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A Qualitative Inquiry Exploring Help-Seeking Behaviors And Resilience Strategies Women With Disabilities Utilize When Experiencing Gender-Based Violence In Rural Communities

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A QUALITATIVE INQUIRY EXPLORING HELP-SEEKING BEHAVIORS AND
RESILIENCE STRATEGIES WOMEN WITH DISABILITIES UTILIZE
WHEN EXPERIENCING GENDER-BASED VIOLENCE
IN RURAL COMMUNITIES

by

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SCHOOL OF PUBLIC HEALTH

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by

Kimberly Ann Aguillard, MAHS, PHD

2020

DEDICATION

In loving memory of Harley Fetterman, George Brown, and Donald and Therese Rowland

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IN RURAL COMMUNITIES

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School of Public Health, 2020

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Women with disabilities (WWD) are at pronounced risk of experiencing multiple forms of severe and prolonged violence, and they face barriers to accessing help. A multitude of factors associated with disability and rurality may compound the experience of violence, including geographic and social isolation, forcing WWD in rural settings to navigate extremely dangerous situations with limited avenues for accessing help and securing safety. This research explored how women with disabilities experiencing violence while living in rural communities navigate programs and policies, make decisions about seeking and securing help, and build resilience despite experiencing violence. The current study methodology empowers this marginalized population to use their own words to interpret their lived experiences and addresses an important gap in existing scholarship concerning the intersection of rurality, disability, and violence.

This examination used a qualitative data collection and analysis approach, with descriptive data to summarize the sample. Thirty-three rural women with diverse disabilities and experiences of violence completed one semi-structured in-depth interview. Interview transcripts were analyzed using thematic content analysis.

Women described key personal qualities and supportive networks and services, which contributed to their resilience, despite their violence-related adversity. These findings inform interventions and promote approaches to build on women's strengths and resourcefulness.

WWD also described overarching health and mental health care provider and system factors that influenced their trust and confidence in these services to support their safety. Women described ways interactions with health care during their experience of violence were a missed opportunity for identifying and responding to their abuse and connecting them with resources. Women illuminated important gaps in services and emphasized a need for training and education about disability throughout the health care system and mental health workforce. To be effective providers for WWD, clinicians and counselors need to demonstrate cultural competencies related to disability and have awareness about the forms of abuse WWD experience. WWD are open to, and even welcome, clinician screening for abuse; however, it is crucial screenings preserve women's privacy and, if not conducted at in-person appointments, are available through an accessible tool for women to disclose independently.

Finally, WWD described challenges accessing mental health care services that met their abuse-related needs. Women described overcoming their own stigma, learning about available services, finding an appropriate counselor fit, and struggling to secure resources to continue accessing mental health care. WWD identified opportunities for including individuals with disabilities more prominently in the mental health workforce. Finally, women discussed the necessity to ensure promising telemental health advancements are optimized for accessibility (using adaptive technology), to allow individuals with disabilities to have broader and more flexible access to mental health services.

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STATEMENT OF THE PROBLEM

Violence against women is a severe public health problem, (Tjaden and Thoennes, 2000), with nearly one in three women experiencing physical violence and one in ten surviving sexual assault in the United States (Black et al., 2011). Women with disabilities (WWD) experience social oppression, marginalization, and violence attributable to both status as a female and disability-related dimensions (Mays, 2006; Nosek and Hughes, 2003). Violence against women with disabilities occurs at a higher rate than women without disabilities, particularly when violence is assessed throughout the life course (Smith, 2008; Hughes, Lund, Gabrielli, Powers, and Curry, 2011). Additionally, women with disabilities experience higher rates of severe distress, anxiety, and depression because of violence than men with disabilities and women and men without disabilities (Dembo, Mitra, and McKee, 2018). Women with disabilities have identified violence as the most severe threat to health and a critical area to prioritize in research efforts (Freeman, Strong, Barker, and Haight-Liotta, 1996).

The nature of abuse against women with disabilities is distinct. Researchers and women with disabilities assert applying the prevailing definition of domestic violence, including intimate partner violence, fails to encompass the complexity related to women with disabilities' experiences (Nosek, Howland, and Hughes, 2001b; Radford, Harne, and Trotter, 2006; Saxton et al., 2001; Thiara, Hague, and Mullender, 2011). For example, the duration and type of abuse WWD experience is often more intense (Brownridge, 2006) and may occur in a wide context of settings—including health care settings--by multiple perpetrators

(Hassouneh-Phillips and Curry, 2002; Nosek, Howland, and Young, 1997; Nosek, Young, and Rintala, 1995; Magowan, 2003). Perpetrators of violence against WWD may use different elements of control or oppression, such as withholding medication, removing or damaging medical or adaptive equipment necessary for independence, or creating access or communication barriers to prolong isolation and prevent a safe exit from the relationship (Gilson, Cramer, and Depoy, 2001; Lightfoot and Williams, 2009; Saxton et al., 2001).

Women with disabilities who require personal assistance may have an elevated risk of these kinds of abuse (Nosek, Foley, Hughes, and Howland, 2001a; Saxton et al., 2001). Evidence suggests WWD's experience of violence may be exacerbated by social stigma and devaluation and women's own diminished sexual and body esteem, which may place them at risk for greater emotional, physical, and sexual violence (Hassouneh-Phillips and McNeff, 2005; Nixon, 2009). Finally, WWD report a lack of support from professionals (health care and disability services) in identifying and responding to violence (Powers, Curry, Oswald, and Maley, 2002; Saxton et al., 2001).

A multitude of factors associated with disability and rurality may compound the experience of violence, including geographic and social isolation, a lack of anonymity, few resources, an inadequate response from various formal channels, and physical barriers such as lack of accessible transportation or sidewalks to the facility (Fitzsimons, Hagemeister, and Braun, 2011). Census data suggests the prevalence of disability increases step-wise with more rural locations. Research also illustrates unique barriers to identifying violence and receiving victim services for women who live in rural areas. For example, victims of violence in rural settings have limited available resources and trouble accessing formal services, lack

knowledge and information about services and aid, and have to navigate familial and cultural barriers present in rural communities, which may discourage seeking the services through formal channels (Davis, Hager, and Early, 1994; Dudgeon and Evanson, 2014; Krishnin, Hilbert, and VanLeeuwen, 2001; Tan, Basta, Sullivan, and Davidson, 1995).

Unfortunately, a lack of crossover between researching violence and researching disability has resulted in an important gap in research and understanding (Nosek, Howland, and Hughes, 2001b). The intersection of women with disabilities experiencing violence while living in a rural community may create a cumulative vulnerability. These women also represent an under recognized and unstudied high-risk population. This research explored how women with disabilities experiencing violence while living in rural communities navigate programs and policies, make decisions about seeking and securing help, and build resilience despite experiencing violence.

This research also illuminates the help-seeking process women with disabilities who live in rural communities and experience violence use to get assistance and exit abusive situations. The research describes and explores barriers, which make acquiring aid difficult or impossible. This study helps to answer the question, “What do women with disabilities do in rural communities when they experience gender-based violence?” Secondly, “How do these women build resilience in these traumatic circumstances?” Finally, this study illustrates, using WWD’s own perceptions and experiences, how policies and programs are working in local rural communities, and how they could be improved.

Defining Key Terms

Gender-based Violence

Gender-based violence (GBV) is an umbrella term, to encompass any act of harm, perpetrated against an individual's will, embedded in a disparity in power, which is rooted in socially ascribed gender roles typically between men and women (UN, 1993; Russo and Pirlott, 2006). Additionally, transgender and gender nonconforming populations are victimized based on gender expression, gender identity, or perceived sexual orientation, thus this violence is also gender-based (Wirtz, Poteat, Malik, and Glass, 2018). Physical violence, sexual assault, rape, stalking, psychological aggression, and financial abuse are potential examples of GBV (Rees et al., 2011).

Disability

This research is concerned with women with disabilities. The definition for participation in this study borrows from the Behavioral Risk Factors Surveillance System (BRFSS) and American Community Survey (ACS) to include a self-report of any of six disability categories: difficulty hearing, vision difficulty, cognitive difficulty, ambulatory difficulty, difficulty with self-care tasks, and difficulty with aspects of independent living (Brault, 2009; Okoro Hollis, Cyrus and Griffin-Blake, 2018). The conceptual framework for this research uses the International Classification of Functioning, disability, and health (ICF) from the World Health Organization (WHO, 2001). The term functioning refers to all body functions, activities and participation, while disability is similarly an umbrella term for impairments, activity limitations, and participation restrictions. ICF also details environmental factors that

interact with these components. The ICF strives to focus an understanding of disability at the intersection of interactions between the biological body and social and institutional environments (Imrie, 2004).

Rural Communities

Rural communities are the intersectional component of interest for this research, understood through the experiences and perspectives of WWD who are victims of GBV. The term rural encompasses the population density of the county, as well as geographic isolation. For purposes of this research, participants will self-report their residence during the experience of violence. The area will be classified as rural if the participant indicates category 3, 4, or 5 of the following:

Where did you live during your experience of violence?

1. A large city
2. A suburb or just outside a large city
3. A town
4. The country or a long way from town
5. On a reservation

Lived Experience

Thirty-three women shared their lived experiences through these interviews. This study gathered first-hand accounts from WWD about how they perceive, understand, make sense of, describe, judge, and reflect on experiencing GBV in a rural community (Patton, 2002).

Lived experience is attentive to aspects of time, place, and context (Clandinin and Rosiek, 2007).

RESEARCH AIMS

Aim 1. Identify the help-seeking behaviors rural women with disabilities who are victims of gender-based violence use to find aid, services, and secure safety.

Aim 2. Determine factors that contribute to the personal resilience of WWD experiencing GBV in rural communities.

Aim 3. Describe and characterize barriers (related to disability, rurality, or a combination of both factors) WWD encounter when seeking resources and help.

Aim 4. Determine how policies and programs currently translate in local communities to facilitate or impede access to victim, medical, and legal services for women with disabilities based on their expectations and experience navigating systems.

BACKGROUND

Disability Context

There is no single, consensus definition of disability. The World Health Organization (WHO), in the International Classification of Functioning, Disability and Health, defines disability as an umbrella term, which encompasses impairment of physical body function, limitations on activities, and restrictions on participation (WHO, 2001). This terminology captures the complexity of disability, beyond the health aspects, to include the interaction between features of a person's body and elements of the society where the individual lives. This model recognizes overcoming difficulties associated with having a disability requires

interventions to remove environmental and social barriers (Stuckie, Cieza, and Melvin, 2007; Hurst, 2003).

In the United States, section 4302 of the Affordable Care Act (Understanding Health Disparities: Data Collection and Analysis), focuses on data collection standards for race, ethnicity, sex, primary language, and disability status for Health and Human Services administered surveys in which participants self-report data. The ACS, and other major surveys such as the BRFSS, use a six-item set of questions to gauge disability. A federal interagency committee developed this method, which reflects the change in how disability is conceptualized by function and context, consistent with the ICF. The question set was developed to facilitate monitoring disparities between the “disabled” and “non-disabled” population (Brault, Stern, and Raglin, 2007; Dorsey et al., 2014; Dorsey and Graham, 2011). The six questions used in the ACS to identify persons with disabilities are primarily aimed at identifying sensory, functional, and activity limitations (Brucker, Houtenville, and Lauer, 2015). The minimum data standard for survey questions on disability includes a self-report of any of six types of functional limitations, including current limitations in hearing, vision, cognition, (concentrating/remembering/making decisions), mobility (walking or climbing stairs), self-care (bathing or dressing), or independent living (difficulty running errands alone). The question set went through several rounds of cognitive and field-testing. Extensive testing during development of these measures found the six-item measure tested more accurately than other measures and cognitive testing revealed that the six questions must be used as a set to capture a meaningful measure of disability (Dorsey and Graham, 2011). Respondents could report more than one disability type.

Variations of definitions or methods of asking disability-related questions may identify different populations with disabilities and report larger or smaller disability prevalence. The latest prevalence estimates from the ACS report 12.8 percent of Americans report one or more disabilities (Lauer and Houtenville, 2018). The Centers for Disease Control and Prevention (CDC) analyzed 2016 BRFSS data and reported the number of Americans with disabilities that affect major life activities is 61 million or 1 in 4 adults in the United States (Okoro et al., 2018). These data also indicate disability is more common among women, and individuals with lower incomes. Some researchers have suggested the discrepancy in ACS and BRFSS estimates may be attributed to differences in sampling strategies and BRFSS nonresponse bias. (Gettens, Lei, and Henry, 2015). The BRFSS uses random digital dialing, acknowledged to have some non-coverage challenges, whereas ACS uses an address-based sample, drawn from the Census Bureau's official inventory of known living quarters and selected nonresidential institutions.

Additional factors that influence the environment through which disabled people experience disability include social determinants of health such as unemployment, lower educational attainment, and poverty (Nosek et al., 2001b). In 2016, less than 1 in 4 (23 percent) of working-age people with disabilities were employed full-time/full-year, compared with nearly 3 in 5 (59.4 percent) of the population without disabilities (Erickson, Lee, and von Schrader, 2016). Furthermore, the rate of working-age disabled Americans living at or below the poverty level is 26.6 percent-- which is the highest poverty rate of any group in the United States (Erickson et al., 2016; Drew, 2015). Recognizing that people with disabilities may have significant economic burdens due to their disabilities or health conditions, the

implications of poverty are likely even more pronounced than these statistics suggest, especially for people with disabilities living alone (Mitra, Palmer, Kim, Mont, and Groce, 2017). Another factor contributing to low socioeconomic status among people with disabilities is inequality accessing post-secondary education. Just over one in three working-age people with a disability only have a high school diploma or equivalent (Erickson et al., 2016).

Americans with disabilities also experience additional forms of marginalization, including high rates of preventable health disparities (Goode, Carter-Pokras, Horner-Johnson, and Yee, 2014; Krahn, Walker, and Correa-De-Araujo, 2015). Society, including public health and public policy professionals and researchers, historically examined disability through a biomedical lens. This medical model of disability considers disability as a deficiency in the body of an individual, and as a negative health outcome. Therefore, these inequalities are often dismissed as natural and unavoidable consequences of biological deficiencies (Frederick and Shifrer, 2019) rather than a consequence of demographic characteristics, the role of the environment in the disabling process, or disparities in health care (Nosek and Simmons, 2007).

Violence against Women with Disabilities

An analysis of the 2010 National Intimate Partner and Sexual Violence Survey found that, compared to women without disabilities, women with disabilities were significantly more likely to report experiencing rape, sexual violence other than rape, physical violence,

stalking, psychological aggression, and control of reproductive health (Breiding and Armour, 2015). This is consistent with smaller-scale surveys, which suggest

women with disabilities may be at a 40% higher risk of violence by an intimate partner, than non-disabled women, and they may experience more severe violence (Brownridge, 2006).

Other research suggests women with disabilities were at more than four times greater odds of experiencing sexual assault in the previous year compared to women without disabilities (Martin et al., 2006). Two analyses of different waves of the BRFSS also revealed a higher prevalence of violence among women with disabilities (Smith, 2008; Barrett, O'Day, Roche, and Carlson, 2009). An analysis of multiple waves of the National Longitudinal Study of Adolescent Health also reported higher odds of unwanted sexual contact (sex through force or coercion) among young women with physical disabilities than young women without disabilities (Haydon, McRee, and Tucker-Halpern, 2011). Slayter, Lightfoot, and Leisey (2018) analyzed a nationally representative, population-based data set (the Collaborative Psychiatric Epidemiological Studies) and detected transitional aged women with disabilities (ages 18 to 21) were almost four times more likely to report an experience of partner violence than non-disabled transitional aged women. Finally, analysis of 20,000 college students from the National College Health Assessment II discovered students with disabilities were nearly twice as likely to disclose experiencing violence (Scherer, Snyder, and Fisher, 2016).

Compared to nondisabled women, women with disabilities experience abuse over longer durations and by a greater number of perpetrators, experience more frequent abuse by health care workers and personal care attendants, and have limited options for leaving the violent

situation (Young, Nosek, Howland, Chanpong and Rintala, 1997; Hassouneh-Phillips and Curry, 2002; Powers et al., 2002).

Additionally, women with disabilities have a narrower margin of health than do nondisabled women, violence-related injuries have a significant consequence on their functional ability and overall health (Hassouneh-Phillips, 2005). Women with disabilities experiencing violence report poorer overall health, and more significant trouble accessing health care due to cost factors, than non-disabled women who have experienced abuse (Barrett et al., 2009). WWD experiencing violence also report increased stress and higher levels of depression, than women without disabilities, after controlling for demographic and disability characteristics (Dembo et al., 2018; Hughes, Swedlund, Peterson, and Nosek, 2001; Hughes, Robinson-Whelen, Taylor, Peterson, and Nosek, 2005).

Figure 1 illustrates a power and control wheel, adapted to depict factors and barriers affecting women with disabilities experiencing violence.

People with Disabilities in Partner Relationships



Figure 1. People with Disabilities in Partner Relationships.

Reprinted from SAFE. Adapted with permission from Domestic Abuse Intervention Project. Accessed October 29, 2018. Retrieved from <https://www.safeaustin.org/wp-content/uploads/2018/08/2017-SAFE-Power-an>

Though violence among women with disabilities occurs at disturbing rates, the phenomenon is termed a silent or invisible epidemic in part because research about these women's

experience of violence and information about available and accessible resources and services is scant (Chenoweth, 1996; Mayys, 2006; Lund, 2011). In studies of victim services (sexual assault and domestic violence programs) records of WWD acquiring services are lower than expected based on estimations of the population of WWD and abundant evidence of high prevalence of violence (Barile, 2002; Grossman and Lundy, 2008; Nannini, 2006). This suggests a significant percentage of women with disabilities do not, or cannot, access these resources. Often when women with disabilities do attempt to access counseling, emergency health services, or legal action they find services lack accessibility and accommodations to provide aid (Gilson et al., 2001). In a qualitative study, women with disabilities identified barriers to help seeking such as lack of emergency backup caregivers, inaccessible shelters, inaccessible social and health services, and lack of awareness about disability among law enforcement, health professionals, and social service providers (Hassouneh-Phillips, 2005). A literature review of victim, prevention, and intervention services for WWD revealed a significant disconnect between staff's perceived accessibility of programs and the actual perception of accessibility among people with disabilities (Lund, 2011). Additionally, Lund (2011) concluded a very low number of victim services and treatments for people with disabilities have undergone an empirical evaluation. State level surveys of community-based victim services revealed that most programs had served at least one person with a disability over the previous year and report compliance with basic levels of access (such as having a ramp to the facility and an accessible bathroom). However, programs identified challenges to serving women with disabilities including low funding, lack of training, minimal or no

policies and procedures in place for serving this population, and limitations in the built environment of service facilities (Chang et al., 2003; Frantz, Carey, and Bryen, 2006).

Additionally, service providers, family, and friends may have misguided or harmful attitudes about the woman's disability, which also may create barriers to accessing resources.

Examples of these obstacles include the propensity for service providers to take over (withholding information or making decisions for the woman without asking for input or providing a choice), discounting (not asking the woman directly, not listening, or not believing her report), and objectifying (treating the woman like a "case" of disease) in which instances on treating the disability rather than the abuse (Hassouneh-Phillips, McNeff, Powers, and Curry, 2005). In the context of disclosing violence, women with disabilities may not be believed because of prevailing societal perceptions that women with disabilities are incompetent, passive, asexual/unlikely to have a romantic partner, or they are perceived as unlikely victims because of the assumption that they are pitiable, and thus not targets for abuse (Crawford and Ostrove, 2003; Nosek et al., 2001a).

Among the studies of women with disabilities experiencing violence, there are important limitations to consider. First, studies that sample women who have acquired victim services miss an important population of women. This sampling strategy only recruits a fraction of WWD whose situation has reached a state of crisis and who find the bravery and resources to seek help. Women who do not feel safe asking for help, or are unaware of available resources, or do not have the material or logistical resources to secure help would not be included in samples constructed using this method (Nosek et al., 2001b). Other traditional

methods to identify victims of violence, such as consulting police reports, are hampered because most intake forms do not include a report of disability status.

Rural Context

Compared to their urban counterparts, rural residents are older, poorer, more likely to be obese and to smoke, and have poorer health (Meit et al., 2014; NCHS, 2017). Rural areas have a lower rate of employment, and a higher rate of unemployment, than urban locations. Though the Great Recession's impact was equally severe in urban and rural counties, rural areas' subsequent employment recovery has been much slower (0.8 percent annual employment growth compared with 1.9 percent in urban areas from 2010-15) (Cromartie, 2017). Rural populations experience higher poverty rates, 16.7 percent compared to 13.0 percent among the urban population. Life expectancy decreases as rurality increases (Singh and Siahpush, 2014). Rural counties have poorer health care (access, engagement, and treatment adherence), and health behaviors (lack of physical activity and nutritional food) compared to urban counties (Anderson, Saman, Lipsky, and Lutfiyya, 2015; NCHS, 2017). As in the larger literature examining the influence and context of place on health, rural communities are understudied, and community environments of urban and rural localities are rarely compared.

Rurality and Disability

Census data indicates the prevalence of disability increases step-wise with more rural locations. The rate of disability increases from 11.8 percent in the most urban metropolitan counties to 15.6 percent in smaller micropolitan areas and 17.7 percent in the most rural, or

noncore, counties (von Reichert, Greiman, and Myers, 2014). Research findings underscore that people with disabilities in rural areas have unique obstacles, in addition to commonly accepted barriers in rural areas, to accessing health care services. Examples include transportation limitations and expense, lack of specialist and lack of training about disability in the health system, problems with the built environments of clinics, and a lack of services such as TTY phone services and telehealth options (Lishner, Richardson, Levine, and Patrick, 1996; Iezzoni, Killeen, and O'Day, 2006) and mental health services (Hughes, Nosek, and Robinson-Whelen, 2007). Due to the geographic isolation, there may be few medical facilities within an accessible distance, as well as limited transportation through either para transit or public transportation, within the rural community or to travel from the rural area to adjacent cities for specialist medical visits (Iezzoni et al., 2006).

Rurality and Violence

Most research suggests women living in rural areas experience at least a comparable prevalence of violence as women in urban communities (Edwards, 2015; Breiding, Zeimbroski, and Black, 2009). One difference is that rural women appear to suffer more chronic and severe abuse, than urban counterparts (Peek-Asa et al., 2011; Edwards, 2015). Rural women are more often married and have children with the abusive partner, have poor financial resources, endure more types of violence, have more stipulations associated with restraining orders, and feel less safe, overall, compared to urban women (Logan, Evans, Stevenson, and Jordan, 2005; Logan, Cole, Shannon, and Walker, 2007; Walker and Logan, 2018). Additionally, victims in rural communities may suffer worse psychosocial and physical health outcomes as a result of the lack of availability, accessibility, and quality of

victim services (Edwards, 2015). A study found rural women experiencing violence reported less social support, lower education, lower income, more physical abuse in the previous year, more childhood physical and sexual abuse, and encountering abuse earlier in the relationship (Logan, Walker, Cole, Ratliff, and Leukefeld, 2003). Weapons such as guns and knives are common in rural homes. Limited research has evaluated the prevalence of women killed by an intimate partner comparisons between rural and urban settings. However, research specifically exploring these differences over a 20-year period discovered the annual rates of intimate partner homicides were higher in rural counties than in urban counties (Gallup-Black, 2000). Troublingly, while these rates declined during this period in urban counties, they increased by more than 60% in rural counties (Gallup-Black, 2000).

Rural women have identified cultural beliefs and traditional values influencing their experiences of domestic violence including: belief in the sanctity and lasting commitment of marriage, the importance and privacy of immediate family, and the influence of Christian teaching and beliefs (Wendt and Cheers, 2002). Personal narratives show that, while rural culture, such as self-reliance, gave women strength to endure the violence, it also created internal conflicts between wanting to escape and the cultural beliefs and values that women had internalized (Riddell, Ford-Gilboe, and Leipert, 2009). Rural women tend to use private strategies (placating their abusive partner or planning an escape) or rely on informal support from family or friends, rather than access formal services, least of all help from police (Anderson, Renner, and Bloom, 2014; Shannon, Logan, Cole, and Medley, 2006). Though rural communities may feature aspects of helpfulness and close ties, this neighborliness may not extend to helping victims of violence due to by-stander's beliefs about privacy or

questions about the victim's deservingness of help (Banyard, Edwards, Moschella, and Seavey, 2019; Lewis, 2003).

If a woman in a rural area works through the external and internal values, which may oppose disclosing an experience of violence and ultimately decides to seek help, she may have difficulty learning where to go, finding needed services, or traveling to obtain help. Rural women live an estimated three times further from essential crisis shelters and services (Peek-Asa et al., 2011). Crisis service providers in rural areas describe a double disparity, with fewer available resources in the community, less capacity for professional training, the necessity to cover larger geographical areas, and a greater prevalence of violence than urban areas (Eastman, Bunch, Williams and Caraway, 2007). Other cultural obstacles present in many rural communities may impede accessing help and services, including the dynamic of local, small-town politics and the protective presence of a "good ol' boy" network (Bosch and Bergen, 2006). A lack of confidentiality, in addition to these established political and social networks makes disclosing violence complex. A lack of anonymity in rural communities may be especially salient if the woman has a disability because she is possibly in a recognizable minority of a small handful or fewer with that characteristic. Further research is necessary to examine if women with disabilities in rural areas have different methods for securing help. Studying the intersection of different forms of oppression, such as ableism and sexism, combined with elements of rurality such as social and geographical isolation and chronic poverty, is critical to learn about how women with disabilities experience gender-based violence and resulting marginalization (Mays, 2006). Research has focused minimal attention on the intersectionality of urban and rural geographies and

violence. Rural victims should be evaluated as a neglected population, while also illuminating the reality of diversity among rural populations (Sandberg, 2013).

