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ORIGINAL ARTICLE

Emergency preparedness in a sample of persons with disabilities

Robyn R. M. Gershon, MHS, DrPH; Lewis E. Kraus, MPH, MCP; Victoria H. Raveis, PhD; Martin F. Sherman, PhD; June I. Kailes, MSW

Abstract

Objective: *The objective of this study was to characterize emergency preparedness in this vulnerable population, and to ascertain the role of the personal assistant (PA) and the potential impact of prior emergency experience on preparedness efforts.*

Design: *Cross-sectional Internet-based survey conducted in 2011.*

Setting: *Convenience sample.*

Participants: *Two-hundred fifty-three community residents with cognitive and/or physical disabilities, all receiving personal assistance services.*

Main outcome variables: *Emergency preparedness, operationalized as responses to a seven-item scale.*

Results: *The mean score for the emergency preparedness scale was 2.32 (SD = 2.74), range 0-7. Even though 62.8 percent (n = 159) of the participants had previously experienced one or more large-scale emergencies, only 47.4 percent (n = 120) of the entire sample and 55.3 percent (n = 88) of those with actual emergency experience reported preparing an emergency plan. Sixty-three percent (n = 76) of those reporting a plan had involved their PA in its development. Participants who reported such involvement were significantly more likely to have higher scores on the emergency preparedness scale ($p < 0.001$). Participants who had experienced a prior emergency were also more likely to score higher on the emergency preparedness scale ($p < 0.001$). In general, participants reported limited attention to other basic preparedness recommendations: only 28 percent (n = 70) had prepared a "go-bag" with necessary supplies, 29 percent (n = 74) had developed a strategy for communicating with their PA during emergencies, and 32 percent (n = 81) had stockpiled emergency supplies. Of particular importance, only 26 percent (n = 66) had made alternative back-up plans for personal assistance.*

Conclusions: *Involving the PA in the planning process and experiencing an emergency were both significantly associated with higher emergency preparedness scores in this sample of people living with disabilities. However, critical deficiencies in preparedness were noted, such as lack of back-up plans for replacing their PA. Despite a concerted national effort to improve preparedness in the population of people living with disabilities, important preparedness gaps remain. These findings highlight the need for additional study on emergency preparedness barriers in people living with disabilities so that effective strategies to reduce vulnerabilities can be identified.*

Key words: disabled, disaster preparedness, personal assistant

Introduction

Past emergency events, such as Hurricane Katrina in 2005, the 2010 Haiti earthquake, the 2001 World Trade Center disaster, and many other natural and man-made disasters, underscore the vulnerability of certain segments of the population.[1-4] People with disabilities and those with chronic health conditions may be at increased risk of morbidity and mortality because of difficulties in responding rapidly or taking necessary protective actions during emergency situations.[4-7] In a study by Chou et al.,[6] persons with moderate physical disabilities had a significantly

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greater risk of mortality than persons without such disabilities (OR = 1.7, 95% CI = 1.2-2.3). Similarly, in a case-control study by Osaki et al.[7] that examined the risk factors associated with mortality during the 1995 Hashin-Awaji earthquake in Japan, persons with physical disabilities were much more likely (OR = 5.6, 95% CI = 1.61-19.78) to have died compared to controls matched on sex and age.

Some disaster researchers suggest that this increased risk is due not only to physical vulnerabilities but also to the compounding effects of social vulnerabilities, such as poverty. Data indicate that persons with disabilities have an increased likelihood of lower educational levels, higher unemployment rates, lower income, and fewer social supports compared to persons without disabilities.[8,9] In the aftermath of disasters, people with disabilities also have an increased risk of other adverse outcomes, such as loss of permanent housing, loss of possessions, and increased financial hardship compared to people without disabilities.[10-12]

