them for use in an emergency. There is reason to believe that the one-on-one encounters that the collection of such precise information would entail could help strengthen the interpersonal relationships and establish trust between community figures and the individuals with disabilities. Such an interpersonal relationship is likely to have positive repercussions during an emergency, as well. The social networks, mostly friends with or without disabilities and relatives, are important providers of emotional and social support for people with disabilities. It is worth

considering how to develop and strengthen this resource so that it will be a significant anchor also in times of emergency.

An important observation afforded by this study was the interviewees' lack of familiarity with the existing emergency guidelines created specifically for them by the Office of Homeland Security. Hence, we recommend that people with disabilities be included in finding ways to ensure that they have access to the existing guidelines. Additionally, the findings strongly suggest there is a need to address the emotional and mental challenges that are part and parcel of preparing to manage in emergency conditions. Addressing these aspects, in addition to the practical preparations, could help replace their current fatalistic approach with feelings of resilience and hope.

Neither people with intellectual or developmental disabilities, nor those on the autism spectrum, were included in this study. There are a few studies that have addressed this population in the context of emergency preparedness [28, 58]; however, further studies are needed to gain a comprehensive picture of their needs, preferably by examining some of the major time-and-space-related concerns revealed in the current study. Such research initiatives should be broadened to encompass also people with a chronic illness, who require continuous medical supervision, ongoing treatments, and a constant supply of medications. Hence their dependence on medical staff and facilities is likely to become complicated in an emergency, when most medical staff is needed to attend to the more urgent casualties. We recommend expanding our research, by appealing to a wider number of participants through an online call for participation and a recruitment message sent through various associations of people with disabilities. Approximately half of the participants in our research had an advanced educational degree (BA or higher). We suggest that future research should consider the possible effect this variable might have on the perceptions of people with disabilities about emergencies and preparing for them.

Our findings indicate that often different individuals with different or even the same disabilities present a variety of needs. That raises the dilemma of accommodating so many diverse needs in a common set of policies for emergency preparedness. Although it is recognized that every possible contingency cannot be addressed, we believe that thinking creatively about the needs of people with different disabilities in terms of space and time, as well as by categories of disability, can be valuable.

Finally, given the infrequency of emergency events, the paucity of resources, and the uncertainty regarding what and how many resources are needed, we agree with the view expressed by Fifolt et al. [8] regarding the importance of retrospectively exploring the perceptions and experiences of individuals that have experienced reestablishing a state of normalcy after a disaster. Learning from the hindsight observations of people with disabilities can be highly informative for reducing disaster vulnerability among this population and for helping prepare others who may be called upon to manage similar difficult circumstances.

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