Resilience

Resilience, or the ability to “bounce back” from adversity, is a concept that can inform interventions and victim services. Research on resilience after experiencing violence is minimal, but findings indicate both personal characteristics and a network of supportive relationships contribute to resilience (Anderson, Renner, and Danis, 2012; Humphreys, 2003; Werner-Wilson, Zimmerman, and Whalen, 2000). Multiple emotional, cognitive, and behavioral shifts occur related to resisting the violence/abuser, a woman’s perception of her ability to control her safety and cultivating hope and a positive outlook (Crann and Barata, 2016).

To date, the disability community is almost entirely excluded from research on resilience. The impairment, socially perceived as a personal tragedy, precludes individuals with disabilities from consideration as resilient, rather, they are designated almost universally as “at risk” or “vulnerable” (Runswick-Cole and Goodley, 2013). The limited research on people with disabilities, or their families, examines resilience in terms of overcoming the adversity or cumulative demands related to the disability itself (Alriksson-Schmidt, Wallander, and Biasini, 2006; Jones, Simpson, Briggs, and Dorsett, 2016; Migerode, Maes, Buysse, and Brondeel, 2012; Bayat, 2007; Heiman, 2002; Whittingham, Wee, Sanders, and Boyd, 2013). This research fails to account for people with disabilities’ full and complete lives, including experiences of setbacks and triumphs, losses, and trauma, in addition to

merely navigating through life with a disability. Furthermore, existing research is often flawed because the concept of resilience is strongly associated with normative ideas about what contributes to resilient qualities and resources, potentially dismissing or denying the equally valid strategies to build resilience people with disabilities use to thrive (Runswick-Cole and Goodley, 2013). Most current scholarship on resilience, therefore, is intertwined with judgments about what is considered normal in certain contexts (Ungar, 2004). Therefore, research including people with disabilities, defining their own experiences of resilience is critical and largely absent in scholarly research.

Public Health Significance

The mental health and physical health consequences of enduring violence are wide-reaching and costly. Health consequences may include problems with chronic pain, traumatic brain injury, gastrointestinal problems, cardiovascular problems, immune and endocrine issues, reproductive health complications, sexually transmitted infections, depression, and post-traumatic stress disorder (Black, 2011; Campbell, 2002). There is also a staggering personal and societal cost associated with violent victimization. Women have expenses related to health care; mental health service; victim services; legal and justice system; work and lost earnings; transportation; and lost property (Logan, Walker, and Hoyt, 2012). Women in rural areas and women with disabilities are at an elevated risk for experiencing complex, repeated violence, and may encounter complications accessing needed services. Therefore, women with disabilities experiencing gender-based violence in rural areas may be facing a public health crisis. This is a significant gap in the research.

The majority of research on GBV is quantitative, calculating the number, type, or risk of experiencing violence (Bogat, Levendosky, and Von, 2005) rather than using a survivor's own experience, as she describes and understands it, to further knowledge about this complex social problem (Bender, 2017). Among research on gender-based violence, minimal research has examined what happens when women experiencing violence attempt to access and receive help through service providers or informal networks: What are their experiences like? Does the help effectively address their self-defined needs? Does effective service provision result in safety and positive quality of life outcomes? Furthermore, though ample evidence points to unique risks and increased experiences with violence among women with disabilities, current research on violence against women fails to include the voices and experiences of this population. This lack of representation as research participants has hampered formulating adequate policies and ensuring appropriate, accessible services for women with disabilities in violence prevention and intervention (Plummer and Findley, 2012).

The current research on women with disabilities who have survived an experience of gender-based violence explores self-defined dimensions of resilience and uncovers important insights about how services can bolster components that contribute to their resilience. Additionally, dominant groups have traditionally spoken for women, and people with disabilities. The current study methodology empowers this historically marginalized population to use their own words to relay and interpret their lived experiences. The primary objective of this study is to remedy current gaps in scholarship by characterizing the help-seeking processes and resilience strategies women with disabilities employ when

experiencing gender-based violence in rural communities. This study illuminates unmet needs and barriers to services and explores how programs and policies translate in local communities to impede or facilitate services to women with disabilities experiencing violence. This understanding can inform stakeholders how to target resources and shape future policies and programs.

Conceptual Framework

This study adapted the model of help-seeking and attainment among sexually and physically victimized women to illustrate the influence of social location, cumulative victimization and adversity, community setting, policy contexts, and context of disability (Kennedy et al., 2012). Women with disabilities experiencing GBV define their circumstances and make decisions about seeking help and developing resilience strategies. These processes and strategies are shaped by environmental factors and access issues associated with disability, as well as personal attributes.

The individual-level help attainment process is embedded within and fundamentally affected by contextual factors of social location, prior cumulative adversity and victimization, the community and policy context and availability of resources, and the context of disability. These multiple contexts influence each step of the process of survivors seeking and securing help. The first two components of the process, perceived availability of help/fit and appraisal of needs, co-occur and interlock. The needs appraisal stage is complex, involving identifying the problem, navigating and potentially internalizing social and cultural beliefs about the problem, and considering the costs and benefits of accessing help. Women experiencing

violence must overcome stigma components which may hinder help-seeking processes. For example, cultural stigma promotes societal beliefs that isolate and disempower women experiencing abuse. Stigma internalization occurs when women begin to believe negative stereotypes about victims of violence are accurate about themselves (Overstreet and Quinn, 2013). Anticipated stigma is a term describing the worry about what will happen once others know about the abuse (Overstreet and Quinn, 2013). In addition to these forms of stigma about violence, women with disabilities encounter myriad stigmas related to their disability which may complicate recognizing their situation as abusive and the decision to seek help.

As with needs appraisal stage, women with disabilities may face challenges during the help seeking stage. For example, services may be inaccessible, transportation or child care problems may arise, or they may find restrictions to program eligibility for assistance, particularly in rural areas. The feedback arrows in the model highlight that experiences at any step of the process can affect future attempts to secure help. For example, a woman with a disability may have had experiences accessing help previously when services were unhelpful, perhaps even harmful due to access and attitudinal barriers, and programs failed to meet her needs. This past evidence may change her perspective when appraising her current needs; she may be more likely to opt not to seek help. The large arrow along the bottom of the model demonstrates how these negative experiences are understood as accumulating over time, thus creating more obstacles to attaining effective help.

A constructionist approach to resilience considers outcomes from interactions of individuals and their environments for resources to be healthy (as the individual defines it) despite

adverse conditions (Ungar, 2004). As the model depicts, resilience that facilitates help attainment, safety, and positive quality of life outcomes can occur throughout the process. Building resilience is also embedded in the availability of material resources, relationships, personal and collective identity, cultural adherence, and social justice through equal participation (Ungar et al., 2007).

Social location (social position) is simultaneously a predictor of increased risk for exposure to violence and a significant contributor to chronic stressors such as unemployment, poverty, or housing instability, and negative life events (Eby 2004; Goodman, Smyth, Borges, and Singer, 2009; Kennedy et al., 2012). Social location also limits access to community resources and services available to extend help (Anderson, 1995; Gelberg, Anderson, and Leake, 2000). In this study, rurality and socioeconomic factors contribute to the social location of women with disabilities.

Community and policy contexts capture factors associated with the adequacy and availability of programs helping women with disabilities experiencing violence. Particularly in rural communities, social and economic disadvantage is common, and resources are limited and hard-to-reach. Additionally, community values may prevail that disapprove and blame victims (Logan et al., 2005). The cultural aspects of a community also influence women's options accessing help. Cultural beliefs about violence/marriage/family issues may prevent or impede recognizing violent situations, which limits available services and stigmatizes women trying to access help (Liang, Goodman, Tummala-Narra, and Weintraub, 2005).

Domestic violence shelters and programs who receive federal funding must create and incorporate policies and procedures to ensure compliance with the Americans with Disabilities Act of 1990 (Public Law 101-336). However, these programs are not monitored to confirm that shelters and services are free of architectural and communication barriers and other obstacles, such as a lack of training related to disability, which may prevent women with disabilities from participation. The Violence Against Women Reauthorization Act of 2005 (VAWA) extended additional funding for disability-related education, training, and service enhancements. The Office of Violence Against Women provided grants to 81 communities to help create sustainable systemic changes, such as building collaborative partnerships between victim services and disability service agencies, funding staff, and financing structural modifications to meet the needs of WWD seeking services. Though these policies seem to indicate more awareness and a concerted effort to shift programs and services towards equal access for WWD, there is no evidence that these initiatives have translated in meaningful ways to help women with disabilities in violent situations to exit and secure safety. Asking women who have navigated this situation, and various systems and programs, about their expectations and experiences will provide important information about how national strategies and policies are translating in local rural communities.

The disability context includes functional, activity, and participation limitations, either as a result of the impairment to the body or as a consequence of the social and physical environment.

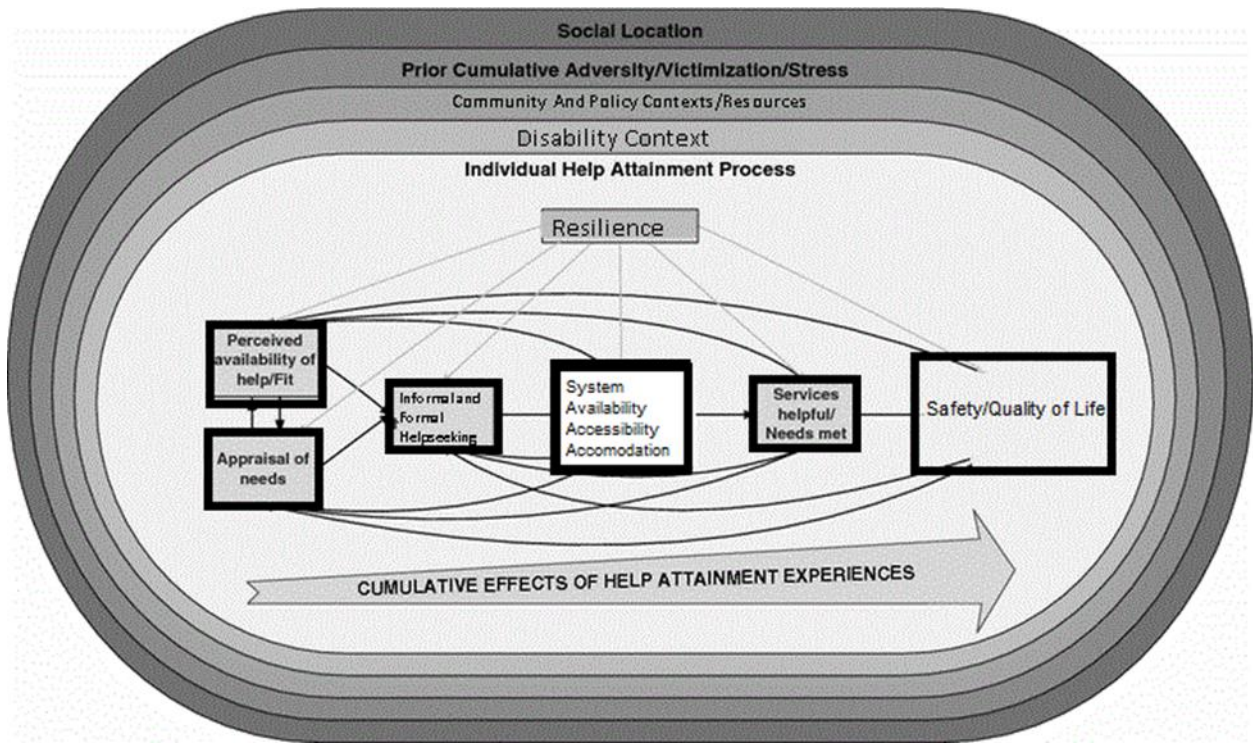


Figure 2. Help Attainment and Resilience Model

METHODS

The overall objective of this study was to characterize the help-seeking behavior and resilience strategies women with disabilities employ when experiencing gender-based violence in rural communities, and to understand unmet needs and barriers to services. This understanding, combined with an analysis of WWD’s policy and service expectations and actual experiences, can inform various stakeholders how to target resources. This research can also shape future policy and programmatic development and implementation.

Study Design

This was an exploratory multi-case study analysis research design. This research design facilitated an in-depth inquiry about a phenomenon (case) set in a real-world context—particularly when boundaries between the phenomenon (GBV) and the context (rurality and disability) are not clear (Yin, 2009). The units of analysis (cases) were women with disabilities experiencing gender-based violence while living in a rural community. This examination used a qualitative data collection and analysis approach, with descriptive data to summarize the sample. Qualitative research describes people’s needs, values, perceptions, interactions, and experiences with their immediate community, and more broadly of policies and processes in social systems. Qualitative evidence is therefore very important for improving understanding of how, and to what extent, people perceive interventions (in this study victim services, programs, and policies) as effective and acceptable, and examine whether policies and programs are working or how they could improve to be more effective. For all study aims, semi-structured in-depth interviews generated the data. Key informants in this research were women with disabilities who lived in a rural community while experiencing GBV.

The principal investigator (PI), Kimberly Aguillard, analyzed interview transcripts through a process of content analysis. Content analysis involves systematic coding and categorizing to examine large amounts of textual information unobtrusively to identify trends and patterns of words used, including relationships of words and phrases, as well as the discourses of language (Hsieh and Shannon, 2005; Vaismoradi, Turunen, and Bondas, 2013). Working

with a large volume of qualitative data, the aim of content analysis is to illuminate consistencies and differences, and make sense of these findings (Patton, 2002). After the researcher reviewed transcripts in entirety, the analyst created working definitions for each code/theme. Text that did not fit under predetermined coding generated additional new codes. Iterative coding organized text into manifest (explicit terms or concepts) and latent (underlying, implicit terms and meanings) to build categories of codes and ultimately themes (Morgan, 1993). The basis of this choice of data collection and analysis is rooted in supporting scholarship, which underscores that the perspectives of individuals who use services is key to developing policies, best-practice standards and program evaluation (Dullea and Mullender, 1999; Hague and Mullender, 2006). Researchers have also underscored the importance and value of including people with disabilities in research, in an empowering role, to generate actionable findings (Ducket and Pratt, 2001; Kitchin, 2000; Niesz, Koch, and Rumrill, 2008).

The results of this study can inform policy-makers and service providers (victim services, law enforcement/legal assistance, disability service agencies, and health care services) about unmet need, barriers, help-seeking processes, resilience strategies, and expectations and experiences related to programs and policies. WWD provided valuable insights on how existing policies are translating in local communities. Participants helped identify new directions for policy and program implementation, based on their own experiences and interactions with victim services.

Table 1 Measurement Matrix

Aim	Concept/Variable	Description	Data Source
<p>Aim 1. Identify the help-seeking behaviors rural women with disabilities who are victims of gender-based violence use to find aid, services, and secure safety.</p>	<p>Background:</p> <ul style="list-style-type: none"> • Type of disability • Type and duration of violence • Length of time since violence ended • Marital status • Number of children • SES (employment, education) 	<p>Descriptive context for help-seeking behavior</p>	<p>Interview with key informants / demographic data collection</p>
	<ul style="list-style-type: none"> • Recognizing and understanding the experience • Deciding to seek help • Selecting a source of support 	<p>Process of needs appraisal and help attainment (Conceptual framework)</p>	
	<p>Avenues for seeking help</p> <ul style="list-style-type: none"> • Individual response <p>Personal solutions to handle or minimize violence?</p> <ul style="list-style-type: none"> • Informal (friends, neighbors, family) • Formal (law enforcement/legal services, health care, emergency shelter/crisis hotline/ disability service agency/org) 	<p>Help attainment, cumulative victimization (Conceptual framework)</p>	
	<p>Creating a safety plan—exiting violence</p> <ul style="list-style-type: none"> • Who helped? • How did the WWD create the plan and see the plan through? • How does the WWD maintain safety? 	<p>Product of help attainment decisions and behavior (Conceptual framework)</p>	
<p>Aim 2. Determine factors that contribute to the personal resilience of WWD experiencing GBV in rural communities.</p>	<p>Describe</p> <ul style="list-style-type: none"> • Personal strategies to enhance resilience • Key relationships/support • Helpful community resources • Recovering-- Thoughts, beliefs, actions 	<p>Describe contextual specificity of solutions, which helped WWD persevere/recover/rebuild. guided by: A constructionist approach to resilience: “the outcome from negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions collectively viewed as adverse” (Ungar, 2004, p. 242)</p>	<p>Interview with key informants</p>
<p>Aim 3. Describe and characterize barriers (related to disability, rurality, or a combination of both factors) WWD encounter when seeking resources and help.</p>	<p>Describe</p> <ul style="list-style-type: none"> • Positive experiences • Attitudinal barriers • Access barriers (physical or communication) • Other challenges/special considerations 	<p>Describe the lived experience of being a WWD in a rural community and accessing various victim services (Conceptual framework) Social location/community and policy context</p> <ul style="list-style-type: none"> • Availability, accessibility, accommodation, and fit 	<p>Interview with key informants</p>
<p>Aim 4. Determine how policies and programs currently translate in local communities to facilitate or impede access to victim, medical, and legal services for women with disabilities based on their expectations and experience navigating systems.</p>	<ul style="list-style-type: none"> • What shaped expectations about engaging with these services? • What was the experience of engaging with these services like? • What policy changes would make this different? 	<p>Provide policy context based on WWD’s experiences and insights about local programs and services and formulate recommendations based on interviews.</p>	<p>Interview with key informants</p>

Study Setting

The setting for this study was rural communities in the United States. Due to the potential challenge recruiting an adequate number of participants for qualitative interviews, this setting was intentionally broad. The number of interviews (33) adhered to sampling size guidelines, which consider between 20 and 30 interviews sufficient (Creswell, 2007), and is in line with previous articles in the target journals for the planned manuscripts resulting from this study. Several aspects of rurality make acquiring victim services complex. Research indicates rural women have a greater need, and encounter barriers to, accessing key resources (such as health, mental health, and criminal justice services), which are critically important to aiding women to safely exit an experience of GBV (Krishnan et al., 2001; Grossman, Hinkley, Kawalski, and Margrave, 2005). Studies have documented problems for victims of violence in rural areas, including limited availability and trouble accessing formal services, a lack of knowledge and information about resources, and familial and cultural attitudinal barriers prominent in rural communities, which may discourage seeking services through formal channels (Davis et al., 1994; Tan et al., 1995; Krishnin et al., 2001). Often, characteristics of rural communities, including social and geographical isolation, little to no communication and transportation options, financial stress, lack of anonymity, and limited access to key social and public health resources, serve as roadblocks to documenting violence and providing appropriate formal responses (Cantin and Rinfret-Raynor, 1993; Riddell et al., 2009). Domestic violence shelters in rural communities report a higher turn-away rate due to a lack of resources or capacity, than urban facilities, indicating a significant unmet need in rural communities (Iyengar and Sabik, 2009).

Rural women living with disabilities are particularly vulnerable for experiencing GBV because of being female, living in a rural community, and having a disability. Women with disabilities also face unique risks and barriers to exiting violent situations. Living in a rural community may exacerbate these factors. The social context of disability may involve inadequate accessibility in the environment and among service providers, necessity to rely on support services such as personal assistants, attitudinal barriers from service providers, poverty, and isolation (Powers et al., 2002; Swedlund and Nosek, 2000). Hughes and colleagues (2007) also identified factors associated with severe depression among rural WWD, including greater problems with pain, more restricted mobility, and feeling dissatisfied with their available social network.

The PI conducted individual interviews by phone and email, extending geographical reach and expanding the diversity of participants (Oltmann, 2016; Holt, 2010; Novick, 2008; Smith, 2005). In the case of a telephone interview, once the recording started the PI did not use the subject's name, to protect privacy. For Deaf or hearing-impaired participants, and participants with cognitive impairments, the PI consulted the participant about most preferred communication.

Recruitment Strategies and Case Set

The PI distributed the study announcement to disability service agencies (such as Lighthouses for the Blind, Centers for Independent Living, and the Association of Programs for Rural Independent Living), and through disability consumer organizations (such as national listservs of the National Federation of the Blind). The PI also worked with national

centers specializing in violence and disability services, such as SAFE Disability Services in Austin Texas, to distribute the study announcement to stakeholders. Finally, the PI shared the study announcement through Facebook and Twitter.

Sharing the study announcement through various avenues representing a variety of different disabilities supported purposeful, maximum variation sampling (ensuring representation from women with diverse disabilities). The disability community is not homogeneous in its needs/strategies for accessing resources. Help-seeking, barriers, building resilience, and perceptions on policy effectiveness and policy improvements differ in important ways. A considerable body of research conducted in the 1990s from the Center on Research on Women with Disabilities (CROWD), primarily involved women with various physical disabilities' experiences with abuse (Nosek, Howland, Rintala, Young, and Chanpong, 2001c). The current study included physical disabilities, to extend and enhance those foundations, as twenty years and many technological changes have impacted help-seeking with a physical disability. This research also extended a small body of research on women with cognitive disabilities. This research also included women with sensory disabilities, such as hearing and visual impairments, to address a gap in current scholarship concerning these populations and violence.

Recognizing that not all women with disabilities affiliate with disability agencies or advocacy groups, this study used snowball-sampling techniques, where the PI asked interviewees to share study information with acquaintances who have experienced violence.

This strategy reached additional women with disabilities, where circulating the study announcements may not have reached.

Study Inclusion and Exclusion Criteria

Criteria for participating in this research required identifying as a woman who is 18 or older, who (1) self-reported at least one of the six disability types (hearing, vision, mobility, cognitive, self-care, or independent living); (2) had the disability for at least one year and had the disability during her experience of GBV; (3) experienced GBV at least one year prior to the study while living in a rural community when violence occurred; and (4) did not have a significant cognitive or intellectual difficulty, or difficulty with the English language, which may have prevented understanding the study and responding to interview questions. None of the participants were vulnerable to coercion because the women decided whether to respond to the study announcement, and most likely did not if they were not comfortable with the study subject. While the PI did not screen out people with physical illness, mental illness, or cognitive disabilities, their participation was entirely voluntary and initiated only by potential participants responding to the study announcement. Screening for cognitive and intellectual impairments helped ascertain if the participant's understanding of elements of the study was sufficient to provide ethically valid consent (Resnick et al., 2007). A participant had to: (1) be able to communicate and explain what participation involved, (2) understand the significant risks and benefits, and (3) understand how to withdraw from the study. The PI discussed these aspects before using a confirmation of consent checklist to confirm decision-making capacity by asking each interested subject to recall as many main points of the study

as possible. To be eligible, women had to recall five of seven of the main points of the study, with one repeat of the procedure offered, if necessary. After screening for study criteria, and confirming the subject's understanding of consent verbally, the PI emailed a consent form for the subject to review. As an additional protection of privacy, this study did not require signature for consent; rather engaging in the interview served as an individual's consent to participate.

Study Enrollment

The case set for this study was 33 interviews, representing women with diverse disabilities (sensory, cognitive, and physical). This number of interviews accommodated an in-depth case-oriented analysis, which is essential and fundamental to qualitative techniques (Sandelowski, 1996). Sampling continued until themes became redundant (saturated), an indication that additional interviews would not be likely to generate new findings (Crabtree and Miller, 1999). Supporting this sample size, Guest, Bunce, and Johnson, (2006) systematically evaluated the degree of data saturation and variability over the course of thematic analysis using 60 interviews and concluded basic elements for themes were evident after 6 interviews and saturation was observed after 12 interviews. Guest and colleagues (2006) did note that the subjects were relatively homogeneous, recommending a more heterogeneous sample may require more interviews to achieve redundancy. Hennink, Kaiser, and Marconi (2017) found through a methodological study of interview analysis that meaning saturation (a point which generates no new insights, or nuances to identified themes) was achieved at 16-24 interviews. Therefore, the current study set was appropriate to

capture themes. Pragmatic considerations, such as time and financial constraints and the complexity of accessing the study population, also contributed to the sample size of 33 interviews. The depth and duration of interviews generated rich data and required an in-depth analysis.

Once a potential participant responded to the study announcement (by emailing, texting, or calling the PI), the PI provided and discussed a prepared consent form in the person's preferred, accessible format. The form provided an explanation of the overall study aims, a statement indicating that interviews would be recorded, delineated risks and benefits of the study, and the individual's right to withdraw from the study at any time. The form also informed participants of the mandatory reporting requirement if any current abuse was disclosed.

After participants reviewed consent forms, the PI scheduled an in-depth interview for each key informant using the interview guide (Appendix 2). Interviewees received a small incentive to compensate them for their time and insight.

Data Collection

Upon UTSPH Institutional Review Board approval of this project, including the key informant interview guide, the PI used the approved interview guide for one pilot interview to address possible challenges during the interview process. The pilot interview did not identify any problems, so the interview guide was not revised. The PI recruited, screened,

and enrolled the participant for the pilot interview, and the interview transcript and field notes contributed to the overall number of interviews for the study.

If at any point throughout the interview the WWD did not understand and needed clarification of questions, the PI restated the question using probes to elicit the thought process and help the participant formulate a response. The interview guide (Appendix 2) includes specific examples of probes.