In an effort to improve disaster-related outcomes and to support community and individual-level resiliency, the US federal government has invested several billion dollars to improve preparedness.[13,14] Although there is recent evidence that this approach has led to improvements on specific elements of preparedness, most community-level studies continue to indicate that a sizable proportion of the population is still unprepared on even the most basic planning elements.[15] For example, a 2010 Zogby survey found that only 46 percent of the general public had an emergency plan.[16] Similarly, a 2011 Marist survey found that while 49 percent had a plan, 30 percent of those with a plan lacked key plan elements, such as emergency supplies of food and water.[17] Some emergency experts contend that the economically disadvantaged and the elderly are especially likely to be unprepared.[15,18] Others suggest that women and non-English speakers,[19,20] and individuals with disabilities should also be included in this group, and in fact, recent studies generally indicate that people living with disabilities are more likely to report subpar levels of preparedness compared to those without disabilities.[21,22] In a large study of respondents to the 2006-2007 Behavioral Risk Factor Surveillance System, Smith et al.[22] noted that only 25.8 percent (n = 1,740) of the participants reporting a disability believed they were "very prepared" for an emergency, with 53.3 percent (n = 3,616) indicating that they were "somewhat prepared" and 20.7 percent (n = 1,397) reporting that they were "not at all prepared." In addition, only 33.5 percent (n = 2,277) of the participants with a disability reported having an evacuation plan.[22] In another study, comparing the preparedness of people with a functional-based disability (in this case, transportation-related special need) to the general population, although special households needs were more likely to have located in a shelter, arranged a meeting place, and packed a go-bag, they were no more likely to have created a plan for evacuation or to have purchased food and other supplies.[23] Other research, focused on preparedness at the home health and personal care agency-level, showed that disaster planning and response capabilities were very limited, with most agencies reporting that they expected the clients' families and local emergency responders to assist clients when necessary.[24] At the caregiver level, preparedness and response is problematic as well. In a 2010 survey that Gershon and colleagues conducted on pandemic preparedness among New York City home-care aides (N = 374), 57 percent of aides responded that they would be unwilling to report to duty at their recipient's home during a disaster and 62 percent had secondary competing obligations that would limit their ability to do so.[25] Taken together, these findings suggest that preparedness at multiple levels may be suboptimal for persons with disabilities living in the community. While improvements in preparedness appear to have been made in the general population, the disabled population appears to be lagging behind, despite nearly a decade of increased activities to improve this by Federal Emergency Management Agency (FEMA), the Centers for Disease Control and Prevention (CDC), the National Organization on Disability, the National Institute for Disability and Rehabilitation Research, Disabled World Towards Tomorrow, American Red Cross, American Public Health Association, disAbility Preparedness, and many other governmental and nongovernmental agencies.[8,9,18,26-36]

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Studying the preparedness of people with disabilities is important because they represent a large proportion of the population. In the United States, there are an estimated 56.7 million people (nearly one in five people) with at least one disability.[37] A large proportion of these, approximately 30 million, report difficulty with ambulatory activities,[37] and more than 15 million American adults have some form of cognitive disability.[37] More than one in five people with a disability require assistance with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs).[37] For people living with a disability and receiving some form of personal assistance, it would seem that involving the personal assistant (PA) in the preparation of emergency plans would be central to personal disaster planning. However, information on disaster planning among people living with a disability is very limited, and even more so with respect to the level of engagement of the PA in the planning process. Similarly, as experiencing a prior emergency should provide strong motivation for developing an emergency preparedness plan,[11,38] we were particularly interested to determine if that same pattern would be replicated in a sample of people living with disabilities.

The objective of this study was to characterize emergency preparedness in this vulnerable population and to ascertain the role of the PA and the potential impact of prior emergency experience on preparedness efforts.

Methods

Study design and participants

This cross-sectional study was conducted in 2011. Over a 6-week period, a self-administered survey was made available on the Internet using a Web-based tool,[39] with participants recruited through public requests on multiple disability list serves (Centers for Personal Assistance Services [PAS] based at the University of California, San Francisco; coalition of People of disAbilities; National Council on Independent Living; etc). The survey was developed with input from experts in personal emergency preparedness planning efforts for people with disabilities and expertise on the issues associated with the independent living needs of those requiring personal assistance services. Survey data were transferred to a statistical software program for analysis.