Interview Guide

The conceptual framework (Figure 2) informed the broad topic areas in the interview guide, to describe and understand aspects of women with disabilities' help-seeking behaviors, strategies to build resilience, barriers and unmet needs, and policy expectations and experiences. The design of semi-structured interviews facilitated thick descriptions, including details about interactions, location, and an in-depth account of how participants felt and responded (Danzin, 1989). The interview guide followed this general outline: beginning with a verbal introduction to review overarching objectives of the study, a discussion of the flow of the interview, and a confidentiality statement. The introduction also made women aware of mandatory reporting requirements regarding any discussion of current abuse.

The interviews began with an “icebreaker” question – one that is simple, non-controversial, and helped the participant feel comfortable sharing information. The PI incorporated other best-practice interview techniques to help generate rich (detailed and complete) narratives. Examples of these strategies included: avoiding leading questions; asking open-ended

questions about a single topic (avoiding “double-barreled” questions that have multiple parts); allowing for pauses; and using reflective statements in which the interviewer paraphrased the participant’s statements to ensure a clear and correct understanding, and to prompt further elaboration (Crabtree and Miller, 1999; Roulston, DeMarrais, and Lewis, 2003).

Data Analysis

First, the PI, or a HIPAA-compliant professional transcription company, prepared data by transcribing interviews verbatim. The PI recorded field notes immediately after each interview to capture additional details and context.

Analysis began with immersion in the data (individual transcripts as they were available) for an overall understanding (Crabtree and Miller, 1999). Reviewing data before beginning to code helps identify emergent themes while maintaining important connections between ideas and their context (Bradley, Curry, and Devers, 2007).

After reading transcripts thoroughly before creating or applying codes, the PI proceeded with a conventional content analysis, whereby the text generated the codes and themes, inductively (Hsieh and Shannon, 2005). The PI categorized and coded collected responses from questions to identify themes among responses from women representing diverse disabilities. Table 2 contains details of study aims and related questions from the interview guide, and analytic procedures.

The PI generated and refined a codebook to include an organized list of the codes and specific definitions and examples to demonstrate application for each code. The codebook helped ensure consistency and reliability throughout coding the entire set of transcripts, and provided an audit trail, illustrating additions, modifications, and clarifications of codes (Bowen, 2008).

Table 2. Analysis Matrix

Study Aim	Interview guide section/questions	Conceptual Framework	Analytic Technique
Aim 1. Identify the help-seeking behaviors rural women with disabilities who are victims of gender-based violence use to find aid, services, and secure safety.	Demographic information	Social Location (Education/Employment/Race, etc.)	Descriptive summary of participants' characteristics (Describing the sample)
	Q1 Describe life in a rural community	Social location (rural)	Open-ended Thematic analysis transcribing, coding, theming data
	Q2-5 Describe recognizing and defining the problem, help appraisal, help attainment	Community context, help appraisal, informal/formal help attainment	Open-ended Thematic analysis transcribing, coding, theming data
Aim 2. Determine factors that contribute to the personal resilience of WWD experiencing GBV in rural communities.	Q6-9, Describe what helped you keep going	Resilience	Open-ended Thematic analysis transcribing, coding, theming data
Aim 3. Describe and characterize barriers (related to disability, rurality, or a combination of both factors) WWD encounter when seeking resources and help.	Q10-12 Discuss acquiring help, identifying barriers, noting any unmet needs	Community context, disability context, cumulative victimization/stress, System accessibility, accommodation, availability	Open-ended Thematic analysis transcribing, coding, theming data
Aim 4. Determine how policies and programs currently translate in local communities to facilitate or impede access to victim, medical, and legal services for women with disabilities based on their expectations and experience navigating systems.	Q 13-18 Describe expectations and experiences of policies and programs.	Policy context/resources/disability context	Open-ended Thematic analysis transcribing, coding, theming data

Cycles of Analysis

The PI completed cycles of analysis to generate themes from open-ended questions, including the following steps:

Step 1: Organized and prepared the manually transcribed responses, using Microsoft Excel sheets for each prominent theme.

Step 2: Continually reviewed transcribed key-informant interviews throughout the data collection process. This provided a general sense of responses as each interview was completed and helped to highlight emerging themes, codes, and sub-codes within text.

Step 3: Based on iterative review of data, began coding emerging concepts by assigning descriptions in short phrases to segments of transcribed text. In this stage, the PI revisited key informant responses several times and recoded if necessary, to identify minimal broad and distinct themes that encompassed all emerging coded categories. This was the 1st cycle of coding. The process was repeated as needed.

Step 4: The PI then moved to generating a narrative summary of findings in order to provide context for themes.

Data Management Software Selection

The PI manually coded data using Microsoft Excel and Microsoft Word files. These are efficient tools that do not pose any accessibility barriers to researchers using screen reading software. Screen reading software is a necessary tool for computer users whose vision loss prevents them from seeing screen content or navigating with a mouse. Both ATLAS.ti and NVivo software packages lack accessibility using screen reading software.

Ethical Considerations: Data Collection and Analysis

The University of Texas School of Public Health Institutional Review Board (IRB) Committee on the Protection of Human Subjects reviewed this study to ensure appropriate study design and data management. The PI demonstrated measures to reduce risk to participants (making clear participants can skip a question, or end the interview at any time, and offering contact information for crisis/mental health services), shared details of informed consent, outlined strategies to make research participation equitable (study materials in accessible, preferred formats and measures to make the interview most convenient for participants), detailed provisions to protect participant privacy, and discussed the incentive for participants.

Upon approval by the board, the PI presented study participants with a consent form describing the purpose of the study, procedures, potential risks and discomforts, potential benefits, confidentiality, the right to withdraw from the study, and detailed the incentive available to participants (Appendix 1). The consent form indicated that personal identifiers would be removed during transcribing recorded interviews. The PI assigned unique identifiers to participants and kept interviews stored on password protected computers.

Strengths and Limitations

This study was among the first to specifically explore rurality, disability, and GBV, using qualitative research. Rigorous qualitative research allowed a richly detailed narrative to emerge to help build an in-depth understanding of the subject. Qualitative techniques are

appropriate for this subject because no current research examines the intersection of disability, rurality, and GBV, and qualitative techniques facilitated an initial understanding of this complex problem, based on the interpretations and experiences of WWD, to inform future research. The research involved strategies to strengthen study validity, including redundancy and maximum variation techniques to sample for heterogeneity (Lincoln and Guba, 1985; Marshall and Rossman, 1998; Patton, 2002). This strategy engaged and included women with diverse disabilities, including sensory, cognitive, and physical impairments. The rationale for gaining a heterogeneous sample is that any commonality found across a diverse set of cases is more likely to generate generalizable themes than a commonality found in a homogenous set of cases (Robinson, 2014). The qualitative interviews also included generating thick descriptions (descriptions that are deep, dense, and detailed) through observational field notes, research memos, and verbatim transcriptions of the interviews (Denzin, 1989). To enhance transparency, the PI created a code book, which included a list of specific definitions and examples for each code. The codebook also provided an audit trail, illustrating changes to codes over time throughout the analysis process (Lincoln and Guba, 1985; Bowen, 2008). The PI also used member checking (also referred to as respondent validation) to increase the trustworthiness and confirmability of data (Lincoln and Guba, 1985; Creswell and Miller, 2000). This technique used the participant's own words through direct quotes in the research findings, and shared transcripts and concepts with a selection of participants to confirm accurate and appropriate understanding and representation of their experiences.

One limitation of this project is findings from this specific study are not statistically generalizable to other populations (such as men with disabilities or rural women without disabilities experiencing GBV). However, this research yielded important concepts and contributes to an understanding of this phenomenon to launch additional research, and allow for logical, transferrable inferences (Sandelowski, 1996; Small, 2009).

Qualitative techniques are difficult to replicate. This project addressed this limitation by including details about the recruitment strategy, interview guide, and data analysis (including a code book).

A common limitation in academic research is a failure to permeate the boundaries of academic scholarship and front-line or community level translation. Community partners often help recruit for research studies without the benefit of learning research findings (Logan et al., 2008). The PI shared research findings with participants and community partners who helped circulate the study announcement.

An additional limitation is that recruitment for this study was challenging due to complicating factors surrounding disability and GBV, including stigma and shame. Reaching this population through various contact points including disability service agencies and disability activist organizations, as well as contacting leaders and “connectors” in the disability community to share study information, helped to reach a large pool of WWD. The study announcement clearly stated the aim of the study, as well as strategies to protect privacy and anonymity (unique participant ID and password-protected computer for data analysis). Confidentiality is of special concern in rural communities (Logan et al., 2008).

Both the disability and rural communities may have some hesitancy because often researchers who are not members of the community study these populations. Interviewers who do not have a disability may cause psychological distancing (Nosek et al., 2001b). Similarly, rural communities have had negative experiences when research on their community presents and circulates mostly negative reports in media (Logan et al., 2008). One strength of this study is the PI is a woman who grew up in a rural community and is a member of the disability community, having a disability herself, as well as twenty years of activism through disability organizations. Matching characteristics with participants is a recommended strategy when interviewing marginalized groups (Logan et al., 2008; Brown, Long, and Milliken, 2002).

The interviews relied on WWD self-report of violence, therefore, report bias is a possibility. Victims who recount violent events may downplay severity as a method of coping (Eisikovits and Winstok, 2002); however, this research primarily focused on the WWD's response to GBV, in the form of help-seeking and strategies to build resilience, rather than in-depth exploration of features of the violence. Due to the sensitive nature of the research, the PI offered participants contact information for mental health services/victim support options in an accessible format (large print/Braille, audio, electronic text, or in plain language).

JOURNAL ARTICLE 1

“Helping Somebody Else has Helped Me Too”: Resilience in Rural Women with Disabilities with Experiences of Gender-Based Violence

Target Journal: Violence Against Women

Abstract

This qualitative study engaged rural women with disabilities who experienced violence to learn about how they cultivated resilience to support recovery and growth after experiencing abuse. Women described key personal qualities and supportive networks and services, such as internal drive, connectedness, dedication, healthy and helpful outlets, and an evolution of thoughts and behaviors. These insights build a more comprehensive understanding of strategies and supports to bolster women with disabilities’ resilience. These findings inform interventions and promote approaches to build on women’s strengths and resourcefulness.

Introduction

Violence against women is a pervasive public health problem (Modi, Palmer, and Armstrong, 2014), with more than 1 in 3 women in the United States (36.4% or 43.6 million) during their lifetime experiencing contact sexual violence, physical violence, or partner-stalking (Smith et al., 2018). Research suggests that many women can make positive adaptations, recover, and even flourish after exposure to violence. The study of resilience attempts to identify and understand the supportive factors and processes which facilitate recovery and growth, despite adversity

(Grych, Hamby, and Banyard, 2015). Women with disabilities¹ (WWD) face multiple layers of adversity. They experience social oppression, marginalization, and violence attributable to both their status as female and related to their disability (Crawford and Ostrove, 2003; Mays, 2006; Nosek and Hughes, 2003). Throughout their life course, WWD experience all forms of violence (physical, sexual, psychological, and stalking) at a higher rate than women without disabilities (Breiding and Armour, 2015; Hughes, Lund, Gabrielli, Powers, and Curry, 2011). WWD have identified violence and abuse as the most severe threat to their health and a critical area to prioritize in research efforts focused on their health needs (Freeman, Strong, Barker, and Haight-Liotta, 1996).

The nature of abuse against WWD is distinct. Researchers and WWD assert that applying the prevailing definition of domestic violence, including intimate partner violence, fails to encompass the complexity related to WWD's experiences (Nosek, Howland, and Hughes, 2001b; Radford, Harne, and Trotter, 2006; Saxton et al., 2001; Thiara, Hague, and Mullender, 2011). For example, the duration and type of abuse WWD experience is often more intense (Brownridge, 2006) and may occur in a wider context of settings—including health care settings (Hassouneh-Phillips and Curry, 2002; Magowan, 2003; Nosek, Howland, and Young, 1997; Nosek, Young, and Rintala, 1995). Perpetrators of violence against WWD may use different elements of control or oppression, such as withholding medication, removing or damaging

¹ In this article, the authors alternate between the terms “women with disabilities” and “Deaf/disabled women.” This is intentional, to acknowledge two courses of disagreement about language use. First, some Deaf individuals do not identify as disabled, while others identify as both Deaf and disabled. Second, while person-first language “women with disabilities” is still encouraged among social science and health researchers and other professionals, identity-first language “disabled women” is preferred by many in Deaf and disability communities to recognize disability as an important cultural and political identity.

medical or adaptive equipment necessary for independence, or creating barriers to access or communications to prolong WWD's isolation and prevent a safe exit from the situation (Cramer, Gilson, and Depoy, 2004; Lightfoot and Williams, 2009b; Saxton et al., 2001). WWD who require personal assistance may have an elevated risk of these kinds of abuse (Nosek, Foley, Hughes, and Howland, 2001a; Saxton et al., 2001). Women with disabilities also suffer serious physical and mental health consequences, including high rates of depression (Nosek, Taylor, Hughes, & Taylor, 2006), and diminished self-esteem (Nosek et al., 2001a).

Evidence suggests WWD's experience of violence may be exacerbated by social stigma, devaluation, and WWD's own diminished sexual and body esteem, which may place them at risk for greater emotional, physical, and sexual violence (Hassouneh-Phillips and McNeff, 2005; Nixon, 2009). Prevailing discourses concerning WWD as genderless, asexual, childlike (naïve and lacking agency), and dependent extend to assumptions of women lacking the ability to be sexual, wives, partners, or mothers (Zitzelsberger*, 2005). Particularly when WWD have nondisabled partners, the pairs may garner curious attention, inappropriate scrutiny, and myriad misconceptions predicated on the societal belief that WWD are burdens (Fine & Asch, 1988). Furthermore, while the disabled woman may be an object of pity, the public may view her partner as saint-like for staying in the relationship (Fine & Asch, 1988). The reality of these harmful stigmas may make confronting and disclosing abuse more challenging and less feasible for WWD.

In rural settings, WWD are at an elevated risk for experiencing complex, repeated violence, and may encounter additional complications accessing needed services. For WWD living in rural settings, a multitude of factors associated with rurality may compound their experience of

violence, including geographic and social isolation, anonymity and privacy concerns, few resources, an inadequate formal response, and physical barriers such as lack of sidewalks and accessible transportation options to reach service facilities (Fitzsimons, Hagemeister, and Braun, 2011; Nelson and Lund, 2017). Therefore, WWD experiencing violence in rural areas may be facing additionally isolating and dangerous adversity. It is critical to identify protective strategies women use to adapt despite adversity (personal, contextual, and cultural), in order to target programs and resources to bolster these processes.

Resilience, or the ability to “bounce back,” from adversity, is a concept that can inform preventive interventions and victim assistance services. A social-ecological approach to resilience considers the complex contexts and cultural components that lead to positive developments in spite of stress and adversity (Ungar, 2011a). This framework has four pillars: navigating, negotiating, self-defining meaning, and availability and accessibility of resources (Ungar, 2011b). Therefore, individuals’ ability to build resilience is also imbedded in the availability of material resources, relationships, personal and collective identity, cultural adherence, and social justice through equal participation (Ungar et al., 2007). Consistent with other marginalized groups that experience disparities, disability identity may encompass cultural components (Olkin, 1999). Research illustrates that in circumstances of adversity, resilient individuals engage in strategies and behaviors that aid them in navigating to necessary resources to flourish (Ungar, 2011a). Therefore, an individual’s social ecology (formal and informal social networks) must have capacity to provide culturally meaningful resources to support help-seeking processes. Policies, adequate funding, family and societal structures, cultural values, and even the “chance” of life circumstances influence the likelihood an

individual disadvantaged by traumatic events will experience resilience (Leadbeater, Dodgen, and Solarz, 2005).

Although internal motivation to adapt is still an important factor in bouncing back after adversity, the social ecology is integral to restricting or enhancing people's options for coping strategies that result in pro-social behavior and even altruism (Staub, 2005; Staub and Vollhardt, 2008; Ungar, 2004; Vollhardt, 2009). Furthermore, in some individuals who have endured traumatic life events, pro-social behavior manifests, not only despite, but largely because of negative life experiences that may contribute to motivation towards altruism (Staub and Vollhardt, 2008).

A social ecological interpretation of resilience recognizes cultural sensitivity and specificity. A resource will be useable and useful only to the extent an individual considers it valuable and meaningful. Personal resilience is possible in environments that facilitate access to resources combined with cooperation from those who control resources to meet individuals' needs in ways that are congruent with WWD's personal and collective identities (Bottrell, 2009; Ungar, 2013). Ungar argues (2013) that we should expand our understanding of effective coping after trauma to encompass the variable of culture, which challenges fundamental social assumptions of what is "functionally adaptive" behavior. This understanding implicitly recognizes that, in certain contexts of adversity, resistance may be required (Bottrell, 2009). For example, an investigation of Deaf-disabled mothers found they adopt specific strategies to resist stigma and manage the hidden labor associated with disability, including techniques of visibility, respectability, and disengagement (Frederick, 2017), all of which may be considered as coping techniques deviating from "normal" strategies.

Research on resilience after violence is minimal, but findings support a social-ecological interpretation, indicating that both personal characteristics and a network of supportive relationships contribute to resilience (Anderson, Renner, and Danis, 2012; Humphreys, 2003; Werner-Wilson, Zimmerman, and Whalen, 2000). Multiple emotional, cognitive, and behavioral shifts occur related to resisting the violence/abuser, perceiving herself as able to control her safety, and cultivating hope and optimism (Crann and Barata, 2016).

To date, research on resilience has almost entirely excluded the disability community. The impairment, socially perceived as a personal tragedy, precludes individuals with disabilities from being considered as resilient; rather, they are designated almost universally as “at risk” or “vulnerable” (Runswick-Cole and Goodley, 2013). The limited research on people with disabilities, or their families, examines resilience in terms of overcoming the adversity or managing cumulative demands related to the disability itself (Alriksson-Schmidt, Wallander, and Biasini, 2006; Bayat, 2007; Heiman, 2002; Jones, Simpson, Briggs, and Dorsett, 2016; Migerode, Maes, Buysse, and Brondeel, 2012; Whittingham, Wee, Sanders, and Boyd, 2013). This research fails to account for people with disabilities’ full and complete lives, including experiences of setbacks and triumphs, losses, and trauma, in addition to merely navigating through life with a disability. Contributing to this narrow perception about people with disabilities’ lived experiences, most literature on care work and disability is one-directional, examining people with disabilities as beneficiaries of care. However, growing evidence documents how people with disabilities are also benefactors in multiple capacities (Shandra and Penner, 2017). In particular, feminist and disability critiques have challenged the prevailing and problematic dichotomy between care and dependency and underscored the interdependency and

reciprocity inherent in many caring relationships (Reindal, 1999; Shandra and Penner, 2017; Thomas, 2007; Walmsley, 1993). In addition to serving as care providers in different contexts, people with disabilities can and do volunteer, both formally and informally, in their communities although this has not received as much exploration as volunteerism in other marginalized groups (Shandra, 2017). Finally, existing research is often flawed because the concept of resilience is strongly associated with normative ideas about what contributes to resilient qualities and resources, potentially devaluing the equally valid strategies and resistance people with disabilities use to build resilience and thrive (Runswick-Cole and Goodley, 2013). Most current scholarship on resilience, therefore, is interlocked with judgments about what is considered “normal” in certain contexts, minimizing the importance of cultural diversity and social positioning (Bottrell, 2009; Ungar, 2004).

Resilience research is largely hegemonic, so it is likely that exploring underrepresented groups, such as WWD, will identify new protective processes and adaptive techniques which accrue positive outcomes, on their terms (Bottrell, 2009; Ungar, 2013). Ungar, a pioneer in resilience research, advocates that qualitative research is effective for exploring resilience for several reasons: qualitative methods are useful for eliciting the “unnamed protective processes” relevant to the participants’ lived experiences; qualitative techniques construct thick descriptions of phenomenon in very specific contexts; qualitative researchers engage and amplify marginalized voices, which account for unique and self-defined positive outcomes; and qualitative research avoids generalizations while conferring transferability of results, which promotes acceptance for these context-specific constructions (Ungar, 2003).

The Rural Safety and Resilience Study (RSRS) engaged WWD who have survived an experience of gender-based violence (physical abuse, sexual violence, psychological violence, and/or stalking) while living in a rural setting through in-depth qualitative interviews. This study is unique because it explored WWD's resilience in response to and in spite of experiencing violence-related trauma. Previous research involving the disability community has only explored resilience related to living with or adjusting to having a disability, which minimizes and overlooks other complexities individuals with disabilities encounter and navigate in their personal, cultural, and social lives. This qualitative study explores WWD's self-defined dimensions of resilience and uncovers important insights about how services can bolster components that contribute to their resilience. The current study methodology empowers this historically marginalized population to use their own words to relay and interpret their lived experiences.

Methods

This study draws on 33 semi-structured in-depth interviews with WWD who experienced gender-based violence in a rural setting in the United States. Interviews were conducted from June 2019 through December 2019. This study was approved by the University of Texas Health Science Center at Houston (UTHealth) Institutional Review Board.

Recruitment Strategies and Case Set

The research team distributed the study announcement to disability service agencies (such as Lighthouses for the Blind and the Association of Programs for Rural Independent Living), and through disability consumer organizations (such as national listservs of the National Association

of the Deaf). We reached out to faith-based initiatives who partner with disabled members in communities of faith. We also worked with national centers specializing in violence and disability services, such as SAFE Disability Services in Austin Texas, to distribute the study announcement to stakeholders. Finally, we shared the study announcement through social media, (Facebook and Twitter). This study also used the snowball sampling technique, asking participants to share study contact information with other disabled women in their networks. The lead author, K.A., is a blind woman who was raised in a rural setting and is therefore uniquely equipped to conduct research that elucidates and presents the perspectives of this group of women. This background means K.A. was well situated to follow best-practice recommendations and recruit participants directly from Deaf and disability organizations and communities, rather than relying exclusively on social service agencies (Lightfoot and Williams, 2009a; Rivera Drew, 2009).

Criteria for participating in this research required identifying as a woman who was 18 years or older, who (1) self-reported at least one of the six disability types (hearing, vision, mobility, cognitive, self-care, or independent living); (2) had the disability for at least one year and had the disability during her experience of violence; (3) experienced violence at least one year prior to the study while living in a rural community when violence occurred; and (4) did not have a significant cognitive or intellectual difficulty, or difficulty with the English language, which might have prevented understanding the study and responding to interview questions.

Participants were not vulnerable to coercion because the women decided whether to respond to the study announcement. While we did not screen out people with mental illness or cognitive disabilities, their participation was entirely voluntary and initiated only by potential participants

themselves responding to the study announcement. Interviewees received a small incentive to compensate them for their time and insight.

The case set for this study was 33 interviews, representing women with diverse disabilities (sensory, cognitive, and physical). This number of interviews accommodated an in-depth case-oriented analysis, which is essential and fundamental to qualitative techniques (Sandelowski, 1996). Sampling continued until themes became redundant (saturated), an indication that additional interviews were not likely to generate new findings (Crabtree and Miller, 1999). Once a potential participant responded to the study announcement (by emailing, texting, or calling the lead author), K.A. provided and discussed a prepared consent form in the person's preferred, accessible communication format. The form provided an explanation of the overall study aims, stated that interviews would be recorded, delineated risks and benefits of the study, and emphasized the individual's right to withdraw from the study at any time. The form also informed participants of the mandatory reporting requirement if any current abuse was disclosed. After participants reviewed consent forms, the lead author scheduled an in-depth interview for each key informant using the interview guide.

The lead author conducted individual interviews by phone and electronic communication, extending geographical reach and broadening the diversity of participants (Holt, 2010; Hunt & McHale, 2007; Oltmann, 2016). For Deaf or hearing-impaired participants, and participants with cognitive impairments, the interviewer consulted the participant about most preferred communication mode. Eight interviews were conducted through electronic written interview exchanges to accommodate participants' communication preferences. The interviewer conducted these interviews in stages of email exchanges; the interviewer sent two or three questions at a

time. Next the interviewer reviewed answers, responded to what participants shared, and adapted questions accordingly. This method mirrored a natural in-depth interview by probing when necessary, and using reflexivity, reframing and repeating responses, to confirm the interviewer's understanding (Hund & McHale, 2007; Ison, 2009). The remaining 25 interviews began by confirming it was a convenient time for women to talk (they had adequate privacy and time to have an unrushed interview). Next, the interviewer briefly reviewed the research objectives, topic areas, and the participant's right to skip questions or end the interview. The interviewer obtained permission to audio record the interview. Phone interviews were 45 to 90 minutes long.

Twelve participants reported a physical impairment that affected their mobility. Nine women were blind. Four participants were Deaf. Five women were Deaf-Blind. Seven women had cognitive impairments. Four participants had multiple physical, sensory, or cognitive disabilities. The severity of participants' impairments varied. For example, the category "blindness" includes visually impaired individuals with some useable vision as well as women with no useable vision at all. In addition, some women had conditions that cause episodic flare-ups resulting in heightened physical limitations during these periods.

Participant ages ranged from 19 to 72, with most participants in their 30s and 40s. Twenty-four women identified as white. Three women identified as Black. Two women identified as Latina or Hispanic. Two women identified as Native American. One woman identified as Pacific Islander and one woman identified as multi-racial.

Ten women were either married or in a relationship. Of the 23 remaining participants, two were widowed, 5 were divorced, and 16 indicated they were single. Eighteen women had children.

Education levels ranged from some high school to holding a master's degree. Ten women worked part- and eight women worked full-time. Three participants were students, and two women were retired. The remaining 10 participants were not currently working, either by choice or because they were having trouble finding a job.

Data Collection and Analysis

Interviews were transcribed verbatim, omitting any personal identifiers such as names or places. Next transcripts were analyzed through a process of content analysis, which involves systematic coding and categorizing to examine large amounts of textual information unobtrusively to identify patterns and relationships of words and phrases (Hsieh and Shannon, 2005; Vaismoradi, Turunen, and Bondas, 2013). After the researcher reviewed transcripts in entirety, she created working definitions for each code/theme. Text that did not fit under predetermined coding generated additional new codes. Iterative coding organized text into manifest (explicit terms or concepts) and latent (underlying, implicit terms and meanings) to build categories of codes and ultimately themes (Morgan, 1993). The researcher used member checking, sharing tentative themes and direct quotes with a subsample of participants to ensure accuracy. The researcher discussed emerging themes and shared supporting interview quotes with an additional researcher with subject matter expertise to clarify concepts and themes. Finally, a codebook template recorded changes in codes over the duration of analysis, providing an audit trail.

Findings

We use fictional names for all participants to protect privacy. WWD shared lived experiences of disentangling from abusive relationships, which were fraught with violence, threats, isolation,

and controlling behavior. Relaying these stories also highlighted important insights about how they kept going during and after the experiences of violence in rural communities. One important finding is that more than half (18 of 33) of participants moved towns after the experience of violence. In many cases women started over in communities with more available resources and options for enhancing their independence (such as more transportation options). This is significant because it suggests planning for a major life transition (such as going away to college) was an important component to WWD in rural settings securing safety and beginning to heal.

Women described internal drive, connectedness, dedication, healthy and helpful outlets, and how their own beliefs about themselves and the experience evolved. Women explained strategies to build resilience took work and time. WWD also communicated that resilience does not make them impervious to negative thoughts and feelings, but techniques do contribute to their overall stability and wellbeing.

Internal Drive

Women described personal qualities they relied upon to help them keep going. Many of these qualities were refined and strengthened because of their experience living with a disability. In other words, the experience of having a disability, and problem-solving, negotiating, and navigating a world not built for them, enhanced many women's ability to push through difficulty and persist. WWD described that their disability necessitated familiarity working through complex systems to receive services and information. Women shared experiences of being the first person with their disability (blindness, deafness, mobility impairment) that many people had

ever met, particularly in their rural town. They explained this placed an unavoidable responsibility upon them to educate and advocate daily.

Meredith, a woman with a visual impairment, shared,

You have to keep pushing yourself a lot harder than someone without serious disabilities. Because you're constantly proving, having to prove yourself and you know, you're not just accepted for what you may know or what you can do. But you have to prove that you can do it in spite of the disability.

She continued explaining how she kept going after experiencing years of spousal abuse, “Well, I guess necessity. You know, you have two choices, either collapse and not do anything or move forward. And I've never been a collapse.”

Sheila, a woman with a mobility impairment, described her approach to conquering problems,

I've always had to think out of the box because the box wasn't my box, it was everybody else's box. I was already out of the box. (laughs) So anyway I had that creativity going for me and I think that, I think I've done very well and I think that I rarely say 'Can't.' So there's always a way to do it.

Sonia, a woman with a mobility impairment, echoed the sentiment of underlying determination.

She explained, “In spite of all the negatives I thought and felt and experienced, there seemed to be some inner drive I can do better.”

Women also discussed gaining confidence, learning to speak up for themselves, and setting healthy boundaries. These shifts often challenged women's learned behavior and adherence to submissive roles, which society perpetuates for individuals with disabilities, and rural culture perpetuates for women.

Cynthia, a woman with a cognitive disability, described, “I am now more outspoken, maybe not the most helpful at times (haha!) but I stick up for myself more and I am not afraid to hurt someone’s feelings by saying no when necessary.” Meredith acknowledged she has also become more aware and firm, “Well, I’m much less tolerant of how I get treated. I’ve recognized more quickly when someone isn’t treating me the way I should be and taking steps to prevent it without being, you know, too prickly.” Sheila observed, “I was frightened a lot of being alone. I’m no longer frightened of being alone. I have filled my house myself. I guess that this whole experience has given me a lot more ultimately confidence in and comfort in being in this space.” Jennifer is a Deaf woman who left an abusive marriage. Distance from the abuse allowed her to see how her marriage negatively affected her thoughts and behaviors. She explained her transformation this way, “I found myself again. Before I was married, I was very, very independent. Before I was married, I had a job. I communicated with people.” Reflecting on how she had lived before entering a violent marriage gave her the confidence to build the drive and outgoing personality she liked about herself again. Finally, Theresa, a blind woman with a mobility impairment, explained her mindset,

Somehow something sparked in me when I moved to (current place) um, which is where I live now. Um, and I got off the couch, I started a nonprofit and I went back to school. So, um, a lot more productive things than I did and it’s more about bettering myself, than pitying myself.

Connectedness

Women described how connecting with others gave them validation and strength. Women found, after disclosing their experience of abuse, that they were not alone: many people understood and had experienced something similar. This was meaningful to WWD and it was key in how they began to reframe their experience and heal. Family, friends, coworkers and communities of faith

were important forms of support. For example, Emily, a wheelchair user, who exited an abusive relationship where her partner was also her primary personal care attendant. She reflected,

It really helps to find your people, you know, it's one thing to have friends, it's something completely different to have people who you can call when you're having a panic attack and they'll rush right over. That is a completely different feeling. I know who my family is now whereas I didn't have that before. So, I really learned who I can lean on and they can do the same with me as well and I will always, always be there for them.

Hannah, a blind woman, who reported being sexually abused by her mother's boyfriend sexually abused her. Her mother did not believe her. Her grandparents did believe her but discouraged her from getting help to deal with the abuse. Hannah shared that, due to the abuse and her family's way of dealing with it by simply pretending it never happened, going home for family gatherings is still "toxic." Hannah ultimately created another form of family. She relied on close connections through her church, "I'm in a very small church. We maybe only had 25 people on a Sunday. So, it was like having a whole building full of grandparents that genuinely cared and that were kindhearted people."

Women described combatting the unique isolation of having a disability that people without a disability could not understand. Often their experience of violence seemed to reinforce the message that there was something wrong or inadequate about them. Connections with other individuals with disabilities was affirming and empowering because it allowed WWD to feel like a member of the majority community for the first time in their lives. Members of the disability community experienced and understood the microaggressions, low expectations, discrimination, and hidden labor associated with navigating society and encountering obstacles daily. These shared experiences were supportive and gave women a sense of acceptance and belonging.

Lauren described what a difference even one meaningful connection with another person with a disability made for her. She found friendship online that wasn't available in her immediate community. She said,

I found a friend online who really helped me. He was autistic, too, though neither of us knew it at the time. We were so similar we believed that there must be some kind of quantum entanglement happening. He was long distance, though, so I didn't have any local help.

Emily reflected that cultivating an identity with the disability community was a crucial shift for her confidence. She explained,

I had zero disability pride when I first met him. I didn't want anybody to call me disabled. I just didn't want to identify. And as, you know, I learned more about the community and I got to know people I started getting that pride. And, they gave me a form of self-esteem just in knowing that there wasn't actually anything wrong with me. And so, when he would make comments to me, and they were nasty ones I just started to stick up for myself.

Alicia, a blind participant, also got more involved with a community of disabled individuals when she was obtaining blindness skills training. She recalled how important it was to meet people who believed in her abilities, and who had high expectations of her. She said,

I really was empowered by all of the people there who believed in what I could do. And, um, nobody ever looked at me like I had three heads and it was, I think it was the best. I think it really was the best thing and the real thing that made the healing take off.

Dedication

Counter to prevailing narratives about people with disabilities being innately dependent and vulnerable, women identified factors related to a responsibility to keep going to take care of others who were depending on them. Women articulated a dedication to protect, serve, and support others and illustrated that WWD are integral, responsible, and dependable members of

families, social networks, and their community. Being present and available when people need them and supporting others through difficulties was important to many women in this study.

Dana, a blind woman, explained,

I think because of my self-esteem issue, when I see the same behavior starting with (son), I want to try to cut that off now while he's still young enough. And the only way to teach him how to have good self-esteem is to model that behavior. So I'm trying to figure that out (laughs) and, and work on the negative self-talk and try to change around the positive to show him how to do that.

She explained how being a mother was a key motivator and contributor to her determination to keep going and work on healing. She said, "I think if I had not had a child, yeah, it would be great to not have any permanent ties to my ex, but at the same time I wouldn't have had a reason to get better."

Being a parent drove many of the WWD to make a change. Monica, a woman with a cognitive disability, recalled her moment of clarity when she decided she had to plan an exit from her abusive partner. She told her daughter, "I said okay I want to get you out of here. I told her. 'I'm going to get you safe and then I'm going to get some help.' This was a do or die situation, I told her." Lauren expressed passion for fighting injustices because she is raising an autistic daughter and she is determined to prevent some of the negative experiences she has lived through from repeating in her daughter's life. She said,

The very little I have to give goes to my daughter. She is the happiest child in the world. She is so richly loved and cherished and validated and embraced and respected. I need to live longer so this isn't her one day. I have to fix the world so this isn't her one day.

Many women in this study were dedicated to taking care of service animals or other pets. Emily said, “Honestly, my friends and my cats were the reason to keep going. Because if I wasn't, you know, anything could have happened to them.”

Another component discussed was staying busy with school or work. This activity enabled women to get out of the house and interact with people. Hard work helped to occupy their time and thoughts. Cynthia recalled her work as a teacher was an important factor,

At the time I was teaching special education and my students really were a huge part of keeping me going. They needed me and honestly I needed them more. Knowing they depended on me being there every day kept me going and gave me a purpose for going to work and often on the weekends I would spend endless amounts of time planning activities for them to do, just to keep my mind off of everything else.

Additionally, many women were motivated by the concept of altruism, or giving back. Their lived experience of oppression, attributable both to living with a disability and experiencing violence, gave them purpose, to work towards helping others. Jennifer shared, “ And through this experience I've learned that I either want to be a Deaf advocate or I want to become like a, I don't know, a mediator to communication to help the hearing world understand Deaf people and Deaf autism more and oppression against the Deaf community.” Beth, a blind participant, reflected that helping was reciprocal, “I have a cause. Helping somebody else has helped me too.” Diane, a blind participant, who was in very abusive marriage reflected, “I learned from it and I've learned how I can help other people in the future who find themselves in similar situations. So, I think I'm a good resource for people.”

Many WWD decided to pursue careers in helping professions such as social work or psychology. Lauren is building a nonprofit. “I plan to just keep building an empire of platforms for autistic people to report people for being abusive. The truth is all we have.”

Healthy and Helpful Outlets

Another prominent theme shared was the importance of finding ways to work through their feelings by journaling, exercising, meditating, praying, and enjoying nature. Women explained that they learned they had to take care of themselves and their needs to be able to be there for others.

Physical activity offered important benefits, including allowing women to feel physically strong, building their confidence, and allowing them to process complex emotions. Sonia said, “Dance was my source of joy. It helped me build a healthy relationship with my body as my disability kept making me feel mad at my body. Dance was also how I released my emotions. Tap and hip-hop specifically were great styles for releasing anger.” Whitney, a woman who is Deaf-blind, credited physical activity with building her confidence. “In my 50s I participated in Tae Kwan Do, a self-esteem and physical strength booster. I made it to the Recommended Black Belt level.”

Writing and journaling were important to women’s self-expression, and emotional healing. Many women discovered they were skilled writers and learned that writing could also be a tool for them to reach others. Olivia is a Deaf-blind woman who explained, “Writing the blog gave me a voice. It let me reach out to other people who might be going through the same thing. Or it could

help spread awareness about different topics of my life. At some point when I was writing the blog, I don't know exactly when, I stopped thinking of myself as a victim. Now I'm a survivor.”

Several women described how their spirituality was important. Some women, as described, were involved in their local communities of faith, while other women described a more individualized spirituality. Meredith explained that due to a lack of available transportation, she was not always able to worship at church. However, she explained, “I've always had to have my own ability to be spiritual on my own. And yes, a lot of praying and just meditating and yeah, I've always done that. “ Monica survived years of violence and verbal and emotional abuse. Her ex-husband and his family members stalked and frightened her, destroyed her personal belongings, and spread lies to discredit her. She talked about trying to find peace,

Only thing that was calming was I need a place where I can pray, a place where I knew nobody was watching. The battering and the stalking and the slandering, you know, all those words and the things that he had with his money, I was just nothing compared to all that. You know, and all these people cheering right on with him. And you know, I would have to go someplace and I'd have to tell myself over and over again, ‘Nope that's not true. Nope that's not true. This is what you say about me.’ This is what you say. You say ‘I'm your child.’ You say ‘I can do this,’ you know, and reminded him, remind my creator to help me.

Several participants talked about working through their experience and finding validation and healing with support groups and mental health services. Sharing commonalities with other individuals helped women to interpret their own experiences and change their self-blame and self-perceptions. Dana found a domestic violence support group that was safe and accessible. Police patrolled the meeting, the group offered a sliding fee scale, and the book the group used to guide discussions was available as an audio recording. She explained how pivotal the group was in helping her. She said “I learned an awful lot in the beginning and learned that I wasn't just

making things up. I really was in an abusive marriage. Um, but it also showed me the psychology behind it and how to put things in place for my and my child's safety without him (husband) knowing what I was doing.”

Other women discussed methods for navigating and negotiating to attend counseling or support groups. Whitney explained that she selected her therapist based on proximity to the fixed bus route. Isabelle, a blind woman, described that she was thankful to access a counselor in high school, but she would have preferred to access counseling online, through telehealth, because she had to rely on her family to drive her to appointments, and she wasn't always able to attend consistently. Amber has a mobility impairment and suffered with shame because her son was abusive. She explained how she started to get help through Adult Children of Alcoholics. She described, “Like, oh my God, somebody else knows what I'm talking about. They know how I feel. I'm not crazy. Somebody else has experienced that. And that was the beginning of me being around people and opening up and talking about things.” Kelly, a Deaf-blind woman with minimal useable hearing and vision, agreed that connecting with 12-step programs provided important support and insights. She said, “The 12 step program helped me the most. And, um, I would actually, maybe not necessarily the sponsors, but, um, maybe just the other people that I talked to.” However, the group did present certain challenges that she had to negotiate. She reflected,

I really had to continually advocate. And in fact, a person who continually reminded people in meetings and otherwise, especially in meetings, reminding people to speak up ends up being rude and nobody wants them around. People just get aggravated.... So the end result was I would advocate for people to speak up as long as I felt comfortable doing it, but mostly I just sat, at least once or twice, I would just sit through meetings, try to read lips, try to follow

what was going on, in bits and pieces of what was said. And after a while, choose to stay home.

Women who had the opportunity to find counselors who were either disabled, or who were familiar with disability, explained how those experiences were particularly valuable. Diane recalled, “So, my therapist had had experience with disability but she also had experience with domestic violence and was really able to help me sort of work through all of the things emotionally and physically that I needed to do.”

Lauren went through dozens of therapists before she found one who was willing to work with her in a way that was helpful. She explained, “I later found a therapist who did Dialectical Behavior Therapy (DBT)—a neurodivergent therapist. He saved my life. He was simply the person who didn't think I was too much. That was how I found help and hope.”

Two study participants were involved in a support group for victims of crime who are Deaf. They explained that not having to negotiate the usual communication barriers enhanced their experience and ability to share and participate.

Life-transitions also provided new opportunities to access supportive communities. Hannah described an empowering experience in college,

I participated for the first time in a college wide program that's called Take Back the Night. And I think they still have that. And that was the first time I ever spoke openly about what had happened to me, to a group of people that was very supportive. And then after that point I was inspired to go, um, I received help through our campus services.

Thoughts and Behaviors Evolved

Women described how their thoughts evolved over time, which helped to reinforce healthier behavior and meaningful relationships. They discussed the shifts and retraining of their thoughts and actions, as well as the constant work of overcoming patterns of negative thinking and diminished self-esteem from enduring abuse. Cynthia explained, “I have learned that I really can rise above and make changes in my life when I want to and am willing to work towards that change.”

After Alicia took steps to learn strategies for living independently as a blind person, she noticed significant benefits in other areas. She explained,

Part of why I'm, I'm so okay now is the fact that I have really good skills and I know that if something goes sideways or if I'm somewhere I don't want to be, I can leave. Um, I have a lot of tools in my toolbox. I can just leave if I need to. I'm a lot, I'm a lot stronger and I'm just like, my philosophy is what's next?

Diane reflected,

And recognizing the fact that I'm a survivor of abuse like even saying these words has taken me about 15 to 20 years to say. You know, and now the fact that I can talk about it is healing in itself. I remember and it's good to remember but at the same time it doesn't have to be who I am today.

Emily said the adversity made her realize she is resilient: “I never really considered myself to be emotionally strong but that really tested me. And, I made it through. So, I no longer think that negatively. And, I figured if I can get through that I can get through most things.”

WWD described that overcoming patterns of negative thinking and diminished self-esteem requires continuous work. Close friends and mentors were also important to support transformational thinking. Sonia said,

The biggest turning point in my life was meeting my best friend. His persistence in calling me out when I was perpetuating patterns from my childhood or when I was refusing to see my own worth is a large part of what made me start to unlearn bad patterns and to start sticking up for myself.

Kelly agreed that having mentors and friends helped her stay accountable,

I had many, many great mentors who would correct my faulty thinking, who would help me to realize when I was, um, (long pause) when I was blaming others for, for something that I had control of. They helped me to realize how much power I did have over my own life.

Discussion

This qualitative study explored how WWD build resilience during and after exiting violence in a rural setting. To this date research on disability and resilience has been limited to inquiring about how individuals with disabilities remain resilient despite their disability-related challenges.

The current research helps to create a more robust understanding of resilience mechanisms among women with disabilities. Findings underscore that women's lives encompass more than their disability; they lead multi-faceted lives and fill many important roles. Women indicated that new techniques and behaviors, such as connecting in interdependent and supportive relationships, finding ways to promote physical and mental health, and giving back and supporting others going through difficult situations, were a necessary part of beginning to heal from abuse.

Women highlighted several important dimensions they utilized to build resilience. The prominent themes support the social-ecological model of resilience; personal qualities, interpersonal connections, and access to social resources were key in shifting thoughts and behaviors (Ungar, 2011a). Women's thoughts about themselves and the experience of abuse

evolved over time, a process that other research on violence and resilience has also identified (Anderson et al., 2012; Cran and Barata, 2016; Humphreys, 2003; Senter and Caldwell, 2002).

However, this finding may have added significance in the context of WWD because it confronts and refutes socially ascribed characteristics such as learned helplessness and vulnerability.

WWD in this study learned to reframe their self-perceptions and self-identification from a powerless victim, to a resourceful and determined survivor. WWD articulated an internal drive that is distinctly shaped through their experience of disability. For example, navigating complex service systems and advocating for their rights and needs was an integral and necessary part of WWD's lives; they honed that skillset and relied on that strength when they faced abuse and adversity. The very element which appears to make women vulnerable (their disability) also was fundamental to their ability to adapt and build resilience. This is a unique element of resilience not reported elsewhere in the limited research on violence and resilience. It is possible other marginalized groups employ similar strategies of drawing on personal experiences forged by sociocultural contexts, and future research should explore those processes.

WWD described components of social connectedness which supported transformational thinking and confidence-building. Family, meaningful friendships, and spirituality were important components, which align with previous research on protective factors for survivors of abuse (Anderson et al., 2012; Cran and Barata, 2016). One specific finding in this study is that WWD who were spiritual before experiencing violence remained spiritual, while those who did not consider themselves as spiritual before typically built resilience through other mechanisms; the adversity did not increase spirituality among those who were not previously spiritual or religious.

Personal networks were essential to many women in the current study's healing process. Sharing experiences, receiving validation, and being a friend to other women going through similar circumstances was fundamental to women's recovery and rediscovering confidence. WWD in the current study also described that being accountable, responsible, and dependable to family, friends, or a church community gave them strength. Being essential supports to the important people in their lives gave participants pride. Care and reliance in these relationships were reciprocal and mutual.

Another important finding is many women gained strength and support by connecting with other people with disabilities and cultivating their disability identity. Women shared strategies that may not mirror normative adaptation, but that were significant to their pathways to resilience as disabled women in rural areas. For example, women described becoming more outspoken and less tolerant, which resists the stigma of WWD and traditional gender roles in rural areas, where women are perceived as demure and dependent. Furthermore, in order to connect with other disabled people, some WWD relied more on virtual connections through on-line discussion groups, which served as "lifelines" for WWD living in rural areas. These strategies are important and contribute to women developing a collective identity. WWD reported identifying as a member of the disability community was affirming and granted them a sense of belonging and acceptance.

WWD also demonstrated support for the concept of "altruism born of suffering" wherein the experiences of discrimination and oppression attributable to sexism and ableism, combined with the experience of violence contributed to a desire to help others and give back (Staub, 2005; Staub and Vollhardt, 2008; Vollhardt, 2009). Anderson and colleagues (2012) noted similar

motivations among women in their study who wanted to help “break the cycle of violence” and “speak the unspeakable” through supporting other abused women. This concept of healing through giving is an important contribution to studying disability and violence.

Women not only need access to resources; they also need opportunities to be a resource for others. WWD may be especially effective as peer navigators or peer counselors. Survivors with disabilities could be important partners in developing interventions and preventive techniques to raise awareness of abuse and serve as a bridge to the disability community in particular. Service providers (health care, legal systems, and domestic violence/victim services) should consider ways to collaborate with WWD in both volunteer and paid positions. For example, among all state-wide domestic violence coalitions, only a small number have a taskforce or committee for survivors with disabilities. Thus, the lens of disability is missing in the majority of violence and victim services across the country. Every state should engage survivors with disabilities to inform targeted and inclusive prevention and intervention programs.

Other techniques WWD relied on were contingent on availability and access to resources such as exercise groups, support groups, training specific to building independence, securing necessary adaptive equipment (such as hearing aids or home modifications to increase independence), and counseling. These components helped women to feel physically and emotionally strong. The notion of people with disabilities identifying ways to engage in self-care for their emotional and physical well-being is not widely recognized in existing research, and it is an area that deserves future study. Nosek and colleagues (2004) studied how WWD define and maintain health, finding both social support and emotional wellbeing to be essential contributing factors, concordant with findings from the current study.

In rural areas where transportation is a well-documented barrier, access to these important services may be limited. There is an opportunity to build on telehealth and other virtual strategies to make services and groups more accessible and minimize the low resource and transportation barriers in rural areas. Furthermore, awareness of domestic violence services, support groups and self-help programs, and opportunities for physical activity need to be shared through different channels to reach and welcome WWD.

Strengths and Limitations

This study is the first to examine resilience among WWD survivors of violence, relying on their own insights and interpretations to inform future interventions. Rigorous qualitative techniques allowed a richly detailed narrative to emerge to help build an in-depth understanding of the subject. The research involved strategies to strengthen study validity, including redundancy and maximum variation techniques to sample for heterogeneity (Lincoln and Guba, 1985; Marshall and Rossman, 1998; Patton, 2002). This strategy engaged and included women with diverse disabilities, including sensory, cognitive, and physical impairments. The rationale for gaining a heterogeneous sample is that any commonality found across a diverse set of cases is more likely to generate transferrable themes than a commonality found in a homogenous set of cases (Robinson, 2014).

To enhance transparency, we created a code book, which included a list of the codes as well as specific definitions and examples for each code. The codebook also provided an audit trail, illustrating changes to codes throughout the analysis process (Lincoln and Guba, 1985; Bowen, 2008). We also used member checking (also referred to as respondent validation) to increase the trustworthiness and confirmability of data (Lincoln and Guba, 1985; Creswell and Miller, 2000).

This technique uses the participants' own words through direct quotes in the research findings, and shares transcripts and concepts with a selection of participants to confirm accurate and appropriate understanding and representation of their experiences.

One limitation of this project is findings from this qualitative study are not generalizable to other populations (such as men with disabilities or rural women without disabilities experiencing violence). However, this research yielded important concepts and contributes to an understanding of this phenomenon to launch additional research, and allow for logical, transferrable inferences (Sandelowski, 1996; Small, 2009; Ungar, 2003).

Recruitment methods likely led to an oversampling of highly educated women with connections to activist disability communities, with politicized Deaf and disability identities. Sharing this study announcement widely on various platforms, including social media, may have helped to remedy this problem because individuals did not need an affiliation with an agency or organization to view the announcement. An additional potential limitation is that complicating factors surrounding disability and violence, including stigma and shame, created recruitment challenges. The study flyer used affirming language, and we shared study goals before the interview to help women understand the value of their personal experience. We also reached out to well-respected and trusted leaders in the disability community to share the study information on our behalf. Though we made special efforts to reach minority disability populations, such as Latinx and African American divisions of prominent disability organizations, the majority of our participants were white.

Confidentiality is of special concern in rural areas and Deaf culture and disability communities (Lightfoot and Williams, 2009a; Logan et al., 2008). We shared our precautions with participants, such as storing transcripts on password-protected computers, assigning participants a unique identifier, and removing any names or places from transcripts. We also obtained a waiver of written consent as an extra measure to protect participant privacy.

Both the disability community and rural communities have reasons to resist participating in research studies because often researchers who are not members of the community study these populations. Interviewers who do not have a disability may cause mistrust and psychological distancing (Lightfoot and Williams, 2009a; Nosek et al., 2001b) Similarly, rural settings have had negative experiences when research on their community presents and circulates mostly negative reports in media (Logan Walker, Shannon, and Cole, 2008). One strength of this study is the lead author is a woman who grew up in a rural community and is a member of the disability community, having a disability herself, as well as twenty years of activism through disability organizations. Matching characteristics with participants is a recommended strategy when interviewing marginalized populations (Logan et al., 2008; Brown, Long, and Milliken, 2002).