Eligibility criteria included: 1) disability status and 2) receipt of personal assistance services. The first two questions of the online survey reiterated the requirements for participant eligibility and individuals who did not meet these eligibility criteria were not able to further complete the survey. In some cases (2 percent, n = 5), the survey was completed by the parent of a child with a disability. All study procedures had human subjects protection approval of the Public Health Institute's Institutional Review Board.

Questionnaire development and design

A 37-item study questionnaire included several contingency questions, such as "if you had made a plan for communicating with your PA, how would you do so?" The questionnaire was written in English and prepared at a 6th grade reading level using the Flesch-Kincaid Grade Level Readability Test.[40] The final draft was reviewed by disaster preparedness and disability experts for content validity. The questionnaire included items that addressed four major domains: demographics; disability and personal caregiver status; emergency preparedness planning; prior emergency experience, including the level of engagement of the caregiver during that event and lessons learned from that experience. Most items had categorical or dichotomous response formats although there were several open-ended questions.

Study measures

Demographics. The four items addressed were age, gender, race, and ethnicity.

Disability and personal assistance status. With items derived from the American Community Survey of the US Census Bureau,[41] respondents were asked to indicate if they had hearing, visual, cognitive, and/or mobility disabilities, and if they needed assistance in bathing and dressing. They were also asked if they needed help performing errands or chores. With respect to their PA, respondents were asked how many

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hours per week they used paid or unpaid assistants and the source of their assistant (eg, governmental agency, private agency, consumer-directed model, or other).

Emergency preparedness planning. Seven items addressed preparedness planning; respondents were queried as to whether or not they had prepared the following: 1) a personal emergency plan; 2) an evacuation plan; 3) an easy-to-carry go-bag with critical items, such as cell phone, medications, flashlight, etc; 4) emergency supplies on hand, such as extra food, batteries, supplies, and equipment; 5) a communications plan for contacting their PA; 6) an emergency contacts list; and 7) a back-up plan for assistance in the event their PA could not reach them during an emergency. Additional items determined whether or not the respondent had tested their plan, if they had shared their plan with some or all of their assistants, followed by one open-ended question on reasons for not sharing their plan with their PA.

Prior emergency experience. Several items collected information on the type of emergency event respondents had experienced, the length of warning that they had before the event, the personal assistance they received during and immediately after the event, whether or not they evacuated to a shelter, and whether or not their assistant accompanied them to the shelter. Respondents were asked if they had found any aspects of their preparedness plans in place at the time of their last emergency experience particularly helpful to them and, if so, to explain how these were helpful. There was also an open-ended question on any lessons learned from that experience, including changes that the participants made to their emergency planning and advice they might want to share with other people with disabilities.

Statistical analysis

After data cleaning and editing procedures, frequency distributions and descriptive summary statistics and other analyses were performed. The level of significance was set at an alpha level of 0.05, two-tailed. Pearson's χ^2 analysis was used to assess relations between categorical items and the outcome variable (preparedness). To determine the association between emergency preparedness and both the PA involvement in the planning and prior emergency experience, the emergency preparedness scale was dichotomized (1 = score of 0-2; 2 = score of 3-7) and then odds ratios and their 95% confidence intervals (CI) were estimated. All analyses were conducted using SPSS 21.0.[42]

Results

Demographics

The majority of the sample was white (67 percent, n = 169). Twelve percent (n = 31) of the sample self-identified as Hispanic. Forty-nine percent (n = 124) of the sample reported that they were female, 39.1 percent (n = 99) reported that they were male, with 30 individuals declining to answer this question. The mean age was 47.8 (SD = 14.55), mode = 55, median = 50 and ranged from 8 to 87 years.

Disability and personal assistance status

Mobility disabilities were most commonly reported, with 69 percent (n = 175) of the sample reporting this type of disability. Many participants also reported difficulties with activities of daily living; 58.5 percent (n = 148) reported serious difficulties with dressing or bathing and 53.4 percent (n = 135) required assistance with doing chores or doing errands. Twenty-one percent (n = 53) of the participants reported serious difficulties with concentrating, remembering, or making decisions; 13.8 percent (n = 35) reported serious difficulty seeing (even when wearing glasses); and 5.5 percent (n = 14) reported serious problems with their hearing.

Participants received varying hours of paid help per week: 20.2 percent (n = 51) received over 40 hours per week, 21.3 percent (n = 54) received 25-40 hours per week, 17.8 percent (n = 45) received 9-24 hours per week, 24 percent (n = 60) received 8 hours or less a week, and the remainder (17 percent, n = 43) did not indicate any paid assistance and presumably they had unpaid assistance. A sizeable proportion (39.5 percent, n = 83) of those reporting paid assistance (n = 210) hired their own help, 26.7 percent (n = 56) reported

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that the PA was provided to them through a government agency, 14.2 percent (n = 30) said their assistant came from a private agency, 6.2 percent (n = 13) indicated that they had used an "other" resource for obtaining assistance (Center for Independent Living, family member, etc), and the remainder (13.3 percent, n = 28) did not indicate the source of their assistant.

Emergency preparedness planning

The seven-item emergency preparedness scale had a mean scale score of 2.32 (SD = 2.74), mode = 0, median = 0, and a range of 0-7 (each item was assigned 1 point, if the respondent did not indicate having *any* of the seven items, they were assigned a score of 0; more than 50 percent of respondents had a score of 0 and thus the median is zero). The Cronbach alpha was .93 (95% CI = 0.916-0.942), indicating a good internal consistency for this scale. Nearly half of the sample (n = 120, 47.4 percent) reported that they had an emergency plan, and of these, 63.3 percent (n = 76) indicated that they had involved their PA in its development. Fifteen percent (n = 18) of those with a plan (n = 120) indicated that they shared their plan with all of their PAs, 8.3 percent (n = 10) indicated that they shared their plan with only some of their PAs, 10 percent (n = 12) reported that they did not share their plan with any of their PAs, and 66.7 percent (n = 80) declined to respond to this question. Of the individuals (36.7 percent, n = 44) who reported having a plan yet not involving their PAs in its development, the common reasons given for not sharing their plan with PAs included: "My PA will be busy tending to the needs of their own family members," "The PA is just not that dependable," "Experience tells me I can't count on them," "I have a new PA and they did not help me develop the plan," "She is not family," and "I might not be with my PA when an emergency occurs." Of those reporting a plan, 57.5 percent (n = 69) reported that they had actually tested their ability to implement the plan. Involvement of the PAs in the emergency plan was strongly associated with emergency preparedness; 90 percent of the respondents that had involved the PA in the planning had an emergency preparedness scale score of 3 or greater (OR = 41.66, 95% CI = 18.18 - 90.91). Because of the different size n's for those that involved and those that did not involve the PAs, and the small n in one of the cells of the crosstabs, the odds ratios are unstable and should be interpreted with caution.

Responses to specific preparedness planning elements for the entire sample of 253 respondents were as follows: 34.8 percent (n = 88) of the participants reported having an evacuation plan, 27.7 percent (n = 70) had a go-bag ready, 32.0 percent (n = 81) had emergency supplies available, and 29.2 percent (n = 74) had a way to communicate with their PA in case of an emergency. Of the 74 people who indicated that they did have a way to communicate, the following means of communication included one or more of the following: cellphones (94.6 percent, n = 70), landlines (60.8 percent, n = 45), text messages (43.2 percent, n = 32), e-mails (43.2 percent, n = 32), online social networks (10.8 percent, n = 8), two-way radio (2.7 percent, n = 2), ham radio (1.4 percent, n = 1), and pager (1.4 percent, n = 1). In terms of having an emergency contacts list, 34.8 percent (n = 88) of the respondents indicated that they did have such a list. For the item that asked if they had emergency items on hand, such as medications, 30.4 percent (n = 77) of the participants indicated that they did have these items readily available at all times. Regarding the planning for an alternative source of personal assistance in case their regular PA would not be available to assist them during an emergency, only 26.1 percent (n = 66) of participants reported that they had made alternative back-up plans. For those participants indicating an alternative back-up plan, respondents reported that they would rely on one or more of the following: family members, friends, neighbors, roommate, church members, coworkers, and local nursing home. A very small proportion, 4 percent (n = 10) reported that they intended to hire another PA "on the spot." A modest proportion of all respondents, 20.2 percent (n = 51), reported that the agency providing for their care would allow their PA to accompany them to continue to provide services if they were evacuated to another area (such as a shelter or a hotel).