Conclusion

This study contributes to existing research on resilience by exploring the contextual specificity of how WWD overcome violence-related adversity. WWD illuminated dynamic personal, interpersonal, and sociocultural pathways of resilience which helped them recover from their experience of violence. Women discovered personal strengths that helped build confidence and

self-efficacy. Participants relied on reciprocal, mutually supportive connections with family and friends, including meaningful and affirming relationships in the disability community. Lastly, WWD cultivated strategies to process trauma in ways that supported their physical and psychological health. Women used individual, private techniques, such as meditation or journaling, as well as external actions, working with community resources such as exercise classes and support-groups.

This research also uncovered new components of resilience not previously reported in the literature. WWD identified personal qualities honed by the lived experience of disability; the motivational element of dedication to healing in order to take care of and support others; and ‘altruism born of suffering’ the desire to give back to help others in challenging circumstances. These findings are significant because, while illustrations of WWD as vulnerable, dependent, and lacking agency are widespread, this study describes personal attributes and social connectedness counter to this narrative. Women expressed viewing themselves as a resource and a help to other women, a position society fails to acknowledge.

Study findings can be applied to clinical practice and programs designed to support WWD recover from violence. Conceptualizing resilience as a process that women and service providers can work together to foster in various ways will support growth and recovery. A resilience framework may also help to change WWD’s perception of control by inviting them to define and adapt internal and external strategies that will best suit their lives. Providers could facilitate introductions to individuals or groups with shared experiences; meeting other individuals with disabilities and meeting other survivors of violence were both particularly supportive and validating experiences that helped WWD to realize they were not alone. Finally, WWD

themselves may be an important and overlooked resource for helping other women and improving inclusive program design and delivery.

Physical health care and other forms of self-care are neglected but potentially useful avenues for cultivating resilience among WWD with histories of violence. Service providers need to promote support-groups and other self-care classes offered through domestic violence shelters or community services, and ensure resources are inclusive and accessible for WWD. Providers should partner with local disability service agencies and disability-consumer organizations for guidance on how to create inclusive and accessible environments.

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JOURNAL ARTICLE 2

“They Didn’t Ask.” Rural Women with Disabilities and Experiences of Violence Describe Interactions with the Health Care System

Target Journal: Qualitative Health Research

Abstract

The Institute of Medicine and the United States Preventive Services Task Force recommend clinicians screen women for abuse. Women with disabilities are at risk of experiencing multiple forms of severe and prolonged violence, yet guidelines for screening this population are unclear, screening rates are historically low, and screening tools may be inadequate to capture disability-related aspects of abuse. We conducted qualitative in-depth interviews with 33 rural women with diverse disabilities and experiences of violence. They described overarching health care provider and system factors that influenced their trust and confidence in health care delivery as an avenue to support their safety. Women described ways their interactions with the health care system during their experience of violence were a missed opportunity for identifying and responding to their abuse and connecting them with resources. We conclude with policy and practice recommendations based on women with disabilities’ perspectives and insights.

Background

Violence against women is a grave public health problem with a myriad of harmful consequences to women’s physical and psychological health. Approximately 36 million women in the United States have a disability (Zhao, Okoro, Hsia, Garvin, and Town, 2019), placing

them at increased risk for experiencing violence in many forms and in various contexts. An analysis of the 2010 National Intimate Partner and Sexual Violence Survey found that, compared to women without disabilities, Women with disabilities² (WWD) were significantly more likely to report experiencing each form of violence measured, including rape, sexual violence other than rape, physical violence, stalking, psychological violence, and controlling reproductive health (Breiding and Armour, 2015). This is consistent with smaller-scale surveys, which also suggest women with disabilities may experience more severe and prolonged violence (Brownridge, 2006), from multiple perpetrators including partners, family members, caregivers, and health care providers (Curry, et al., 2009; Powers, Curry, Oswald, and Maley, 2002; Saxton et al., 2001). In addition to experiencing typical modes of violence (physical, sexual, emotional), WWD are often also subjected to abuse and exploitation related to their disability. For example, abusers may damage tools necessary for independence (such as hearing aids, canes, or mobility devices); refuse to help with daily tasks (bathing, feeding); manipulate medication (withholding or overdosing); or isolate women (leaving women in bed or refusing transportation) (Nosek et al., 2001; Saxton et al., 2001). Finally, components of socioeconomic status, living arrangements, and social and geographic isolation may compound vulnerability and impede the securing of services and safety for women with disabilities (Nelson and Lund, 2017; Nixon, 2009; Nosek, Hughes, Taylor, and Taylor, 2006; Thiara et al., 2011). The prevalence of

² In this article, the authors alternate between the terms “women with disabilities” and “Deaf/disabled women.” This is intentional, to acknowledge important disagreement about language choice. First, some Deaf individuals do not identify as disabled, while others identify as both Deaf and disabled. Second, while social science researchers and other professionals encourage using person-first language “women with disabilities”, many in the Deaf and disability communities strongly prefer identity-first language “disabled women”, to recognize disability as a valued cultural and political identity.

disability increases stepwise with rurality; the highest rates of people with disabilities reside in the most rural locations (Zhao, et al., 2019). Furthermore, research suggests violence in rural settings is at least as prevalent as urban areas (Edwards, 2015), and some methodologies reveal small towns may have the highest prevalence of violence against women (DuBois, Rennison, and DeKeseredy, 2019). Therefore, women with disabilities enduring violence in a rural setting may experience cumulative risk with limited accessible channels for accessing help, placing them in danger and threatening physical and psychological health.

Despite prominent assumptions, presence of a disability is not synonymous with poor health; rather, a range of biological, behavioral, structural, and social factors (Nosek et al., 2004) determines health. WWD have poorer access to health care and are more likely to have unmet preventative health care, medical, dental, and prescription needs than women without disabilities (Horner-Johnson, Dobbertin, Andreson, and Iezzoni, 2014; Iezzoni, Kurtz, and Rao, 2016; Mahoudi and Meade, 2014; Marrocco and Krouse, 2017; Parish and Ellison-Martin, 2007; D. Smith, 2008). People with disabilities face financial barriers to health care services more often than their non-disabled peers. This is partially attributable to higher medical expenses related to their disability; regardless of insurance status (Hall, Kurth, Gimm and Smith, 2019; Iezzoni, 2011). Access barriers in rural communities are even more pronounced due to limited accessible transportation, few specialists, providers' lack of awareness and training about disability, and out-dated inaccessible facilities (Horner-Johnson, Dobbertin, and Iezzoni, 2015; Iezzoni, Killeen, and O'Day, 2006). These widely acknowledged access barriers also affect women with disabilities who experience gender-based violence (emotional, physical, or sexual abuse rooted in a power disparity). Studies indicate women with disabilities who have experienced violence

are 35% less likely to report their health as excellent or good and 58% more likely to report an unmet health care need due to cost than their disabled counterparts not experiencing violence, accounting for sociodemographic factors (Barrett, O'Day, Roche, and Carlson, 2009).

Experiencing abuse also places WWD at greater risk for health complications, potential loss of independence, or inability to work (Hassouneh-Phillips, 2005; Powers et al., 2002; Saxton et al., 2001; Thomas, Joshi, Wittenberg, and McCloskey, 2008).

Given the complexities at the intersection of violence, disability, and health, informed strategies for recognizing and responding to abuse among WWD are crucial. Consistent with other marginalized groups that experience disparities, disability identity may encompass cultural components clinicians need to be aware of when engaging patients with disabilities (Eddey and Rodey, 2005). Culturally competent providers and organizations deliver health care services that are sensitive to social, cultural, and linguistic contexts of patients and align with patients' expectations and values (Haegele and Hodge, 2016). Furthermore, access and communication accommodations are legally required under the Americans with Disabilities Act (ADA).

Research on women with disabilities' interactions with health care highlight patterns of invalidation, including clinicians taking over care without patient input, and treating women as a case of disease rather than a complete person (Hassouneh-Phillips, McNeff, Powers, and Curry, 2005). Clinician assumptions about people with disabilities' lives and abilities may jeopardize health care experiences, patient trust, and health outcomes. Often clinician misconceptions are shaped by societal stigma surrounding disability (Iezzoni and Long-Bellil, 2012; Shakespeare, Iezzoni, and Groce, 2009).

Research on physician perceptions and engagement strategies regarding patients with disabilities illuminates troubling mismatches with disabled individuals' self-defined needs (Agaronnik, Campbell, Ressalam and Iezzoni, 2019a; Drainoni et al., 2006). For example, a recent study found physicians bypass ASL interpreters or auxiliary aids, instead using uninformed communication techniques with Deaf or hard of hearing populations; physicians reported writing notes, expecting patients to lip read, altering pitch, speaking slowly, and 'shouting' into the patient's 'good ear' (Agaronnik et al., 2019a). Physicians in the same study admitted that, based on their perception of a patient's ability to make decisions, they often opt to communicate with someone accompanying the patient rather than engaging the patient directly (Agaronnik et al., 2019a). Physicians also reported feeling pity for patients with disabilities, considering them a challenge to work with, and assuming that certain services (particularly related to sexual and reproductive health) were inappropriate and unnecessary (Agaronnik, Campbell, Ressalam, and Iezzoni, 2019b). Eliminating stigma about individuals with disabilities in health-care systems necessitates a multi-layered approach including educating health care professionals about the social-ecological context of disabilities (beyond the medical model), improving communication, removing environmental barriers to care, and increasing compliance with all ADA mandates (Iezzoni, 2016).

Health care providers are uniquely positioned to be valuable resources for women with disabilities by addressing safety needs and connecting women to key services. Acknowledging the significant health consequences of violence against women, the Institute of Medicine (IOM) recognized clinicians could be one key to safety and recommended all women should be screened and counseled for violence in the health care setting (Institutes of Medicine, 2011). The

United States Preventive Services Task Force (USPSTF) concurred with the IOM's recommendation; the USPSTF recommended health care providers screen all women of reproductive age (18–46) for lifetime exposure to intimate partner violence (IPV), and provide appropriate follow-up (Curry et al., 2018; Moyer, 2013). The USPSTF provided a B recommendation for women of childbearing age and an I statement for abuse in older or vulnerable adults (Curry et al., 2018). The grade B recommendation means “high certainty that the net benefit is moderate or there is moderate certainty that the net benefit is moderate to substantial”, while the I statement “concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined.” (USPSTF, 2018). The legal definition of “vulnerable adult” varies by jurisdiction but the USPSTF recommendation defines the term as ‘a person who is or may be mistreated and who, because of age, disability, or both, is unable to protect him or herself’ (Curry et al., 2018). The Health Resources Services Administration's (HRSA) Women's Preventive Services Initiative extends their abuse-screening recommendation to women of all ages (including adolescents), on an annual basis (HRSA, 2017). The Affordable Care Act (ACA) requires private plans and Medicaid expansion programs to reimburse physicians who provide abuse screening and brief intervention services as part of women's preventive care, at no additional cost to women.

National health professional associations, such as the American Medical Association, the American Nurses Association, and the American College of Obstetricians and Gynecologists, have created best-practice guidelines for contexts and techniques for screening and counseling following abuse disclosure (American Medical Association, 1992; Ghandour, Campbell, and

LLOYD, 2015; ACOG, 2012). Best practices regarding abuse screening recommend screening periodically and in private (ACOG, 2012; McCall-Hosenfeld et al., 2013). Disclosure of abuse necessitates an immediate discussion. Next steps should assess the safety of the patient and other household members, ascertain abuse severity, and collaborate to develop a safety plan if violence escalates (Ghandour et al., 2015; ACOG, 2012). Research supports providing information about violence resources for all patients, regardless of disclosure. This strategy is associated with increased patient satisfaction (McCaw and Kotz, 2005).

The most updated systematic review found that routine screening rates are inconsistent and generally low. The range of clinicians reporting “always” or “almost always” screening for partner violence ranged from 2% to 50% (Alvarez, Fedock, Grace, and Campbell, 2017).

Importantly, research findings indicate that a high majority of violence victims (between 70 percent and 87 percent) reported they would not mind, and would prefer, if health care providers screened them for violence exposure (Alvarez et al., 2017). Research on screening in rural communities is limited, but existing studies concur with other findings that barriers to disclosure for women include stigma, minimal support, and lack of education (Hill, Cantrell, Edwards, and Dalton, 2016; McCall-Hosenfeld, Weisman, Perry, Hillemeier, and Chuang, 2014).

The preventive taskforce’s updated recommendations do not provide explicit guidance for screening women with disabilities of childbearing age. Using the term ‘vulnerable adults’ seemingly relies on clinician perceptions and judgment to determine if a woman’s disability (visual, hearing, cognitive, or mobility impairment) designates her as part of the ambiguous ‘vulnerable’ group. The taskforce did not have enough evidence to recommend a net gain to screening vulnerable adults. As Agaronnik and colleagues reported (2019b), some physicians

assume WWD do not need sexual and reproductive information and services. This impression of disabled women as nonsexual also means it is unlikely physicians holding these beliefs would consider the possibility of a disabled woman experiencing intimate partner violence, or the importance of screening this population for abuse. Studies suggest only about 15-21 percent of WWD report a health care provider has ever screened them for abuse or initiated a discussion about safety (M. Curry et al., 2011; Powers et al., 2002). Other studies report WWD are open to screening and appreciate when health care providers have awareness and concern about their safety (Alhusen, Bloom, Anderson and Hughes, 2019; M. Curry, Powers, and Oschwald, 2004). Participants reported it would be most helpful if clinicians asked these questions respectfully and confidentially (Alhusen et al., 2019). Screening for abuse among women with disabilities is an important first step to preventing harm and appropriately treating violence-related health consequences.

Traditional abuse screening tools may not accurately encompass the types of abuse women with disabilities experience; therefore, assessments including questions about disability-sensitive abuse are essential for supporting and serving WWD (M. Curry et al., 2011; MacFarlane et al., 2001). Subject matter experts have developed two abuse-screening tools specifically for WWD, both based on the widely used Abuse Assessment Screen (AAS), which is a two-item tool to assess sexual and physical abuse (Soeken, McFarlane, Parker, and Lominack, 1998). The Abuse Assessment Screen-Disability (AAS-D) adds two items assessing disability-sensitive abuse (i.e., refusing to provide assistance with essential daily activities such as bathing and withholding assistive devices such as a wheelchair) to the original two items on sexual and physical abuse (McFarlane et al., 2001). Research demonstrates that this screening tool performed significantly

better than the AAS when administered to women with physical disabilities. Curry and colleagues (2004) developed a second tool, which they tested with women with physical and/or cognitive disabilities. This tool has eight items, including original items from the AAS about physical abuse and sexual violence, with additional items assessing emotional abuse, financial exploitation, feeling unsafe, having personal needs withheld or neglected, and having access to adaptive equipment restricted or refused (Curry et al., 2004). These instruments represent important progress toward identifying and responding to violence against women with disabilities.

Research suggests that computerized screening techniques are also effective, particularly for addressing and engaging marginalized women as this method enables easier abuse disclosure and minimizes the feelings of judgement (Anderson et al., 2019; Chang et al., 2005; MacMillan and Feder, 2012). In some cases, computer-assisted tools may be a valuable strategy for screening and supporting women with disabilities, particularly when communication barriers prevent a health care provider from asking screening questions in private. Researchers developed and tested an anonymous computer-assisted self-interview Safer and Stronger Program screening tool, which is fully accessible (captioning, audio, and text-to-speech features) and educates WWD about abuse and facilitates disclosing abuse anonymously (Oschwald et al., 2009).

The Rural Safety and Resilience Study (RSRS) interviewed women with disabilities who experienced gender-based violence while living in a rural setting to illuminate their process of learning about and accessing help and services. Gender-based violence may include physical or sexual violence, emotional abuse, stalking, and other controlling behaviors. This umbrella concept was intentionally selected to expand the understanding of violence to include

acquaintances, family members, caregivers, and strangers, in addition to learning about partner violence. WWD in this study interacted with health care providers and services during and after exiting violence. In sharing their experiences, participants contribute to a small body of research surrounding health care screening for abuse and responding to signs and disclosures, among female patients with disabilities. WWD's experiences will further the understanding of how current professional guidelines concerning cultural competencies and best-practice recommendations related to screening for and responding to abuse are working in local communities for women with disabilities. Additionally, participant insights highlight effective provider and system qualities and recommend improvements to the health system response to women with disabilities experiences of abuse.

Methods

In this exploratory qualitative study 33 WWD from rural settings in the United States completed one semi-structured open-ended interview. WWD discussed their experiences learning about and accessing services to support physical and mental wellbeing and a safe exit from a situation of gender-based violence in a rural community. Interviews were conducted over a six-month period, from June 2019 through December 2019. This study obtained approval from the University of Texas Health Science Center at Houston's Institutional Review Board.

Recruitment Strategies and Sampling

We posted study announcements in ways that allowed women to initiate contact with the research team, a best practice to ensure safety and avoid coercion (Hardesty, Haselschwerdt, and Crossman, 2019). We distributed flyers to disability-related agencies, and through disability

consumer organizations. We reached out to faith-based initiatives who provide accessible services and work with disabled church members. We also shared the study announcement with violence and disability services programs, using the VERA Institute on Justices' online directory. Additionally, we posted the study announcement on various social media platforms. This study also used the snowball sampling method, asking participants to share study contact information with their personal networks of disabled women.

Eligibility for this study required being an adult woman (aged 18 or older), who (1) had a disability (physical, sensory, or cognitive); (2) had the disability during her experience of violence; (3) experienced violence at least one year before the study while living in a rural community when violence occurred; and (4) did not have a significant intellectual difficulty, or problem understanding the English language which might have impaired their ability to comprehend and respond to interview questions. While we did not screen out people with mental illness or cognitive disabilities, their participation was voluntary and initiated only by potential participants themselves responding to the study announcement. Interviewees received a small incentive to compensate them for their time and expertise.

Thirty-three women with diverse disabilities (sensory, cognitive, and physical) provided interviews for this study. We concluded sampling when themes became redundant (saturated); additional interviews were not likely to generate new information (Crabtree and Miller, 1999). Women interested in participating used contact information from the study flyer to email, text, or call about the study. The research team shared and discussed a prepared consent form in the person's preferred, accessible communication format. The form outlined and explained the overall research objectives, stated that interviews would be recorded, discussed potential risks

and benefits of the study, and emphasized the individual's right to withdraw at any point. As an additional step to protect confidentiality and remove any accessibility burdens (such as a blind participant needing sighted assistance applying a signature), this study obtained a waiver of written consent. After participants reviewed consent forms and had any questions answered, the lead author scheduled an interview. We used an interview guide, covering four broad topic areas (help-seeking; resilience; barriers/facilitators to access; and policy expectations and recommendations).

The lead author conducted individual interviews by phone and electronic communication, expanding reach and enabling higher diversity (Holt, 2010; Hunt & McHale, 2007; Novick, 2008). In the case of a telephone interview, once the recording began the interviewer did not use the subject's name to protect privacy. The lead author conducted all interviews. She began each interview by confirming it was a convenient time to talk, garnering permission to record the conversation, and providing a summary of the study. Interviews ranged from approximately 45 to 90 minutes. The research team assigned each participant a pseudonym for all write-ups of research findings. Women also completed a demographic sheet at the time of their interview, either through email or orally on the phone.

For Deaf or hard of hearing participants, and participants with cognitive impairments, the interviewer consulted the participant about their most preferred communication mode. In response, eight interviews were conducted via a series of electronic written interview exchanges to accommodate participants' stated communication preference. The interviewer sent small batches of questions at a time and reviewed and responded to answers to tailor questions throughout the interview (Hunt & McHale, 2007; Ison, 2009). This technique more closely

mirrors oral interviews because it facilitates probing and reflexivity (reframing to confirm understanding). The remaining 25 phone interviews were audio-recorded.

Among participants, 12 had a physical disability that limited mobility; nine were blind; four were Deaf; five were Deaf-Blind; and seven had cognitive impairments. Four participants had multiple physical, sensory, or cognitive disabilities. The severity of participants' impairments varied. For example, the category "Deaf-Blind" includes both women with severe hearing and vision loss, ranging from some useable hearing or vision to no useable vision or hearing at all.

Participant ages ranged from 19 to 72, with most participants in their 30s and 40s. Twenty-four women were white; three women were Black; two women were Latina or Hispanic; two women were Native American; one woman was Pacific Islander; and one woman was multi-racial.

Most participants (23 of 33) were not currently in a relationship. Eighteen women had children. Education levels ranged from some high school to holding a master's degree. Eighteen women worked at least part-time. Three participants were students, and two women were retired. The remaining 10 participants were not currently working, either by choice or because they were having trouble finding employment.

Data Collection and Analysis

Interviews were transcribed verbatim to be attentive to the specificity of language and context. All personal identifiers (names, places) were removed to protect confidentiality. The interviewer also recorded field notes to include additional observations and context to build thick descriptions. Analysis began with open coding after reading transcripts multiple times. Next, codes and themes were developed and refined, to identify patterns and connections, through a

process of content analysis (Hsieh and Shannon, 2005; Vaismoradi, Turunen, and Bondas, 2013). The researcher created working definitions for each code/theme. Text that did not fit under predetermined coding generated additional new codes. Iterative coding organized text into manifest (explicit terms or concepts) and latent (underlying, implicit terms and meanings) to build code categories and resulting themes (Morgan, 1993). We created a codebook to maintain a record of how codes and themes evolved. We also performed member checking, sharing quotes and themes with select participants to increase trustworthiness. Finally, the researcher discussed themes and shared supporting quotations with another researcher familiar with the subject to clarify and confirm interpretation and analysis.

Results

An overwhelming majority of participants (26 of 33) indicated they experienced more than one type of violence (either physical, sexual, psychological, or disability-related abuse), with twenty-four women describing abuse related to their disability. Twenty-four women endured abuse for years; three women reported abuse lasting for months; and six women reported one incident of violence (the women did not know the perpetrator in five of these situations).

Women in this study interacted with the health care delivery system during and after their experiences of violence. Three important themes and five subthemes emerged relating to these interactions. Women described overarching health care experiences that shape trust and expectations, including clinicians' perceptions of disability, health system responses to disability, and health care policies that affect disabled women's day-to-day experiences and safety. The second main theme women discussed was missed opportunities related to their experience of

violence and interaction with the health care system, including inaccessible or absent screening techniques, and discounting abuse or failing to respond to signs of abuse with appropriate referrals. Finally, the third theme, positive and supportive care, identified supportive and appropriate clinician responses to women's experiences of violence or abuse.

Overarching Health Care Experiences

Clinician perceptions of disability

Interactions with health care providers influenced women's trust and confidence levels in the health care system as an avenue to help support healing and safety. Most women in this study admitted they did not believe their health care provider knew about disability or how to work with someone with a disability. In some cases, women felt that providers were willing to learn. In other situations, physicians' perceptions diminished women's trust and confidence in the health care system. Lauren is an autistic woman who described multiple problems with health providers, stating "I tell doctors I'm autistic and they tell me 'Good job' like a two-year old and pat my back for filling out a form. They interrupt me. They see my notes (accommodations for if I go mute) and just cut me off with, 'I don't have time for any of that.'" Lauren also described how doctors "gaslight" her and ignore her symptoms, experience, and needs. She concluded, "There is literally nothing I can do to be taken seriously." Another participant, Theresa has a mitochondrial disease, which has caused mobility impairment and blindness. She remarked:

It would have been helpful if there was more understanding, um, about my particular disease, um, that because a lot of times they would just assume that my ailment was all in my head. A lot of them assumed that it was psychological and um, that was more damaging than them just saying, 'Oh, I don't know what's wrong.'

Women also explained problems due to few health care provider options in their rural community. Melissa has a mobility impairment and she explained that her local rural doctor's office did not want to certify that she needed handicapped parking. She stated, "He wrote a paper saying, 'Oh, I've seen her around town. She gets around really good in her wheelchair. She goes all over town in her wheelchair.' And he's like, 'Well I don't think she needs handicap parking.'"

Theresa explained when asked if her health care provider knew about disabilities,

No! [Emphatic] I would go there with the group of people that I was with, um, either from the assisted living facility or from the [country residence]. I stayed with the same doctor because it's a small rural place. And, um, so they only have so many doctors that accept Medicaid. Um, and he was abusive. He would, like make people weigh themselves out in the lobby. Um, so everyone could hear what your weight was and then he would make comments to the nursing staff in front of everybody about how so and so gained so much more weight than her and they were not HIPAA compliant.

Sonia reflected, "Honestly, it's hard to think of how to improve a service that didn't exist in the first place. I think having more providers available is the key."

Health System Response to Disability

Most women with disabilities in this study described less than satisfactory exchanges with health care systems. Issues of privacy and respect were key in determining how women felt about their health care. Hannah is a visually impaired woman, who explained,

I don't think that people were trying to be cruel or that they were even trying to be ablest, but it would've been helpful if they would have known just how to help a person who was blind to fill out a form in a way that preserves privacy. We could've just stepped back in another room for a minute.