Communications during an emergency was problematic. Only 20.6 percent (n = 52) of participants reported that there was an emergency warning alert

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system in their community, with 14.2 percent (n = 36) unsure if such a service was available in their community. Participants were generally not involved in preparedness planning within their community; only one (0.4 percent) participant reported being involved in community emergency drills.

Prior emergency experience

A large proportion of the sample reported prior emergency experiences (62.8 percent, n = 159). The types of previous emergencies that the participants had experienced were varied and included one or more the following: a) weather-related natural disaster storms: (28.3 percent, n = 45), hurricanes (19.5 percent, n = 31), earthquakes (10.7 percent, n = 17), heat waves (9.4 percent, n = 15), tornadoes (8.2 percent, n = 13), tsunamis (3.8 percent, n = 6), and cold waves (4.4 percent, n = 7); b) fires (10.7 percent, n = 17); and c) terrorist attacks (1.3 percent, n = 2). Most participants who had experienced a prior emergency and who also provided information on the type of warning they had received prior to the event either reported no warning (37.6 percent, n = 60), or one of a very short duration (less than one day, 29.4 percent, n = 47). However, a sizable number did report receiving longer advance notice (at least a day's notice) (32.9 percent, n = 52). During or immediately after the event, 61.6 percent (n = 98) of participants reported that their PA was with them, and, of these, a large proportion (85.7 percent, n = 84) said that their PA stayed with them. If the PA was not with the participant at the start of the event, 27.7 percent (n = 41) reported that their PA did manage to get to them at a later point, although the time it took to reach them ranged from several hours to several days. Therefore, during or soon after the event, 87.4 percent (n = 139) of the participants had the assistance of their PA and 12.6 percent (n = 20) did not. Those without their PA's immediate help were provided with assistance by family members (including young children), friends, neighbors, coworkers, building managers, other source (FEMA, National Guard, fire department, state school for the blind, etc), or no one. Many participants (61 percent, n = 97) reported that they were able to stay in their home during the event because of their preplanning, others stated that they were forced to stay in their home because of the lack of preplanning. A small proportion (5.7 percent, n = 9) was evacuated to shelters, others (28.3 percent, n = 45) were evacuated to another location (including hotels, family members, friend's home that was wheelchair accessible, fire station, military base, and PA's home, etc), and eight (5 percent) individuals declined to answer this question. Prior emergency experience was significantly associated with higher scores on the emergency preparedness scale (OR = 4.42, 95% CI = 2.45-7.99).

The things that participants found helpful during an emergency included: a) having emergency items, such as medications, phone, etc, immediately available to them (71.7 percent, n = 114), b) having stores of emergency supplies at home such as food, blankets, and batteries (48.4 percent, n = 77), c) having a go-bag (39 percent, n = 62), and d) having an evacuation plan (39 percent, n = 62). Of those people (n = 120) who had a plan prior to the emergency event, 41.5 percent (n = 66) said they had changed aspects of their plan after their most recent emergency. As shown in Table 1, the aspects of the plan that were changed relate to: a) revised items to be carried/included in the go-bag; b) having made a relocation plan; and c) changes made to safely stay at home.

After having experienced a disaster, specific advice that participants would give to other people with disabilities, included: a) having all essential information and contacts' information readily available and a plan for maintaining communication with these contacts; b) anticipating the need for alternate care providers, planning for back-up power for assistive devices, having back-up supplies of medications and other supplies readily available; c) preparing a specific plan, practicing and updating it, and being ready to fully implement it; and d) making preparations for evacuating on short notice. These tasks are detailed in Table 2.

Discussion

Having a plan and engaging the PA in the plan was clearly associated with higher emergency preparedness scores. However, serious deficiencies in emergency

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Table 1. Changes made to existing emergency plan after experiencing an emergency (n = 69)

Revised items to be carried/included in go-bag:
• Added a list of all medications that I routinely take.
• Added money to the easy-to-carry go bag.
• Put actual supplies in the grab bag.
• Started carrying all of my grab bag items in case I am out of the home during the emergency.
• Now I carry 3 days of medications with me at all times.
• Added more supplies to grab bag, including pillow and blankets to help me be more comfortable.
• Added more flashlights, solar lights, batteries, and nonperishable food to grab bag.
• I packed my grab bag to last me a month instead of a week.
• Now I keep copies of important documents in more than one place.
Made a relocation plan:
• Made an off-site evacuation plan.
• Added my name to a special needs shelter.
• Found an alternate living situation that is completely accessible.
• Moved to a more accessible area.
• Added myself to the evacuation list at the Department of Health.
• I found a list of evacuation shelters in my area.
• Planned for who would take care of my pet.
• Changed agencies as my agency would not let my PA take me to the hospital.
• I started advocating better for people with disabilities and for our inclusion in any community planning.
Made changes to remain safely at home and maintain in contact:
• Prepared an emergency contacts list and shared this list with my providers and family members.
• Developed a communications plan.
• Bought a home generator.
• Added a back-up PA to my plan.
• Added a landline phone.
• Now keep my call button within better reach.

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Table 2. Preparedness advice for persons with disabilities, from persons with disabilities with actual emergency experience

Have essential information readily available • Have an updated contacts list. • Let your PA know who has your Power of Attorney. • Have an updated list of your medications and care needs.
Anticipate alternative care providers, access to devices, medication, other key resources • Remember that your PAs may be restricted in traveling for several days after a bad storm. • Stay with your caregiver no matter what. • If possible, hire a live-in attendant. • Always have a back-up PA in case yours cannot come. • Train others on some of your special needs (eg, feeding tube, so that they can help you in case you need extra help). • Talk to plenty of other people besides your PA about your plan and get a commitment from them that they will provide help. • Have several back-up contacts; network with everyone you know. • Make sure the local fire department knows that you may need help. • Know the manual operations for your medical equipment. • Always keep your cell phone charged. • Keep extra cash to pay your PAs in case they cannot get paid through their regular mechanisms. • Get a home generator if you rely on electricity for your care. • Have a battery operated radio in your home; have batteries handy. • Keep your medications in a water proof tub along with a list of the medications. • Always keep large plastic bags available to fit over controls and wiring of wheelchair if you use one. • Keep water purification tablets handy—it was hard to reach the large water tankers that came around my neighborhood and I could not carry the bottles.
Develop an emergency preparedness plan • Do not procrastinate about making a plan. • Write out your plan and update it. • Always communicate your plan with your PAs. • Be prepared and practice your plan. • Drill through your plans several times.

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Table 2. Preparedness advice for persons with disabilities, from persons with disabilities with actual emergency experience (continued)

• Talk with others who have been through an emergency. • Understand your local community's emergency plans. • Prepare for all types of different emergencies. • Prepare a contract between you and the PAs regarding their responsibility to you during an emergency. • Hire PAs that agree with your plan. • Make sure your PA is in agreement with staying with you if you have to shelter in place. • Share your plan with the agency and make sure they agree to it.
Preparations for an emergency evacuation • Know where the public safety centers are located (fire stations, police departments, etc). • Have a plan to access various shelters—you do not want to start looking for them in an emergency. • Make a very specific list of things for your PA to pack for you in case you are evacuated. • Do not rely on your shelter for all of your needs; bring bedpans, catheters, med supplies, and anything else you may need with you. • Check the expiration date periodically on your medications designated for your evacuation. • Have at least two transportation options. • Heed the weather advisories and do not wait until the last minute. • Set up a meeting place for all family members.
Other advice • Stay calm. • Have patience.