Rural communities underscored accessibility barriers, such as limited to no transportation options and inaccessible facilities. Often women required someone to accompany them as a sign

language interpreter, driver, or reader to assist with paperwork that the office would not help them complete. In several instances, the individual who accompanied women was an abusive family member or partner, who then was involved in their health care consultation. In some instances, even scheduling appointments was problematic. Jennifer is a Deaf woman, who described the complexity of health care appointments,

It's not like I need an interpreter for this appointment, and then boom, I keep the appointment and the interpreter shows up like magic. Um, you have to make an appointment and then you have to educate them and to remind them to start searching for an interpreter. And so all appointments always take a lot longer because they have to locate an interpreter and coordinate schedules and all of that.

She continued to explain an additional complication, “So we can't really as Deaf people have any kind of emergency or any kind of last second meetings because there's never an interpreter available.”

Women in this study spent valuable time and effort searching for health services to meet their needs. Several women reported they were one of the first persons with a visible disability many clinicians or medical office staff had ever met. Alicia is a blind woman who was sexually abused repeatedly in her teens by a family member. She tried to take care of health care needs when she moved away to attend college. She said, “I think I was the first blind person a lot of them had seen. And they just didn't know how to, how to deal with me even though I was, you know, in college providing for my, you know, providing for myself and I was taking care of myself.”

Women also described the responsibility to advocate and educate health service providers. Diane is a blind woman with hearing loss. She exited a very violent marriage after over a decade of abuse. She has three children. She explained, “A lot of times when I would go in to get help the

fact that I had to not only sort of advocate for myself as a person with disability and I was there as a person trying to get services my first thing was educating them on my disability.”

Emily uses a wheelchair and had numerous health complications during her abusive relationship; her abusive partner was also her primary caregiver. She explained how even health care services designed to reach and support underserved communities lack disability training. She explained,

I mean I even reached out to LGBT Plus community centers and clinics and things like that to see if they have any resources because I do identify as a queer woman. It’s just nobody had anything that was outside of what their main services do. So yeah, they could handle queer issues but they could not handle disability issues.

Health policies supporting safety

For women in the study who rely on personal assistance services (an attendant helps with daily personal care) and medical equipment (home modifications, mobility or hearing aids, hospital beds), the changing landscape of health care and fluctuation of Medicaid Waiver programs in their states made exiting abuse and securing safety more difficult. Emily explained that worries about finding necessary caregiver support kept her in the abusive relationship longer and limited her options once she left. For example, domestic violence shelters would not allow her personal attendant to come in and assist her. Emily finally moved into a hotel for several weeks “hemorrhaging money.” She explained how finding someone to provide necessary assistance right after she left her abusive relationship was a huge stressor,

So, I begged a friend of mine to come over and to assist me helping go to the bathroom and things like that, you know, in tears and she agreed. You know, she agreed to discounted rates for attendant services until I could get back on my feet, get signed up for Consumer Directed Care. And then, you know, I could sign up with her through that and she would get paid for that. But in the

very beginning I was paying her out of pocket and that became an extremely expensive thing, something I could not afford to do.

She explained that training and keeping personal attendants is an ongoing problem, which puts her health in jeopardy:

I've had attendant services for the last four years. And, I've only had one really good attendant, just one. And, she moved away. So, I'm now reaching 15 people I have worked with even for a brief amount of time. Because there's so much turnover, I don't consistently have access to the services I need.

Jan has a cognitive disability. A caregiver sexually abused her. When she confided in her parents, and they reported the abuse together, the caregiver was fired; however, Jan's family later learned that the caregiver was working again in a group home setting. Jan and her mother participated in the interview. They described problems due to low pay for caregiver staff and turnover. The state where Jan lives is trying to limit Medicaid spending, and the result is low wages for caregiver roles, and extremely long waiting lists to access the consumer-directed services program, which give more autonomy to the individual. Jan said low wages cause staff to "come and go," creating a disruptive instability and uncertainty for individuals with disabilities. Jan described finding appropriate care and getting into the self-directed program as "a real battle." Being in the self-directed program allows Jan and her family to hire good and qualified staff, and work with the local Independent Living Center.

State and federal funding for home modifications also support independence and safety. Amber is paraplegic and uses a wheelchair. She experienced abuse by a family member and reported feeling isolated and depressed. She explained how modifications helped her to travel independently in her community, which also allowed her to access important health and community services. Her father purchased an accessible van Amber could drive, but repairing

parts was cost-prohibitive. She said the state Medicaid Waiver program paid to repair her van ramp. She reflected, “I wouldn’t have been able to get around in the community and go to work if I didn’t have that. So the funding being cut from these programs through Medicaid was crucial. And we lost a little bit of our services for a while.” She continued, “So if the funding and the granting of money to these programs to help people with disabilities stay in their homes and get help with their vehicles and paratransit, you know, which is part of that line, without those policies in place, like I would be destitute.”

Women also discussed the complexity of working through a fragmented system to learn about and secure services to help them exit abusive situations and begin to heal, physically and emotionally. Megan has a mobility impairment and went on to work in care coordination. She suggested, “I think that if victim services felt and were treated by health care as more part of the continuum of care that would go a long way and helping survivors, especially those that have chronic health conditions and a behavioral health issue.”

Finally, women pointed out that the intersection of women with disabilities experiencing abuse is not acknowledged or recognized. Beth is a blind woman who works at a hospital now. She described a board with statistics about partner violence, and she noticed there were no statistics about the prevalence among disabled people. She thinks this is key because without that information being shared as prominently as information about other groups (different ethnicities, sexual orientations, etc.), she said hospitals and health care providers will not grasp the problem and will not screen disabled patients for abuse.

Missed Opportunities

Screening Techniques, Absent or Inaccessible

Most women in this study indicated health care providers never screened them for abuse at doctor visits while they were enduring the violence in a rural setting. Importantly, as a course of securing safety, most women in the study (18 of 33) relocated to a new place, often a larger city with more available resources. Several women reported they were screened for the first time after starting over in a new city. Olivia is Deaf-Blind and she explained,

After I left, I had a doctor appointment in (new town). We were filling out the new patient paperwork. Mom read all the questions to me and marked the answers. The last one asked ‘Are you being abused?’ It chilled me to the bone. I never could have checked that box in (previous town). (Ex-husband) filled out the paperwork and acted as my interpreter.

Isabelle is a blind young woman who experienced years of abuse as a child and adolescent. She agreed that in cases where she was filling out paperwork that asked about abuse, she never felt comfortable disclosing because she did not have privacy. The person who drove her to doctor appointments typically filled out paperwork for her. Sonia has a mobility impairment and she reported that she was never screened at her medical appointments, “I was never screened, no. My doctor never once asked my mom to leave the room, so I couldn’t tell them.” Although Emily had many interactions with the health care system, and even necessary trips to the hospital when her health suffered due to the abuse, no one screened her for abuse, identified her situation as abusive, or offered her resources. She concluded, “I think they don’t think about our [disability] community at all. I think that they don’t think that we need these resources too, and it goes back to that stigma that disabled people don’t have sex. So, they can’t get into sexual violence situations because they don’t have sex.”

Women in this study who were raped by an acquaintance did not seek medical assistance, either because they had no way to get to the emergency room, or because they did not think anyone would believe them. Participants who were sexually abused in childhood and adolescence also reported receiving no medical attention. At routine doctor visits, no one asked screening questions or identified or inquired about any injuries in the medical exams. Women who experienced abuse as a child also reported being extremely fearful of child protective services getting involved. They were taught that the agency took you away from your family and often placed you in worse circumstances.

Women acknowledged that disclosing abuse to a health care provider was complex and depended on several factors. Theresa had an abusive caregiver who controlled her living arrangement. She was afraid of adult protective services getting involved if she disclosed her abuse to her doctor, “I didn't want to risk them saying, ‘Well, you can't go home,’ because then I didn't know where I would end up and I didn't want to have a situation like what happened that precipitated all this, which was being placed in the assisted living facility.” Diane was never screened during her abuse, but she wishes she had been. She acknowledged that, if she were screened, disclosing would have been difficult. She explained,

I thought about this a lot because if they had asked, well that would have been fantastic. But if they had asked what would I have said? You know, what I have felt I can say something, probably not. But if I had maybe given them a little bit of doubt about the abuse or the fact that there was abuse maybe they could have asked more questions but they didn't ask.

Jennifer was in a program after her child was born that offered home visits. She explained how her husband thwarted her opportunity to reach out to the nurse for help, “I couldn't be honest. He would be there every single moment if I said anything.”

Discounting Abuse or Ineffective Response

Several women in the study developed other health problems related to their experience of abuse that should have raised red flags, such as depression or major weight changes. One participant developed an eating disorder. Some women went to seek medical treatment related to their experience of violence, specifically. Women shared that they were treated with respect and sensitivity in the emergency department. Deaf women brought a family member who could sign for them until an interpreter arrived. Absent an interpreter, women wrote down their responses and questions until hospitals were able to provide an interpreter. These women reflected if they had not had a family member or friend with them to interpret, they would have had major problems understanding and communicating with health care providers. Additionally, even though women were in the hospital to receive treatment from physical or sexual assault, they did not receive any referrals to connect with other supports, such as mental health counseling.

Women described searching on their own for mental health counseling or support groups. Maya was sexually assaulted in her home and explained she decided to seek therapy to help her process the traumatic event. She said she had to look in the phone book because, “You really don’t see things like that advertised”.

In other circumstances, women spoke to their health care providers about abuse, yet no action followed. Beth experienced multiple forms of partner violence, including abuse related to her disability. In one instance, her abusive partner took her phone away, which had voice over technology, and left her behind a building after hitting and biting her, with no way to contact anyone for help. She explained, “I had more than two healthcare workers that questioned the

validity of my abuse and what had happened to me. And unfortunately, I know it's a problem but I had the expectation that they would believe me.”

Molly is a woman living with multiple sclerosis who experienced repeated psychological abuse from a neighbor. This escalated to physical violence when her neighbor shoved her and Molly fell backwards off her scooter. She went to the doctor for lingering pain related to the incident. She shared, “I made an appointment to see my doctor and to explain the abuse to the local doctor, who just didn't—I have access to the notes. I went in later to see and make sure that she had written down that this person who I named that attacked me at that point and my back hurt. She didn't. She just noted that my back hurt.” Molly's experience of abuse did not fit the traditional form of domestic or partner violence, and her doctor dismissed it.

Proactive and Supportive Health Care

Women said they expected health care professionals to believe them, to take their situation seriously, and to provide help. Women also wanted professionals to understand the complexities of their situations, including fear for their children, and weariness of government involvement which could affect their ability to continue living independently. One woman shared an experience where a specialist health care provider did talk to her about abuse and healthy relationships. Melissa remembered “I talked to my doctors 'cause I was kind of like getting into that 21-year-old adult range or whatever it was a while ago. But um, so they're always talking about like dating and relationship with my, with regard to my disability. So it kinda just like turned into a conversation.” Two important things to note about this helpful experience are that this exchange was, as mentioned, with a specialist who was familiar with disability, and Melissa traveled to a larger city three hours away to see this specialist. Jan located a doctor who was

sensitive and took the time to listen during her appointments. He diagnosed her with post-traumatic stress disorder (PTSD) related to her abuse. Jan described, “He’s very gentle with me.” Though this type of validating connections with health care were minimal in this study, women who did experience the positive interactions reported important health and mental health benefits. Melissa’s doctor talking openly about healthy relationships and sex helped her identify patterns of abuse in her relationship. Effective clinicians also diagnosed and treated PTSD or depression.

Discussion

Women with disabilities routinely interact with the health care system. Women reported clinician misconceptions and their discomfort about disability lowered women’s trust and confidence in the avenue of health care as a support during and after their abuse. The ways in which office staff treated women also affected their perception that their privacy was important, and they would have confidentiality. When receptionists or medical assistance asked women to disclose medical information in open places or announced their medical details aloud in a waiting room, women felt disrespected and violated. Women also shared feeling responsible for educating clinicians and medical staff about their disabilities, a responsibility that was often a burden.

Larger policies, such as the way different states operate Medicaid programs, fund adaptations to make homes more accessible, and distribute funding for caregiver support, also influenced women’s ability to exit abusive situations and secure safety. In some instances, women had to choose between sacrificing essential services and sacrificing their safety from abuse. For a more

comprehensive review of personal attendant service payment policies, see Iezzoni, Gallopyn, and Scales, (2019).

Women described several ways the health system was a missed opportunity for help and safety from abuse. Providers did not screen women for abuse, or women could not disclose because of lack of privacy or confidentiality (a family member filled out paperwork or the doctor never asked their partner or family member to step out during the appointment). Women indicated that they would have been open, and grateful for, screening questions. Often, they wanted to tell someone, but did not know how.

Women admitted that other fears also discouraged them from initiating a conversation about their abusive situations. For example, women who experienced abuse as children under the age of 18 were fearful of child protective services taking them away from their family. Some participants feared adult-protective services removing them from independent living and putting them in a nursing home. In addition, mothers were scared their abusive partners would gain custody of their children. Some women did not recognize or reconcile their experiences as abusive.

Only a few women in the study did initiate a conversation or mention their experience of abuse. Dishearteningly, doctors did not act on this information in any way. Even when women's health was compromised, causing more interactions with the health care system, the health system failed them. Health systems did not connect WWD's symptoms and health complications to experiencing abuse. Furthermore, hospitals treating victims of physical or sexual assault were not prepared to provide referrals to mental health or other victim services. These missed

opportunities meant women either did not acquire these services or were left to try to overcome their own abuse-related shame and stigma and learn about resources independently. This finding identified the importance and need to bridge silos and integrate health care, disability services, and domestic violence resources.

A small number of women in the study reported that health care providers and systems supported their safety and helped them to understand their abuse and receive proper treatment. Women appreciated and trusted their clinicians who were willing to talk about healthy relationships and recognize abusive behavior and associated health and mental health consequences in their patients. They described these health professionals as good listeners who took time for the important discussions. Significantly, these professionals were comfortable with the woman's disability and comfortable talking about her experience of violence.

Policy and Practice Implications

Health policies affect the daily lives of women with disabilities by contributing to or undermining their ability to self-direct their care and maintain independence. Adequate funding for personal attendants, the right and decision-making authority to manage support services, and necessary home and vehicle modifications are key supports to protecting and optimizing health. In the circumstances of women who experience violence or abuse, these services are also essential components to safety. Lack of funding to pay competitive wages for personal attendants or make necessary accessibility modifications may jeopardize health or prolong a woman's necessity to remain in an abusive situation.

The USPSTF found insufficient evidence regarding screening vulnerable populations. The report indicates a vulnerable adult is an individual who “because of age, disability, or both, is unable to protect him or herself.” Including an ability to protect oneself is particularly problematic, since arguably women’s ability to protect themselves partially or even frequently does not negate the fear, danger, and physical and emotional harm that characterizes the abusive situation. Women in the current study had varying levels of activity and functional limitations, yet there was strong support among participants for health-system abuse screening. Given the evidence that some health care providers struggle with understanding the need for sexual and reproductive services among women with disabilities, the taskforce should define the population of concern more precisely and carefully explore and report nuances for both the elderly population and individuals with disabilities (particularly women of child-bearing age). For example, there are important distinctions between a medically frail elderly adult living in a nursing home, and a woman in her thirties with two children who happens to also be blind, or use a wheelchair. The finding in this study that the vast majority of WWD who experienced violence in reproductive years were not screened for abuse suggests that, absent more precise guidance, clinicians are not making distinctions between the elderly population and patients with disabilities. Participants in this study who were abused during childhood and adolescence could have also benefited from screening, as the WPSI guidelines recommend.

Clinicians hold common misconceptions about patients with disabilities, such as not recognizing that WWD need preventive and reproductive health care services. Therefore, it is possible health professionals also assume all WWD meet the fuzzy criteria for “vulnerable adult,” and thus should not have abuse screenings. It is true that clinicians may need to adapt strategies for

screening patients with disabilities. Importantly, however, women in this study indicated they appreciate when health care providers asked abuse-screening questions.

Introducing screening questions may also help women identify abusive patterns and seek help. Many women in the RSRS experienced multiple forms of abuse, including disability-related elements that traditional screening tools may not adequately identify. This finding underscores importance of utilizing research-informed screening tools, sensitive to disability-related abuse, is essential to identifying complex violence (M. Curry et al., 2004; McFarlane et al., 2001). Health systems and professional associations should consult disability consumer organizations at the state or national level to create guidelines and protocols for treating patients with disabilities and respecting their autonomy and privacy. Furthermore, as electronic health records enhance best-practice alerts to prompt clinicians to conduct abuse-screening, systems should also integrate a disability-related screening tool to adequately identify abuse among WWD.

Next, it is critical that all levels of the health care system receive disability-related education and training, from hospital administrators to office receptionists. Several blind women reported they could not access a screening tool if it were part of in-take paperwork because the forms were not accessible. One possible option for correcting this is testing computer-based screening tools for accessibility and incorporating them in patient portals or in the office, giving WWD an opportunity to disclose abuse in private and independently. Researchers have created and tested one such tool in the Safer and Stronger Program (Oschwald et al., 2009).

Strengths and Limitations

First, the scope of this study focused on women who recognized their experience as abusive and made a safe exit. Therefore, recall bias is possible, and women in this sample may have personal and circumstantial characteristics that differ from WWD experiencing current and ongoing violence. Complicating factors surrounding disability and gender-based violence, including stigma and shame, may have hindered recruitment. We made every effort to reach this population through various contact points including communities of faith, disability service agencies and consumer-driven activist organizations, as well as contacting trusted leaders and “connectors” in the disability community to share study information. We also tried to anticipate disability-related difficulties and potential barriers WWD might have learning about and participating in the study. The research team prepared materials in alternative formats (large-print, Braille, and plain language).

Understanding that the Deaf and disability communities often have serious concerns with anonymity and confidentiality, all research-related documents and communications included detailed explanations about measures to protect participant privacy, including password-protected computers, and not collecting written consent, as an extra precaution. The research team also accommodated women’s communication preferences for the interview (videophone for ASL, electronic written interview).

Both the disability community and rural communities have reasons to be hesitant or weary of academic research, due to negative experiences when researchers outside their community “study” them without engaging them as true partners (Logan, Shannon, Walker, and Cole, 2008; Lightfoot and Williams, 2009; Nosek et al., 2001). The lead author, who conducted interviews

for this study, is a woman who grew up in a rural community and, having a disability herself, has twenty years of activism in the disability community. Matching characteristics with participants is a recommended strategy (Lightfoot and Williams, 2009; Logan et al., 2008).

Conclusion

This research project engaged women with disabilities from rural areas to discuss their lived experiences during and after facing violence. Women discussed perceptions and interactions with health care systems both during and following a safe exit from the abusive situation. Women illuminated important gaps in services and emphasized a need for training and education about disability throughout the health care system, as well as raising the reality of abuse among women with disabilities to a higher profile. To be effective providers for WWD, clinicians need to demonstrate cultural competencies related to disability. WWD are open to, and even welcome, clinician screening for abuse; however, it is crucial screenings preserve women's privacy and, if not conducted in face-to-face appointments, are available in an accessible format or tool for women to disclose independently. Screening tools and self-disclosure programs tailored to women with disabilities are important, and the health care system should build on and expand existing work in this field. The health care system could serve as a critical mechanism to identify abuse among WWD, and support their safety, but this will require clinicians, health systems, and health policies to work together to recognize and effectively respond to the complexities of violence in women with disabilities' lives.

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JOURNAL ARTICLE 3

“I wanted confirmation I was okay and that what happened to me was not okay.” Rural Women with Disabilities Share Experiences Accessing Mental Health Care after Experiences of Gender-Based Violence

Target Journal: Journal of Counseling Psychology

Abstract

Introduction: Women with disabilities experience high rates of violence and abuse. Mental health services are a critical component to trauma-related recovery and healing; however, little is known about how women with disabilities access mental health services during and after exiting violence, or about their perceptions of mental health services in this context.

Methods: We conducted 33 qualitative interviews with women with diverse disabilities who experienced violence in rural communities in the United States. We used thematic content analysis to identify major themes and subthemes from the data.

Results: Women described four themes: expectations of mental health services and experience learning about mental health service options (availability), the challenge of finding an appropriate ‘fit’ and therapy approach (acceptability), positive connections with mental health professionals (accommodation), and barriers to maintaining counseling or mental health support due to financial, environmental, or communication barriers (affordability and accessibility).

Discussion: Women with disabilities recommended strategies to make mental health services more available, acceptable, and accessible. They identified training needs throughout the mental

health workforce related to disability, opportunities for including individuals with disabilities more prominently in the mental health workforce, and the necessity to ensure promising tele mental health technological advancements are accessible to individuals with disabilities.

Introduction

Violence against women is a human rights violation, causing victims serious physical and mental health consequences. Over 1 in 3 women in the United States (36.4% or 43.6 million) throughout their lifetime experience sexual violence, physical abuse, or stalking by an intimate partner (Smith et al., 2018). Women with disabilities³ (WWD) face social prejudice, marginalization, and violence rooted in pervasive societal sexism and ableism (Mays, 2006; Nosek and Hughes, 2003). Throughout their life course, WWD experience violence at a higher rate than women without disabilities (Breiding and Armour, 2015; Hughes, Lund, Gabrielli, Powers, and Curry, 2011). Additionally, women with disabilities experience higher rates of violence-related distress, anxiety, and depression than women without disabilities (Dembo, Mitra, and McKee, 2018).

The nature of abuse against WWD is distinct. Researchers and WWD assert that applying the prevailing definition of domestic violence, including intimate partner violence, does not adequately incorporate the contexts related to WWD's experiences (Banks, 2008; Nosek, Howland, and Hughes, 2001; Radford, Harne, and Trotter, 2006; Saxton et al., 2001; Thiara,

³ In this article, the authors alternate between the terms “women with disabilities” and “Deaf/disabled women.” This is intentional, to acknowledge important disagreement about language choice. First, some Deaf individuals do not identify as disabled, while others identify as both Deaf and disabled. Second, while person-first language “women with disabilities” is still encouraged among social science researchers and other professionals, identity-first language “disabled women” is preferred by many in Deaf and disability communities to recognize disability as a valued cultural and political identity.

Hague, and Mullender, 2011). For example, the duration and type of abuse WWD experience is often intensified (Brownridge, 2006) and may exist in a wider context of circumstances (Hassouneh-Phillips and Curry, 2002; Magowan, 2003; Nosek, Howland, and Young, 1997). Abusers could be partners, family members, personal assistants, drivers, or strangers. WWD's abusers may use different coercive or oppressive tactics, such as withholding or breaking medical or adaptive equipment necessary for independence, refusing help with transportation or daily tasks (bathing, toileting, or dressing), or creating barriers to access or communications to prevent a safe exit from the situation (Gilson, Cramer, and Depoy, 2001; Lightfoot and Williams, 2009; Saxton et al., 2001). Disabled women's safety from abuse is also influenced by their socioeconomic status and geography (Nelson and Lund, 2017).

Gender-based violence⁴ (GBV) is an umbrella term, which is broader than intimate partner violence. GBV is rooted in gender inequality, typically between men and women, and encompasses any act or threat of harm, inflicted against an individual's will, embedded in a mismatch in power, (Joachim, 2007; Russo and Pirlott, 2006). Additionally, transgender and gender nonconforming populations are victimized based on gender expression, gender identity, or perceived sexual orientation, thus this violence is also gender-based (Wirtz, Poteat, Malik, and Glass, 2018). Physical violence, sexual assault, rape, stalking, psychological aggression, and financial exploitation are potential examples of GBV (Rees et al., 2011). This definition of violence encompasses a wider context of abuse; it is not predicated on the assumed partner

⁴ In this article we use the terminologies gender-based violence, abuse, and violence interchangeably.

relationship thus it may be a more appropriate concept to apply to research and discussion about violence against women with disabilities.

Evidence suggests social stigma, devaluation, and WWD's own lowered sexual and body perceptions may exacerbate their experience of violence (Hassouneh-Phillips and McNeff, 2005; Nixon, 2009). Additionally, women with disabilities have a narrower margin of health than do nondisabled women. Violence-related injuries may have a significant and cumulative consequence on WWDs' functional ability and overall health (Hassouneh-Phillips, 2005).

Women with disabilities experiencing violence report poorer overall health, and more trouble accessing health care due to cost factors, than non-disabled women who have experienced abuse (Barrett, O'Day, Roche, and Carlson, 2009). WWD experiencing violence also report increased stress and higher levels of depression, compared to women without disabilities, after controlling for demographic factors (Dembo et al., 2018). Particularly in rural and underserved areas, women with physical disabilities, and women with sensory impairments (visual or hearing impairments) report a higher prevalence of depression than nondisabled women (Armstrong, Surya, Elliott, Brossart, and Berdine, 2016; Hughes, Swedlund, Peterson, and Nosek, 2007; Hughes, Robinson-Whelen, Taylor, Peterson, and Nosek, 2005).

Mental health services can be an important aspect of women's safety from violence, and an integral part of their healing process. There is a shortage of comprehensive behavioral health services for mental illness, substance use, and other psychological conditions across the country, but particularly in rural communities (Andrilla, Patterson, Garberson, Coulthard, and Larson, 2018), where socioeconomic and cultural components also contribute to higher rates of depression among rural women (Simmons, Braun, Charnigo, Havens, and Right, 2008). Barriers

to accessing mental health care in rural areas may include lengthy travel distances for patients and providers; minimal or no public transportation options; high rates of uninsured and underinsured residents; and stigma surrounding mental health needs and services (Gustafson, Preston, and Hudson, 2009). Rural settings also lack specialists to serve diverse populations including individuals with disabilities (Iezzoni, Killeen, and O’Day, 2006). Research also demonstrates that, compared to urban areas, individuals with mental illness (including serious mental illness diagnosis) in rural areas have fewer visits with mental health professionals, even when they are receiving medication to manage their mental health (Kirby, Zuvekas, Borsky, and Ngo-Metzger, 2019). However, one encouraging new study comparing behavioral health staffing at community health centers in urban and rural areas found that from 2013–2017 the overall staff-to-patient ratio in behavioral health rose by 66 percent in rural centers, surpassing the 49 percent growth in urban centers (Han and Ku, 2019). Most of the growth in both settings was driven by clinical social workers and other licensed mental health providers; changes in psychiatrists and psychologists staffing were slight (Han and Ku, 2019).