preparedness remained, even for those who had involved their PA in their planning effort. Of particular note was the lack of sharing the plan with all of their PAs for those with multiple PAs. Also of concern was the absence of planning for back-up assistance in the event that the PA was unavailable to provide help. For the proportion reporting that they were without personal assistance from any source during an actual emergency, it is not known to what extent their assistance needs were adequately met and what impact this may have had on their health and well being. Identifying back-up care providers and sharing the plans with all PAs are critical preparedness strategies for people with disabilities. For some participants, distrust in the PA's reliability seems to be a barrier to sharing the plan, and this requires further investigation to understand the roots of this lack of trust. There was also evidence of a lack of preparedness on other basic elements of a plan, such as having an emergency contacts list or back-up sources of necessary supplies and medications. This could be a problem if relocation is needed, as many shelters will most likely not be able to quickly supply these essential items. FEMA[28] provides sample lists of durable medical equipment and

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consumable medical supplies to assist emergency managers in their planning and preparation to meet the needs of individuals with disabilities, but the extent to which these items are actually available at shelters is not well known. An example of one of the many preparedness tip sheets for people with disabilities is provided by the American Public Health Association. Their "Get Ready"[33-36] tip sheets advise people with disabilities to conduct a personal assessment of the items that are needed on a daily basis, while emphasizing the need to know the types of disasters most likely to occur in their community. Importantly, people living with disabilities are advised to consider how a disaster might affect critical medical equipment, such as powered medical equipment and assistive devices, and how emergency back-up power will be provided. This guidance echoes many of the recommendations that the study participants offered, following their own experience with a disaster (see Table 2).

Besides the lack of involvement with the PA, including sharing the plan with them, study participants rarely reported that they had planned for communicating with their PA during an emergency. Almost one-third of the participants experiencing an emergency reported that their PA was not with them, and that, in some cases, there was an extended delay before the PA could finally reach them. Having a communication plan in place might have helped them to stay in contact with either their PA or back-up providers. Multiple sources of communication should be considered in case land lines are not in operation or if cell phone towers are inoperable or overloaded. Engagement with community disaster planners is encouraged for all community members, and especially for people living with a disability, as this may be an excellent source of information on various options available for obtaining back-up power, or obtaining help with transportation. Participation in community drills would inform people with disabilities about the steps their own community has taken in terms of community-level preparedness. Our findings also underscore the need for determining if the PA will be able to accompany the client to a relocation site. The need for the PA's assistance in performing activities of daily living may be needed wherever the individual relocates.

Our results are similar to those of other fairly recent studies exploring preparedness of people with disabilities. For instance, Smith et al.,[22] in a much larger sample, found similarly low levels of preparedness in this population. Ballantyne et al.[43] observed that perceiving external agencies and authorities as responsible for one's personal safety can reduce an individual taking action to reduce his/her risk of harm.[43] The reliance on PAs for assistance may have a similar impact on preparedness planning for persons with disabilities and it may explain the deficiencies in preparedness reported in this sample.

We found that there was a fourfold increased likelihood of preparedness given a prior emergency experience. Other studies have also found that prior disaster experience correlates with some improvements in emergency planning at the individual level.[38,44,45] Research is mixed, however, on the extent of changes in planning that are sometimes made following disaster experience, with simpler changes, and those that are perceived to be more controllable, most likely to be made.[46,47] The changes that the participants made in improving their preparedness after they had experienced an event focused on the gaps that became evident during the experience. Some of the changes that were made as a result of actually experiencing a disaster were quite simple, such as adding cash to their go-bag, but other changes required much more complex action and resources, such as moving to a more accessible location and buying a home generator. The specific advice that the participants provided for other people living with disabilities similarly covered a range of planning activities, from sharing the plan with the agency, to hiring a live-in attendant. Some of the advice was very heartfelt, such as "have patience" and "be calm," while other advice was very practical, such as heeding weather advisories. All of the advice was based on the "lived experience" of the participant, thereby making it very valuable.