Alternate mental health delivery models and a paraprofessional workforce have attempted to help meet the critical need created by these shortages. For over 30 years, peer support specialists (people with lived experiences of mental illness, addiction, or trauma) have filled an increasingly integrated role in programs designed to provide support and care to people with behavioral health conditions (Gagne, Finch, Myrick, and Davis, 2018). As of 2016, 41 states and the District of Columbia have established statewide certification and training curriculum for peer providers and Medicaid reimbursement for mental health peer support (Kaufman, Kuhn, and Stevens-Manser, 2016). Titles and roles may differ slightly, but peer workers typically (A) connect through shared

lived experiences; (B) mentor or coach; (C) link and help navigate through community services; and (D) support recovery or wellness goals (Gagne et al., 2018). This workforce is associated with the recovery movement, which could shape and reform mental health policies and delivery through promoting individuals with mental illness' full participation in society (Davidson, 2016). This growing workforce may augment mental health delivery and offer key support to mental health professionals.

Another service with the potential to extend the reach of the mental health workforce is tele counseling (delivering mental health services by phone). A 2011 meta-analysis of tele counseling programs and people with physical disabilities found positive outcomes such as significant improvements in coping skills and techniques, community integration, and depression immediately after tele counseling, with modest improvements in quality of life maintained one year post-intervention (Dorstyn, Mathias, and Denson, 2011). Telemental health (TMH) uses telehealth technologies to deliver mental health care at a distance (Lambert, Gale, Hartley, Croll, and Hansen, 2016). Advancements and improvements in TMH technology are also generating more cost-efficient options. TMH also can minimize travel-time and stigma because patients can access counseling in a setting not specifically identified as a specialty mental health setting (Lambert et al., 2016). Various TMH strategies are increasing and a study of Medicare beneficiaries identified individuals with a disability are more likely to use telemental health than other beneficiaries (Mehrotra et al., 2017), indicating these innovations could be important for increasing mental health access to rural residents with disabilities.

Formal mental health professional organizations have provided some guidance for working with individuals with disabilities. The American Counseling Association, through the American

Rehabilitation Counseling Association division, has created a resource of disability-related counseling competencies or ‘aspirational guidelines’ for engaging people with disabilities (Chapin et al., 2018). The American Psychological Association (APA) created guidelines for assessing and providing interventions for individuals with disabilities (APA, 2012). Minimal scholarship has urged special consideration of the gender and disability intersection (Banks, 2008). The APA guidelines will expire in Feb. 2021, thus providing recommendations based on women with disabilities’ own experiences interacting with the mental health workforce is particularly relevant and timely.

The Rural Safety and Resilience Study interviewed women who have survived gender-based violence, while living in a rural setting. The interview asked women to describe (through personal narratives) their experience learning about and accessing help. Women identified both barriers and facilitators to receiving satisfactory mental health services. Women described aspects of access (the ‘fit’ between their expectations and experience). The article organized these interdependent elements using Penchansky and Thomas’s (1981) Concept of Access: exploring elements of availability, accessibility, accommodation, affordability and acceptability, to demonstrate the necessity of each element to create meaningful access to mental health care for WWD. Few studies have examined people with disabilities’ expectations and experiences with counseling services, particularly related to therapy after trauma. Additionally, the mental health workforce is evolving to extend services and address unmet needs, through innovative telemental health service delivery and integrating paraprofessional supports such as peer counselors. These components could broaden access to mental health services to underserved rural populations, and members of the disability community. Research is needed to understand

how to effectively leverage and optimize these initiatives to meet specific needs in different contexts. Exploring aspects of mental health care delivery based on rural WWD's lived experiences will provide important recommendations to inform mental health care practice and strengthen program design and implementation.

Methods

This study involved 33 in-depth semi-structured interviews (from June to December 2019) with WWD who have experienced gender-based violence in a rural community in the United States. The study had the approval of the University of Texas Health Science Center at Houston (UTHealth) Institutional Review Board.

Recruitment Strategies and Case Set

The research team circulated study flyers to disability service agencies (such as Lighthouses for the Blind and the Association of Programs for Rural Independent Living), and through disability consumer organizations (such as national listservs of the National Association of the Deaf). We reached out to faith-based initiatives who partner with disabled members in communities of faith. We also shared the study announcement with national centers specializing in violence and disability services, using a comprehensive list provided by the VERA Institute on Justice. The study announcement appeared in disability-related newsletters and E-magazines. Lastly, we shared the study announcement through Facebook and Twitter. We also used the snowball sampling method, inviting participants to share study contact information through their personal networks.

To be eligible to participate in the RSRS, women had to be at least 18 years old, and (1) self-report at least one of the six disability categories (hearing, vision, mobility, cognitive, self-care, or independent living); (2) have had the disability during her experience of violence; (3) have experienced violence at least one year prior to the study while living in a rural setting when violence occurred; and (4) did not have a significant intellectual difficulty, or difficulty with the English language which might have prevented understanding the study and responding to interview questions. Participants were not vulnerable to coercion because the women decided whether to respond to the study announcement. While we did not screen out people with mental illness or cognitive disabilities, their participation was voluntary and initiated only by potential participants themselves responding to the study announcement. Interviewees received a small incentive to compensate them for their time and insight.

Once a potential participant responded to the study announcement (by emailing, texting, or calling the first author), K.A. provided and discussed a prepared consent form in the person's preferred, accessible communication format. The form provided an explanation of the overall study aims, stated that interviews would be recorded, delineated risks and benefits of the study, and emphasized the individual's right to withdraw from the study at any time. The form also informed participants of the mandatory reporting requirement if any current abuse was disclosed. After participants reviewed consent forms agreeing to an audio recorded interview and the first author addressed any questions, the interviewer scheduled an in-depth interview using the interview guide. The guide covered four broad topic areas (help-seeking; personal resilience; access barriers/facilitators; and policy experiences and recommendations) and had 19 total questions.

The first author conducted individual interviews by phone and email, extending geographical reach and expanding the diversity of participants (Holt, 2010; Novick, 2008). In the case of a telephone interview, once the recording started the interviewer did not use the subject's name, to protect privacy. We have assigned all participants a pseudonym for all write-ups of research findings. Women also completed a demographic sheet at the time of their interview, either through email or orally on the phone with the interviewer. For Deaf or hard of hearing participants, and participants with cognitive impairments, the interviewer consulted the participant about their most preferred communication mode. Eight interviews were conducted via e-mail at the participant's request to accommodate their communication preferences. The interviewer sent two or three questions at a time via email, and reviewed responses carefully before sending the next set of questions. The email exchange allowed for prodding and reflexivity, to more closely match the back and forth of in-depth interviews. The remaining 25 interviews were audio-recorded and conducted by phone, lasting between 45 and 90 minutes.

Twelve participants had a physical impairment that affected their mobility. Nine women were blind. Four participants were Deaf. Five women were Deaf-Blind. Seven women had cognitive impairments. Four participants had multiple physical, sensory, or cognitive disabilities.

Participants ranged from 19 to 72 years old, with most participants in their 30s and 40s. Twenty-four women identified as white. Three women identified as Black. Two women identified as Latina or Hispanic. Two women identified as Native American. One woman identified as Pacific Islander and one woman identified as multi-racial.

Ten women were either married or in a relationship. Of the 23 remaining participants, two were widowed, five were divorced, and 16 indicated they were single. Eighteen women had children. Education levels ranged from some high school to holding a master's degree. Ten women worked part-time and eight women worked full-time. Three participants were students, and two women were retired. Ten women were not currently working, either by choice or because they were having trouble finding a job.

Data Analysis

Interviews were transcribed verbatim to be attentive to the specificity of discourses. The interviewer also recorded research memos to include additional observations and context to build thick descriptions. Transcripts were analyzed through a process of thematic content analysis, which involves systematic coding and categorizing to examine large amounts of text unobtrusively to identify patterns and connections of words and phrases (Hsieh and Shannon, 2005; Vaismoradi, Turunen, and Bondas, 2013). After the researcher reviewed transcripts in entirety, the researcher created working definitions for each code/theme. Text that did not fit under predetermined coding generated additional new codes. Iterative coding organized text into manifest (explicit terms or concepts) and latent (underlying, implicit meanings) to build categories of codes and ultimately themes (Morgan, 1993). Researchers discussed tentative themes with supporting participant quotes to clarify and refine final themes. We also shared selections of text and quotations with a subsample of participants (member checking) to confirm appropriate representation of their perspectives.

Findings

This study examined contexts of mental health care including counseling while still in the abusive situation; finding a counselor or alternate mental health support after exiting the relationship; and handling the financial, communication, and environmental barriers to continue to receive mental health support. Women described a multilayered process to securing and maintaining satisfactory mental health access. Emerging themes included exploring women's expectations of mental health services and experience learning about mental health service options (availability), the challenge of finding an appropriate 'fit' and therapy approach (acceptability), positive connections with mental health professionals (accommodation), and barriers to maintaining counseling or mental health support due to financial, environmental, or communication barriers (affordability and accessibility). WWD offered recommendations for innovations to make mental health services more available, acceptable, and accessible.

Expectations and Experiences Learning about Mental Health Options (Availability)

WWD explained they expected counseling to be helpful, supportive, and a safe space. Hannah experienced prolonged sexual abuse as a child and did not seek counseling until she moved away and attended college. She recalled,

My first, the first time I went to a counselor, I was very, very depressed and my hope was just that they would fix me (small laugh). I kind of had this idea that we were, that I would go in and maybe they would give me some pills and then that would make everything better and I'd be all fixed. I was also very adamant about the fact that I kept saying, I'm not crazy. I'm really not crazy.

Vanessa is a Deaf woman who experienced multiple forms of abuse, including rape in college. She answered she was hoping to find help in counseling, "Dealing with anxiety...dealing with staying calm and rational during frustrating moments, dealing with the black cloud that hovers

above me. Dealing with the broken record that won't stop playing in my head, dealing with learning to love myself.”

Women in this study were not screened through health care or mental health care services in a private manner that would allow them to disclose abuse. Even when injuries brought women to the emergency department or caused a hospital stay, no one offered resources. Maya has a mobility impairment and uses a wheelchair. She was sexually assaulted in her home one night when someone broke in. She went to the hospital and had a rape kit. She said she decided on her own later to find a therapist to talk about the traumatic event. She recalled, “I found the therapist in the phonebook. You really don't see stuff like that listed in the communities.”

Three women were committed to the hospital for psychiatric evaluation, when their abusers created a narrative that the women were mentally unstable. Even in these cases, mental health counseling options were only offered to two of these women. Megan recalled that even in this extreme situation, “I guess I didn't expect the wait times. When I tried to get in at the community mental health center for, uh, therapy, I think I waited three weeks and that was after the referral came from the hospital, from the dropped commitment.”

The process of identifying available mental health service options and beginning counseling was not straightforward or easy in rural communities. Women had to overcome their own shame and stigmatized ideas, and learn about service options on their own, only to discover few counselor options or long waiting lists.

Finding an Appropriate “Fit” and Therapy Approach (Acceptability)

Some women did receive counseling during some part of their experience of violence. Women described their counseling experiences as ranging from partially helpful to harmful. For example, Sonia described brief interactions with counselors when she was experiencing abuse as a teenager, perpetrated by family members. She described, “The counselors I did have (in my high school and the two I shortly had in my hometown) brushed off the severity of the abuse and focused more on helping me ‘manage my anger’ and stop self-harm.”

Jennifer also described her experience with couple’s counseling (her partner was abusive). They used a videophone so she could have an ASL interpreter:

I found text messages from him to the counselor, like private conversations. Again, him trying to make the counselor think that I'm crazy, you know? He's not supposed to have contact with the counselor. It's supposed to be the couples counseling with one counselor, but he would be on the side texting back and forth with the counselor and they'd have full on conversations.

Lauren is an autistic woman who was in an abusive marriage. She discussed some benefits, and some challenges with her first counseling experience,

The woman was great, but she was suited for someone neurotypical with standard anxiety or depression. She helped me to realize that I had been and was currently being abused, that I didn't know how to set boundaries, that my mother was still terrorizing me as a 26 year old woman and controlling my life, and that my husband was a monster-- but she wouldn't help me to leave him. She told me I'd do that when I felt ready. I didn't know how and didn't have the executive function. I was afraid for my life. I had lost the ability to mask. She told me that my issues were above her expertise, and gave me a list of people to call. Most of them were not working anymore. The others wouldn't take me.

Theresa has a mobility impairment, which caused her to live in an assisted living facility. She was threatened because she stood up for other residents that were being mistreated. She left that living situation against medical advice and moved to a scenic farm. A retired social worker

created a community there where she charged people with disabilities rent to live on the farm. The social worker isolated her tenants with disabilities and restricted their access to the internet. Theresa recalled the social worker and her brother, the self-proclaimed caregivers, abused alcohol, and mistreated residents with disabilities. Theresa explained how months of emotional abuse ended,

I did nothing to provoke this that I know of. She called 911 and told them that I was psychotic, and I needed to be taken away. And, um, she's kicking me out of the house and she, she didn't really have any basis for saying any of that. And the ambulance drivers knew that. And, um, my counselor knew that. And adult protective services was called on her, um, because she put my life in danger by kicking me out with no place to live. And what ended up happening is I became, um, they, they hospitalized me on a mental health floor, because she had told them that I was psychotic and I wasn't. And I didn't stay long in the hospital, but when I got out, I had nowhere to go.

Theresa reflected that she stayed in touch with a counselor throughout the experience, “He helped me process what was happening, what was really happening and how it wasn't right. And some ways that I could look to try to get out of this situation.”

Most often, WWD endured long periods of abuse before securing safety, and eventually trying to receive counseling. Alicia is a Blind woman who experienced years of sexual abuse. She explained her struggle to find a therapist who could meet her needs:

I think one of the things that I struggled with was trying to get whoever was talking to me in therapy to not focus on my disability. That wasn't the problem. Um, and if they were so concerned about how much more of a, of a problem that was, that I was blind and also with this and they didn't focus sometimes and I switched therapists a couple of times because of this. They didn't focus on the healing process and the coping process. They were too focused on the disability.

WWD described hoping to be treated with respect and understanding, wanting to be believed, and searching for peace. Isabelle is a blind woman who was concerned her disability would

prevent her counselor from focusing on the important reasons she felt she needed therapy, which were processing years of abuse. She summed it up this way, “I was really hoping that they would treat me like any other person that came through the door and that didn't happen.” Sonia admitted she has never received the counseling she needed to deal with her traumatic experiences. She said,

I encountered the same ableist message over and over again— people assumed I wanted to talk about my disability in a way that was focused on ‘overcoming’ or ‘coming to terms’ with my disabilities. I’m proud of my disabilities. They are my identity, culture, and a source of pride. What I wanted to talk about was having a mom who wanted me dead.

Counselors assume the woman’s disability was the fundamental contributor to her distress. This perception limited exploring actual sources of trauma women urgently needed help processing.

Women felt counselors viewed them as a case of disability, rather than a whole person. Paula is a blind woman who has a sighted daughter. She shared a negative experience she had with the only counseling option in her rural community, prior to her experience of violence in the form of stalking. Based on this previous experience, Paula did not feel comfortable going back to a counselor. She said,

Well, when I had gone in before, we had gone in for family counseling. The first thing that was said to me was, in front of my daughter, ‘Well, as a blind mom you're not going to know what emotions your daughter has, so you're going to have a hard time knowing how she's feeling about different things that are going on in her life.’ I said, ‘My daughter and I have always had a close relationship and I'm probably the one person in the world next to her who knows how she's feeling about what's going on in her life. I don't have to see to know that.’ He said, ‘I'm not sure I believe that.’ I think he did lasting damage to my daughter and my relationship with those statements.

She concluded,

They just don't know how disability fits into the person's life and they want to blame everything ... They want to think that, oh, your problems have to do with your disability and not other things in your life. There are other issues besides your disability that can cause problems.

WWD in this study sought counseling to deal with abuse. Some therapists had preconceived notions about what living with a disability meant to women, and how that influenced their mental health and relationships. Counselors who could not move beyond perceptions or preoccupation with the woman's disability did not provide acceptable counseling services. Failure to address the primary reason WWD initiated therapy, in some instances, resulted in women giving up on therapy altogether.

Positive Connections (Accommodations)

Many women in the study eventually found a supportive counselor who was able to help them process violence and abuse. Whitney has Ushers Syndrome, a degenerative disease that results in severe or complete loss of sight and hearing, she shared her experience working with a caring and resourceful counselor. She explained,

After that my vision and hearing deteriorated. I got lost once and never made it to her office. She volunteered to provide transportation as I had become too nervous of using public transportation, not able to see and hear the bus and its driver and fearing being dropped off at the wrong place. As I continued to lose both vision and hearing, it became a struggle to communicate with her, needing many repeats, and she was patient with me. Once I adapted to cochlear implants, communication was better.

Lauren described how finding the right therapist saved her life. She said,

I told him at the first meeting that I was too exhausted to keep trying to live. I had left my ex and was living alone at this time. I just felt irrevocably broken. I told him that I was going to kill myself if he couldn't help me. That it wasn't a threat of immediate suicide but my life plan, as it was just too hard to keep trying. He said, 'Okay, it's a deal. I can help you.' He didn't try to challenge me or talk me out of it. He was amazing, and so was DBT (dialectical behavior

therapy). This therapist was neurodivergent. He was definitely autistic, though he only confessed of ADHD. He was so blunt and literal, and he spoke of practical solutions, gave me actionable homework to do, told me the neuroscience and the why behind what changing my actions would do to change my mind. He was all about self-validation, self-empowerment, and self-autonomy. He did not speak to my emotions, he spoke to my sense of justice. He realized that fairness mattered to me, and that I deserved to be treated fairly.

She reflected, “I don't think I would ever have been helped by a neurotypical therapist. It would've just been more masking and being taught to perform against my neurology.” Diane, a blind woman whose abusive spouse had her committed to a psychiatric institution, ultimately moved from her town and, in the process of starting over, found a therapist. She reported,

I also began the very long road of healing by putting myself into therapy. And, I was put on an antidepressant. So, my therapist had had experience with disability but she also had experience with domestic violence and was really able to help me sort of work through all of the things emotionally and physically that I needed to do.

Some women worked with other mental health services. For example, Jan is a woman with a cognitive impairment who worked well with a very experienced social worker she found through a local Independent Living Center. He worked with her for many years, and he has experience working with people with diverse disabilities. He created a CD and MP3 for her to listen to when she is preparing for bed. He talks through relaxation techniques and Jan said, “It helps me to focus on the good stuff.” She described it as “very reassuring.”

Other women in the study found participating in domestic violence support groups, or 12-step programs (adult children of alcoholics, CODA), helpful. Kelly, who has Ushers Syndrome, explained how valuable the 12-step programs were, in conjunction with individual counseling, “The 12 step program helped me the most. And, um, I would actually, maybe not necessarily the sponsors, but, um, maybe just the other people that I talked to.”

Kelly described how attending meetings became challenging due to the progression of her disability. She recalled,

So at that time in my life I really had to continually advocate. And in fact, a person who continually reminded people in meetings and otherwise, especially in meetings, reminding people to speak up ends up being rude and nobody wants them around. People just get aggravated.

She concluded,

So the end result was I would advocate for people to speak up as long as I felt comfortable doing it, but mostly I just sat, at least once or twice, I would just sit through meetings, try to read lips, try to follow what was going on, in bits and pieces of what was said. And after a while, choose to stay home.

Amber has a mobility impairment and suffered with shame because her son was abusive. She explained how she started to get help,

I remember looking in the paper for a Co-DA meeting and I didn't see any, but I saw ACA, Adult Children of Alcoholics. And I thought I'm familiar enough with that program to know it's a support group. It's a 12-step program. And I went. Like, oh my God, somebody else knows what I'm talking about. They know how I feel. I'm not crazy. Somebody else has experienced that. And that was the beginning of me being around people and opening up and talking about things.

Several women specifically mentioned the concept of peer counseling as a potential way to support women with disabilities who experience violence. Diane explained,

You know, it would have been really good if I had had an individual who was perhaps like me. You know, I'm not saying somebody that was like the same ethnic background or whatever but somebody that had been a survivor of domestic violence but that also had a disability. You know, I think that that would have been really great to sort of have that person take me under their wing and help me step through these sort of hurdles that I had to get through for applying for services or obtaining services or getting services or whatever. Somebody that could understand not only the disability part but that could also understand the domestic violence part and the abuse and sort of all of the emotions that go along with that.

Melissa is a wheelchair user who did not use the term “peer counselor” but she echoed the sentiment,

I just, I think there needs to be like programs and like people who have been like there, like a committee or something or people who have actually been through something cause I don't, I don't like it when people that don't have a disability tell me what to do when I have one and they don't.

Megan has debilitating rheumatoid arthritis and ADHD. She agreed, saying,

I feel like there are so many avenues for peer support especially in housing and in victim services. Having somebody there that had been through it before and say, ‘Hey, look, I'm doing this now. I'm successful and, you know, I'm here to help you through this. You know, here's what I did. What do you think of this would work for you? Let's find those avenues and those strategies that are going to work for you’. That would have gone so far in just making me feel better and feel not alone.

Theresa was also committed temporarily and mistakenly, to a psychiatric hospital by her abusive caregiver. She said,

I think employing ... they're called peer recovery specialists, which are people who have lived experiences with whatever, um, as part of the people who meet you at the hospital or wherever. Um, like someone who's been through homelessness, been through abusive situations, who's been through psychological trauma. Someone who has lived experiences. Maybe someone else blind, someone else who has a mobility impairment...

Women indicated having someone with shared experiences, particularly living with a disability, to guide them through an overwhelming process would have been helpful and would have improved their experience accessing mental health care.

Challenges to Maintaining Mental Health Services (Affordability and Accessibility)

External factors influenced WWD’s ability to initiate and continue mental health treatment.

Many women described having no transportation, or options that were extremely limited for

making office appointments with counselors. Some women started out by finding therapists based on bus routes, because that was their only option for getting to appointments. Bus routes were often time-consuming, and schedules were not available in evenings or on weekends. Women in this study who attended counseling as adolescents described the conflict and complexity when they had to rely on family members, who were often part of their abusive environment, for rides to therapy. Women suggested that having access to “virtual” or “telehealth” counseling would have eliminated the transportation barrier, and the stress of needing to rely on abusers for access to appointments.

Women also discussed financial restrictions, which affected their ability to continue with counseling. Vanessa said, “It all came down to money and lack of services for those of us on limited salaries. Cynthia has a cognitive disability, and she found counseling helpful; however, she explained her access to counseling was short-term, “I went to a counselor for a little bit, but then stopped when my insurance no longer covered the sessions because I couldn't afford the sessions on my own. Deaf women in the study shared that counselors expected them to pay for interpreters, which was cost-prohibitive on top of paying for counseling. Whitney ultimately got certified as a school psychologist. She explained how the importance of mental health services are underestimated and undermined by funding shortages, “When I was working in the school, there was a period of budget cuts, and the first to go were mental health services, like counselors and social workers, as if these staff were unimportant when it is the contrary.” Women’s ability to consistently continue the mental health care they needed depended on financial and physical and communication access.

Discussion

Women in this study described their experiences accessing counseling and other mental health services after enduring gender-based violence in a rural setting. Women highlighted many aspects that needed to work together to create an accessible experience. Access in health care is typically perceived as insurance coverage, while “access” in terms of the disability experience usually emphasizes physical or communication barriers which might prevent “getting in the door.” Women in this study described how multiple factors influenced their mental health access. Penchansky and Thomas’s (1981) taxonomy of access effectively captured the interlocking components women identified as facilitating or preventing effective mental health services. For women in this study “access” required a service to be available in the rural setting, accessible (absent communication or physical barriers), acceptable (counselors who were prepared to effectively engage with and focus on abuse-related issues), affordable (covered by insurance or on a sliding-fee scale), and accommodating (flexible enough to meet their needs and help problem-solve transportation and other barriers). The interplay of these access components was not linear or hierarchical; the “chain” of mental health access and “fit” was only as strong as the weakest link (Wyszewianski, 2002).

Importantly, many women did not participate in counseling during the experience of abuse, and many could not find services they needed in their rural community, due to a collapse of one or more of the critical components of access. These experiences suggest the availability of services is lacking, as is awareness and knowledge about how to secure services. Women also described their initial expectations about therapy. Women expected that counseling would provide a safe and supportive space, validation, and helpful strategies for processing their feelings about the

traumatic event. Many women described instances when family or people in their community discounted their experiences. Some women's abusers discredited them, implying they were "crazy", and in some instances even committing women to psychiatric facilities against their will. This made reaching out for mental health services more difficult because they had to overcome their own stigmatized ideas about therapy. This underscores that progress is needed in society, including the disability community, about understanding mental health, and destigmatizing counseling services. Health systems, disability service agencies, schools, and churches are important entities to partner with mental health services.