Recommendations

Based on these findings, a number of recommendations are made. The most important of these is to involve the PA in the development of the emergency preparedness plan. Steps needed to ensure back-up assistance, power, and to safely evacuate to another

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location should be discussed and agreed upon. People living with disabilities should be encouraged to prepare a list of their current necessary medications, supplies, equipment, etc, that they are dependent upon. Back-up plans for communicating with their PA, members of their support team, family members, their healthcare providers, or any other key contacts, such as the power company, should be made and included in the emergency plan. Guidance on preparedness is now available from multiple sources, and the responsibility for ensuring that the plans are in place and that guidelines are followed should be shared between the individual and the leadership at the agency overseeing or providing personal assistance. Leadership at agencies representing the traditional agency model (formal provider) or the newer consumer-directed model should ensure that their clients are informed of the agencies' emergency planning. This will allow individuals to tailor their own plans with the full knowledge of the capabilities of the agency, if, in fact, they receive services through an agency. This will also be beneficial in terms of identifying other needed resources (eg, transportation to a shelter).[48] It would be helpful to have the agency provide the necessary linkages to local resources; in the absence of this, clients need to take the initiative in identifying these resources (power companies, local shelters, etc). Plans should include the role and responsibility of the PA in ensuring that the client has adequate transportation prearranged. It is the responsibility of the agency to conduct organizational preplanning, such as identifying alternate transportation and surge capacity to reduce the barriers care providers might have in reaching their clients during an emergency. Agencies are also responsible for emergency preparedness training programs for their care providers, and these programs should stress the importance of communication planning as well as the agencies guidelines and policies on the caregivers responsibilities. These policies should be shared with the client as well to help clarify the capabilities and expectations of both parties and to help build a climate of trust.

Limitations

Because this study used a cross-sectional design, causality cannot be ascertained. Further, since the participants self-reported, it is possible that participants provided socially desirable responses, although the anonymous nature of the survey may have mitigated this to some degree. Finally, this was a relatively small sample of people with disabilities, recruited from list serves, and there may be response bias and lack of generalizability to other people with disabilities. However, our findings are similar to those of a much larger and diverse survey[22] and are an important first step in discerning the potential role of the PA in the emergency planning of people with disabilities. Clearly, additional nationally representative random sample studies are warranted, as well as more in-depth qualitative studies, to increase our knowledge on the barriers to preparedness in this context.

Conclusions

The vulnerability to emergencies that people with disabilities have can be mitigated to some extent by three major factors: the availability of personal assistance, experience with prior disasters, and most importantly, disaster preparedness. In this study, we provided evidence of the important role of the PA in emergency preparedness. Careful preparedness planning, in close consultation with the PA, can result in a higher degree of preparedness. Therefore, there is a compelling need for specialized training and education of the PAs with respect to emergency preparedness. It may be helpful to provide dyad training on emergency preparedness for these and other vulnerable populations, such as homecare recipients and their homecare aides. Clearly, in spite of numerous resources and readiness campaigns launched in the past decade, much more work remains to be done, especially in better understanding the barriers to preparedness in vulnerable populations. Researchers have developed models of preparedness that integrate and build on health research on protective behaviors and suggest that the goal of improving disaster preparedness will be achieved by applying these models.[49] Research is, therefore, needed on the factors that motivate people to prepare for disasters, as well as the barriers to preparedness. This may help inform more effective strategies for preparedness planning and risk reduction with this and other at-risk groups. This avenue of research may lead to more

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effective ways of assuring the preparedness of these populations, thereby reducing their vulnerabilities.

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