More than half (18 of 33) of women in this study relocated to new towns after exiting abuse. Colleges were important connecting points where women were able to find friendship and learn about services, such as counseling options. This suggests that distributing information about campus services to students with disabilities is important, as it may be an opportunity for them to engage with mental health services. This information needs to be delivered through many communication channels to reach women with disabilities. WWD also described how support groups, such as 12-step programs, domestic violence support groups, and faith-based groups were helpful aspects of their journey to healing. Organizations and programs offering support groups should share meeting information with women with disabilities, as this is a key validation and potential entry point to other mental health services, such as individual counseling. Women reported support group programs that included help with child-care during meetings and transportation assistance were extremely helpful and beneficial.

Women also reported connecting with other individuals with disabilities was a meaningful and important element of supporting their mental health. Those who worked with therapists with

disabilities found it helpful, and a source of relief because they did not need to constantly educate about the “hows” of their disability. Counselors with disabilities, or who were very familiar and comfortable working with people with disabilities, understood aspects about the hidden labor of disability, but also recognized that other contexts and experiences shaped the individual and influenced what they sought to gain from therapy. Women perceived that this facilitated a more productive counseling experience because women felt they were able to focus more on their experience of trauma and learn strategies for coping and healing.

Women identified other opportunities for survivors with disabilities to serve as supportive components to recovery and healing, as peer support counselors with “lived experience.” The concept of peer support is not new to the disability community or the mental health sector. Recovery advocates collaborated with disability rights activists to classify serious mental illness as a disability under the Americans with Disabilities Act (ADA), creating a stronger coalition and campaign. The cornerstones of the recovery movement assert that people with mental illnesses can lead productive and meaningful lives even while experiencing symptoms, many will recover from their illnesses, and the major barriers to inclusion are social stigma and discrimination, which have marginalized people with mental illnesses (Davidson, 2016). This foundation aligns with the disability rights movement’s activism and mobilization to replace oppression and marginalization with empowerment and full inclusion (Winters, 2003). The National Center on Trauma created a guidebook for peer support specialists on incorporating a trauma-informed approach when working with survivors of violence (Blanch, Filson, Penney, and Cave, 2012). A growing body of research has demonstrated various forms of peer support are associated with positive outcomes such as empowerment, improved self-esteem, acceptance,

and hope (Corrigan, 2006; Davidson et al., 1999; Ochocka, Nelson, Janzen, and Trainer, 2006; Repper and Carter, 2011; Sells, Davidson, Jewell, Felzer, and Rowe, 2006).

The peer support workforce also has the potential to extend behavioral health services, particularly in rural communities. Women in this study shared that having a peer or “companion” with a disability who had also experienced violence would be particularly helpful. Saxton (1991; 2018) in particular has advocated for women with disabilities to receive training in peer counselor programs for many reasons associated with the double disadvantage that disability and female status create in women’s lives. A scan of existing scholarship did not find any peer counseling programs focusing on the intersection of disability, gender, and violence to date.

Women endorsed making training on disability part of the cultural competency curriculum for counselors and the wider mental health workforce. Women’s experiences underscored the importance of elements of the current APA Guidelines for Assessment of and Interventions with Persons with Disabilities (APA, 2012). Women described feeling frustrated when counselors wanted to talk about ways to “treat” or “overcome” their disability (the traditional medical model of disability), when the primary reason they initiated therapy was to work on talking through and beginning to heal from the trauma of abuse. Guidelines 1 and 2 of the APA document encourage psychologists to learn about different disability paradigms (e.g. the medical model and the social model of disability), and to explore their own perceptions and reactions related to disability. Guideline 8 urges psychologists to recognize that people with disabilities also have diverse social and cultural experiences and lives. Based on women’s perceptions in the study, these examinations and learning are extremely necessary. Women described the burden of being one of

the first people with a disability the counselor may have known, and the often-exasperating feeling of educating and advocating about their disability.

Guidelines 4 and 5 urge psychologists to be familiar with state and national legislation such as requirements of the American's with Disabilities Act (ADA) and to create a barrier-free environment, which includes physical and communication access. Deaf and Deaf-blind women in this study described how they continued to struggle to have access to counseling using their preferred communication (ASL interpreters) rather than other less-preferred techniques such as lip-reading. The APA guidelines and the ACA counseling competencies emphasize that individuals with disabilities are the "ultimate authority" on their own needs (APA, 2012; Chapin et al., 2018). Deaf consumer organizations and advocacy groups are subject experts on deaf communication tools and preferences. Therapists should consult them when trying to create and implement best-practices.

Guideline 11, and counselor competency D.7 encourage psychologists and counselors to be aware of increased risk for abuse and address abuse-related circumstances and consequences appropriately. This includes understanding various forms of abuse, including disability-specific abuse, screening for violence, and helping with safety planning and connecting to other community resources. Women in this study, particularly when attending counseling as young adults, viewed their counseling as a missed opportunity for identifying their abuse and getting help. The guidelines assert WWD's key point in this study: an individual's disability issues may or may not relate in any significant way to the reason a woman with a disability seeks mental health services (APA, 2012).

Finally, women discussed financial and environmental (physical and communication) barriers to accessing counseling services. Transportation for women who could not drive was a time-consuming problem that often resulted in discontinuing therapy. Mental health services should be cognizant of transportation barriers, particularly in rural areas. When possible, mental health providers should explore options to help with transportation assistance, particularly in integrated health care settings. Having appointments available through other mechanisms, such as by phone or through telemental health platforms would minimize the time and cost required to travel to appointments, particularly in rural areas where public transportation is limited or not available. One caveat to on-line platforms is that they may not be entirely accessible with adaptive technology, such as screen-readers for blind and visually impaired clients. It is possible that, though platforms claim to be compliant with accessible standards, when adaptive technology users often discover accessibility problems with using these services. The APA created a “Tip Sheet” for what psychologists should know when using telehealth with people with disabilities with some helpful considerations of advantages and challenges (APA, 2013).

Study Strengths and Limitations

The present study employed a qualitative exploratory design to learn about the lived experiences of rural women with disabilities experiencing gender-based violence: it was not designed to be generalizable to other populations. Qualitative methods are equipped to capture the complexities and contexts of the disability experience (O’Day and Killeen, 2002). Rigorous qualitative techniques supported richly detailed narratives to help build an in-depth understanding of the subject. We created a codebook to enhance transparency. The codebook contains a list of the codes with demonstrative examples for each code, and documentation of changes throughout the

analysis (Lincoln and Guba, 1985; Bowen, 2008). To enhance trustworthiness and confirmability of findings, we used member checking (Lincoln and Guba, 1985; Creswell and Miller, 2000).

This technique uses the participant's own words through direct quotes in research findings, and shares transcripts and concepts with a selection of participants to confirm the research team accurately and appropriately captured their experiences.

Recruitment methods likely led to an oversampling of highly educated women, affiliated with disability communities, with an activist orientation. Sharing this study announcement widely on various platforms, including social media, may have helped to remedy this problem because individuals did not need an affiliation with an agency or organization to view the announcement. An additional potential limitation is that recruitment for this study was challenging due to complicating factors surrounding disability and violence, including stigma and shame. Reaching this population through various contact points including disability service agencies and disability activist organizations, as well as contacting trusted leaders in the disability community to share study information, helped to reach a large pool of WWD. The study announcement clearly stated the aim of the study, as well as strategies to protect privacy and anonymity (unique participant ID and password-protected computer for data analysis). Confidentiality is of special concern in rural communities and Deaf culture and disability communities (Lightfoot and Williams, 2009; Logan, Walker, Shannon, and Cole, 2008).

Both the disability community and rural communities may hesitate to participate in academic research studies. Interviewers who do not have a disability may cause mistrust (Lightfoot and Williams, 2009). Similarly, rural communities have had negative experiences when research on their community accentuates negative reports (Logan et al., 2008). One strength of this study is

the lead author is a woman who grew up in a rural community and is a member of the disability community, having a disability herself, as well as twenty years of activism through disability organizations. Matching characteristics with participants is a best-practice when interviewing members of marginalized groups (Brown, long, and Milliken, 2002; Lightfoot and Williams, 2009; Logan et al., 2008).

Conclusion

The Rural Safety and Resilience Study explored how rural women with disabilities who experience gender-based violence learn about and access help. Mental health services are an important component to achieving safety and positive health and psychological outcomes. WWD discussed finding an appropriate ‘fit’ for mental health services, in terms of availability, accessibility, accommodation, affordability, and acceptability. Each component contributed to WWD’s ability to access satisfactory mental health services. Women worked with various aspects of the mental health field, from individual counseling to participating in self-help groups. Women in this study provided important insights and recommendations for how the mental health sector can best serve women with disabilities who have experienced traumatic events. First, the entire scope of the mental health workforce needs education and training to cultivate cultural competencies for working with people with disabilities. When possible, individuals with disabilities should serve as subject matter experts to create curriculum and facilitate trainings for professional associations. The APA and ACA guidelines demonstrate that mental health professionals are aware they need to cultivate and improve strategies and competencies; however these documents have not translated into practice. This translation is the necessary next step.

Secondly, the evolution of mental health services has the potential to extend reach to rural residents and individuals with disabilities beyond what was previously possible. Integrated health care settings, telecounseling, and telemental health all present opportunities to minimize barriers related to cost, transportation, communication, and physical access. For individuals with disabilities, these opportunities will only be possible to the extent that these innovations feature accessible technologies and platforms to ensure consumers with disabilities can interact and participate.

Women with disabilities experiencing violence need access to a network of mental health services that are accessible, affordable, and that offer accommodations and acceptable support and techniques. Each element plays a critical role in creating the proper ‘fit’ women need to support their recovery from trauma and begin to heal.

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CONCLUSION

WWD in the Rural Safety and Resilience Study shared important insights to help answer the question, what do women with disabilities experiencing violence in rural settings do to build resilience, find support, and secure safety. The first significant finding is that, too often, WWD in rural communities do not find or access local support. Most women in this study (18 of 33) did not secure safety until they moved from the rural setting entirely. This is significant and concerning because it suggests many women with disabilities experiencing violence in rural communities are trapped in those abusive situations. The rural culture, where abuse is considered a private matter, contributed to WWD not confiding in others. Women's history of experiences with rural service providers in health care or mental health or law enforcement also influenced their willingness to pursue those avenues during and after abuse. Often these experiences made WWD feel dismissed or devalued. Finally, WWD had limited awareness about domestic violence resources, crisis hotlines, or strategies for safety planning. This suggests violence prevention and education is needed among the disability community. Service providers need to explore different ways to promote services (e.g. beyond just signage and printed materials, which blind and Deaf/Blind women cannot access). State violence coalitions should engage with disability organizations, and survivors with disabilities, to identify and implement strategies to bridge silos between different service providers.

This study contributes to existing research on resilience by exploring the contextual specificity of how WWD overcome violence-related trauma. WWD illuminated dynamic personal, interpersonal, and sociocultural resilience pathways, which supported recovery from their experience of violence. Women discovered personal strengths that helped build confidence and

self-efficacy. Participants relied on reciprocal, mutually supportive connections with family and friends, including meaningful and affirming relationships in the disability community. Lastly, WWD cultivated strategies to process trauma in ways that supported their physical and psychological health.

Clinical practice can incorporate these findings to design programs to support WWD to recover from violence. Conceptualizing resilience as a process that women and service providers can work collaboratively to foster will support growth and recovery. A resilience framework may also help to shift WWD's perception of control by engaging them to define and adapt internal and external strategies to best suit their lives. Providers could facilitate introductions to individuals or groups with shared experiences; meeting other individuals with disabilities and meeting other survivors of violence were both particularly validating experiences that helped WWD to realize they were not alone. Finally, WWD themselves may be an important and overlooked resource for helping other women and improving inclusive program design and delivery.

Participants discussed perceptions and interactions with health care systems during both violence and following a safe exit from the abusive situation. Women emphasized a critical need for training and education about disability throughout the health care system, as well as raising the reality of abuse among women with disabilities to a higher profile. To be effective providers for WWD, clinicians need to demonstrate cultural competencies related to disability. WWD are open to, and even welcome, clinician screening for abuse; however, it is crucial screenings preserve women's privacy and, if not conducted in face-to-face appointments, are available in an accessible format or tool for women to disclose independently. Screening tools and self-

disclosure programs tailored to women with disabilities are vital, and the health care system should build on and expand existing work in this field. The IOM, USPSTF and HRSA have endorsed screening women for abuse. It is important that WWD are included in screening, as they experience higher rates of abuse, and face unique obstacles to accessing safety. The health care system has the potential to serve as a critical mechanism to identify abuse among WWD, and support their safety, but this will require clinicians, health systems, and health policies to work together to recognize and effectively respond to the complexities of violence in women with disabilities' lives.

Mental health services are an important component to achieving safety and positive psychological outcomes. Women worked with various aspects of the mental health field, from individual counseling to participating in self-help groups. Women in this study provided crucial insights and recommendations for how the mental health sector can best serve women with disabilities who have experienced traumatic events. The entire scope of the mental health workforce needs education and training to cultivate cultural competencies for working with people with disabilities. When possible, individuals with disabilities should serve as subject matter experts to create curriculum and facilitate trainings for professional associations. The American Psychological Association and American Counseling Association guidelines demonstrate that mental health professionals are aware they need to develop and improve strategies and competencies; however, translating these resources into current practice is the necessary next step.

The evolution of mental health services has the potential to extend reach to rural residents and individuals with disabilities beyond what was previously possible. Integrated health care settings,

telecounseling, and telemental health present important opportunities to minimize barriers related to cost, transportation, communication, and physical access. For individuals with disabilities, these opportunities will only be beneficial to the extent that these innovations feature accessible technologies and platforms to ensure consumers with disabilities can interact and participate.

Women with disabilities experiencing violence need access to a network of mental health services that are accessible, affordable, and that offer accommodations and acceptable support and techniques. Each element plays a critical role in creating the proper ‘fit’ women need to support their recovery from trauma and begin to heal.

The Rural Safety and Resilience Study explored how rural women with disabilities who experience gender-based violence learn about and access help, and bolster resilience. The research builds on a small body of work on WWD and abuse. The qualitative techniques employed in this study empowered participants, highlighted important processes, and explored complex contexts. This study also provided an intersectional rural perspective to help providers better understand the unique challenges and barriers rural WWD encounter identifying and accessing help. This study had representation from women with diverse disabilities, including sensory disabilities. Prior research has underrepresented survivors who are blind, Deaf, or Deaf-Blind, thus these are largely absent perspectives. Participants with sensory disabilities in the current study accentuated distinct resource barriers.

Future research should examine how to reach WWD in rural areas who are currently experiencing violence. The RSRS underscores the urgent need for heightened awareness of abuse among women with disabilities and the importance of disability-related education and

training throughout the network of victim services, including health care, mental health services, and programs through domestic violence coalitions. Professionals and agencies should consider survivors with disabilities as a valuable resource, and leverage their unique expertise. WWD should serve as equal partners in designing and implementing inclusive programs and policies to strengthen the pathways to help and safety for all victims, in all settings.

APPENDICES

Appendix 1: Consent for Participation in Interview Research

I volunteer to participate in a research project conducted by Kimberly Aguillard (principal investigator) from The University of Texas School of Public Health. I understand that the project is designed to gather information about women with disabilities' experience of violence and abuse, while living in a rural community. I understand the research is to learn about how women in this situation learn about, find, and secure help; how they cope and reclaim balance in their lives (build resilience); and about how programs and services work in local communities to aid this population. I will be one of approximately 30-35 people interviewed for this research.

1. My participation in this project is voluntary. I will be required to have access to a phone to be enrolled and participate, but there are no additional costs anticipated for the participants. By participating in this study, I may receive no direct benefit, but the information I provide may lead to increased knowledge of abuse and safety for all women with disabilities. I understand that I will receive an incentive of a \$30 gift card for my participation.
2. I understand that the discussion about my experience with violence will help create awareness of this problem, and will lead to important recommendations for organizations that provide services to other survivors with disabilities. I have also been informed that there are no serious risks to taking part in this study although there may be slight risks of fatigue while sitting for the interview or discomfort and upset by recalling earlier painful events. However, I understand that Kimberly will have resources available to share with me if I want to learn about people I can talk to when I am having a hard time. If I feel uncomfortable in any way

during the interview session, I have the right to skip answering any question or I can end the interview. I understand that I may withdraw and stop my participation at any time without penalty.

3. Participation involves an in-person or phone interview with Kimberly Aguillard. The interview will last approximately 60-90 minutes. I understand Kimberly may take notes during the interview, and she will also audio record the interview to so she can remember what I say and be sure she heard me correctly. Kimberly will also type out what I say from the recording. Then she will delete the recording. If I happen to say my name or something that might identify me or someone else, she will not include that when she types out what I say. Kimberly will not share the recording with anyone who is not directly involved in this study. The file of the recording will be stored on a password protected computer.
4. I understand that Kimberly Aguillard will not identify me by name in any reports using information gathered from this interview, and that my confidentiality (the things I share during the interview that may identify me) as a participant in this study will remain secure and private. During the interview recording Kimberly Aguillard will refer to me by my last name initial, then my first name initial (John Smith, S. J.). For all future reports or articles based on this research my identity will be protected, and my name will not be connected to my interview or any reports on the study findings.
5. I understand that no one who is not directly involved in this research study will have access to raw notes (the notes Kimberly takes during or about the interview) or transcripts (the interview written up in a document). This precaution will prevent my individual comments from having any negative consequences.

6. I have also been informed that if I talk about very recent (within the last 12 months) or current violence and abuse that has happened to me, Texas law may require Kimberly Aguillard to report the violence to the authorities.
7. I understand that this research study has been reviewed and approved by the Institutional Review Board (IRB) Committee on the Protection of Human Subjects at the University of Texas at Houston Health Science Center.
8. I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study. Participation in the interview will indicate my consent.

Appendix 2: Interview Guide

Introduction

Hello, my name is Kimberly Aguiard and I am calling from The University of Texas School of Public Health. Thank you for your willingness to take part in an interview as part of our study on safety and abuse among women with disabilities living in a rural area. Are you still willing to be interviewed?

(If the woman declines, thank her for her time. If she agrees, thank her.)

Is this a good time for you to talk with me for an hour or so? Are you in a place in which you feel safe and comfortable to talk about your experience with personal safety? OK, great.

(If this is not a good time or place for the woman, reschedule.)

Thank you for your help with this research study. Before we get started, let me tell you a little more about why we are doing this study.

The goal of this research is to learn more about how women with disabilities who experience violence in a rural community learn about, select, and access help. This research will also highlight strategies women with disabilities use to keep going, or build resilience. I am also interested in learning about your expectations with policies and programs, and your experience working with various service providers and programs while exiting the violent situation. You will have an opportunity to provide recommendations for how policies (rules) could be most supportive and effective for helping women with disabilities who experience violence.

Today, I will ask you several questions. There are no right or wrong answers for the questions. You are the expert on your life. I am here to learn from you. I will not use your name in any analysis or reporting. I will assign you a unique ID number, so your name will be protected and make sure our discussion is confidential.

I will audio record our meeting so I can remember what you say and be sure I heard you correctly. I will also type out what you say from the recording. Then I will delete the recording, because your privacy is important. If you happen to say your name or something that might identify you or someone else, I will not include that when I type it out. If I ask you any questions you do not want to answer, that is OK, you can just tell me to skip ahead.

During the interview, if a question is not clear, or you would like me to explain it in a different way, please just ask me to clarify. I will give you plenty of time to think about your answers, so please do not feel uncomfortable if pauses happen in the interview. Lastly, if you become uncomfortable or upset during the interview, you can skip a question, or end the interview altogether. That is perfectly fine. We can also take a break anytime you need one.

I need to let you know that if you discuss experiencing current violence or abuse I may be required, by law, to report this abuse to the authorities. The interview has four major topic areas: help seeking; strategies to build resilience (keep going and bounce back from this experience); barriers to accessing help; and policy expectations, experiences, and recommendations. Do you have any questions? (Pause to answer questions). If I have answered all your questions, we can begin now. Are you ready to get started? Okay, let's begin. I am turning on the audio recorder now.

Help-Seeking Processes

Q1 (Icebreaker) —Can you describe what living in this rural community is like? What is, for example, a typical week like for you here?

Probe: What are some things you like or enjoy about living in a rural area?

Probe: What is a challenge or negative aspect of living in a rural town, especially as a woman with a disability?

Q2—Can you tell me, at whatever level of detail is comfortable to you (this can be broad), about the violence you experienced?

Probe: Was this one episode or a period of violence?

Probe: Was this violence related to your disability? If so, how?

Probe: Did this affect other areas of your life such as work or social and community aspects?

Can you describe how other areas were affected by your experience with violence?

Q3—Can you describe your turning point, when you decided to get help?

Q4—Can you describe how you learned about what help was available to you?

Q5—Can you talk about how you decided what kind of help to get?

Probe: Did you confide in people? Who, and what was that like?

Probe: What other avenues did you use for help? For example, health care provider or law enforcement or shelter services? What were those experiences with service providers like?

Probe: Did you ever obtain help from a disability organization? If so, how did you feel about the help you received?

Building Resilience/Resilience Strategies

Q6- During the experience of violence and after, who or what helped you the most?

Probe: Did you rely on family, friends, or community services or aid through your place of worship?

Probe: Who/what, helped support you emotionally, that is, to think about and deal with your feelings?

Probe: What helped you materially (with resources and support such as money, clothing, shelter or housing)?

Probe: what helped you logistically (have a safety plan, transportation, or child care)??

Q7—What kept you going during your experience with violence and after you exited that situation?

Probe: Did you have any techniques for finding peace or comfort?

Probe: Did you rely on spiritual beliefs?

Q8—What helped you to heal? Can you share any lessons about recovery you learned?

Probe: Please talk about any personal qualities (ideas, skills, or approaches) that affect your recovery?

Probe: Can you talk about a time, or turning points, when your thoughts and feelings about yourself or the abusive situation changed?

Q9—How did the way you felt about yourself change from the episode of violence till now?

Probe: What kinds of things did you think about yourself before exiting the violent situation?

Probe: What kinds of things do you think are true about you now?

Barriers

Q10—Can you tell me about the process of getting help and securing safety?

Probe: What was your process like gaining information about resources that could help you or traveling to receive those services?

Probe: Can you describe how family, friends, and service providers reacted to your situation?

Q11—Can you talk about any special arrangements before or after leaving the violent situation that were complicated? Can you talk about those steps?

Probe: Can you tell me about any arrangements you had to make specific to your disability? How did this work out?

Probe: Can you think of any other issues you had to problem-solve?

Q12—Can you tell me about any services that you felt you needed, but did not get?

Probe: Were any of those services unavailable to you because of your disability-related needs?

Probe: Did you have any needs that went unmet?

Policies and Programs—Expectations, Experience and Recommendations

Q13—Can you discuss what you expected from service providers when you contacted them for help?

Probe: Were any of these expectations related to you as a woman with a disability?

Probe: How did you come to have these expectations?

Q14—How did your actual experience with service providers match or differ from your expectations?

Probe: Was your actual experience matched or differed as a woman living with a disability?

Q15—Thinking about the service providers you interacted with, do you feel they knew about disabilities and how to help someone with a disability?

Probe: What gave you this impression?

Probe: Can you give an example?

Q16—Still thinking about your experience with service providers and programs, did you feel like they were ready and able to provide you necessary accommodations?

Probe: Can you talk about what gave you that impression.

Probe: Do you have an example?

Q17—Thinking about your experience, what program or service worked well to meet your needs?

Q18—What change to a program or service may have made a positive difference, to make services or help more available to you?

Q19—Do you have anything else to share we have not talked about?

Appendix 3: Demographic Information

1. What is your age?
2. What is your race?
 - White
 - Black or African American
 - Hispanic, Latin American, or Spanish
 - Asian
 - American Indian and Alaska Native
 - Hawaiian and Other Pacific Islander
 - Some other race
 - Bi-racial or Multi-racial
 - I'd rather not say
3. What is the nature, or type, of your disability?
4. How long have you had the disability??
5. What is your highest level of education?
 - Some high school
 - High school graduation or GED
 - Some college
 - Associate's degree
 - Undergraduate degree
 - Master's degree or higher
 - I'd rather not say.

6. Which of these statements reflects your status related to working?

- I work full-time
- I work part-time
- I do not work and am not looking for work.
- I am a student.
- I have had trouble finding a job, so I am unemployed, but looking for work.

7. What is your current relationship status?

- I am single
- I have a boyfriend or girlfriend
- I am married or in a domestic partnership.
- I am divorced or separated.
- I am widowed.
- I prefer not to say.

8. Do you have children? If yes, how many children do you have??

9. What types of violence and abuse did you experience? (please indicate all that apply)

- Physical abuse (hitting, slapping, biting, strangling)
- Sexual violence (physically forcing, threatening, or intimidating for sex, forcing participation in degrading sexual acts, denial of the right to use contraceptives)
- Emotional/psychological violence (isolating from family/friends, belittling, humiliating, threats to cherished objects, other controlling behavior)
- Other abuse/controlling behavior (briefly explain)

10. How long did this violence last? Once, days, months, years?

11. Which of the following services did you work with during or after your experience of violence or being mistreated? (indicate all that apply)

- Health care services
- Law enforcement
- Mental health services (individual or group counseling)
- Emergency shelter
- Crisis hotline
- Other services through a domestic violence shelter or agency
- Help from a disability service agency or organization
- Financial help
- Legal assistance
- Second-stage (transitional) housing
- Help from family/friends
- Help from a community of faith.

12. Are you interested in participating in future studies about this subject?

Thank you so much for your time. I am going to turn the audio recorder off now.

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