DEPENDENCE, VIOLENCE AND NEGLECT IN WOMEN WITH DISABILITIES

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INTRODUCTION

According to the Centers for Disease Control and Prevention, 61 million adults in the United States, or approximately 26% of the U.S. population, report having a disability (CDC, 2018). It is generally understood that people with disabilities experience increased rates of poverty, reduced access to health care services, and social and employment barriers at higher frequencies as compared to the nondisabled population (Vallas, 2018; Rapaport, 2017; NCWD, 2016). According to the National Network to End Domestic Violence, the incidence of domestic and sexual violence is even higher than that of disability, nearing 1 in 3 women (2018). Experiences of sexual violence and abuse in a violent relationship have been associated with food and housing insecurity, losses in education and negative psychological outcomes (NNEDV, 2018). Individuals who have a disability and experience sexual violence are especially vulnerable to compounding injustice.

Women with disabilities appear to experience sexual violence at an elevated rate as compared to the nondisabled population (Basile, Breiding, & Smith, 2016; Martin et al., 2006). Research performed prior to the 1990's failed to identify contributing risk factors to explain this trend, however, Smith (2007) found that being female, disabled, unemployed, single and under the age of 40 increased one's likelihood of experiencing abuse. Recent studies have identified forms of violence unique to disability and aging, such as manipulation of medication, neglect and withholding of care (Powers, Hughes, Lund, & Wambach, 2009). Like traditional forms of sexual and interpersonal violence, this neglect is characterized by power imbalance and the exercise of control over another person. People with disabilities who rely on family members or personal care assistants to complete activities of daily living (ADLs) may be particularly vulnerable, because these relationships include an inherent imbalance of power between the giver and recipient of care services.

Respective circumstances may increase or decrease an individual's risk of experiencing violence or neglect. Individuals with disabilities each live within their own unique circumstances, thus implying that their levels of reliance on others also vary accordingly. For example, some individuals with disabilities may function completely independently, some may live semi-independently (i.e. an individual with a visual or hearing impairment), and some may exclusively rely on personal care assistants to complete ADLs (i.e. an individual with total paralysis or a severe intellectual disability). These differences in dependence may potentially put an individual at elevated risk of sexual violence and neglect; those who retain a significant level of autonomy may rely

very little on others to complete daily activities, while those with comparatively less mobility may depend on care assistants and thus be more vulnerable to abuse.

The intersection between disability, sex, and level of dependence may have significant implications for disability policy, methods of identifying victims of violence and services available to survivors of neglect and sexual abuse. This study explores the relationship between need for assistance on various tasks and experiences of sexual violence reported by women with physical disabilities and motor impairments.

CONSIDERATIONS

There has been little research done to explore sexual violence and neglect in women with disabilities with the inclusion of level of autonomy as a potential contributing risk factor. These topics (disability, autonomy, sexual violence, and neglect) are independently sensitive. For this reason, several considerations must be established in order to pursue the present study in a respectful manner:

The use of person-first language aims to refer to an individual holistically rather than emphasize observable or non-observable characteristics. Its primary purpose is to avoid the use of one's condition as a label, categorization, or definition of who they are. For example, it is more appropriate to use the phrase "person with a disability" rather than "disabled person" or "handicapped person," so as to preserve the entire autonomous individual. Person-first language is used throughout this paper in accordance with the Disability Language Style Guide (National Center on Disability and Journalism, 2018). Additionally, the potential presence of ableism was continually reevaluated to ensure that the purpose and goals of the study were not corrupted by unintentional discrimination.

While the term "sexual violence" itself is not gendered, research and discussions of sexual violence tend to focus on the experiences of women and girls rather than those of men and boys. The present study also focuses on women's experiences of sexual violence and neglect, due to the disproportionate amount of violence experienced by females. This distinction is not intended to imply that men are the sole perpetrators of violence, or that their sex insulates them from experiencing abuse, but that women are impacted at a higher frequency overall.

Lastly, people with disabilities are often labeled as members of a "vulnerable population," despite many people disagreeing with that categorization. In reality, disability exists on a spectrum and each individual has a differing set of abilities and necessary accommodations. This study continues the discussion of whether 'dependency' is synonymous with 'vulnerability' (Mackenzie, Rogers, & Dodds, 2014), and contributes to the conversation of how women with physical disabilities might preserve their senses of autonomy and forfend unwanted advances.

DATA/METHODS

Data used for the present study was collected by the Developmental Disabilities Institute at Wayne State University and the United Cerebral Palsy Association in Michigan in 2000-2001. This data is publically available on ICPSR through the University of Michigan. The variables of interest for this study are:

1. the types of tasks where assistance is needed (getting out of bed, eating, dressing, toileting, personal hygiene, moving around the home, taking medication, meal preparation and home maintenance)
2. total number of tasks where assistance is needed, and
3. women's reported experience of violence and neglect.

The hypotheses of this study are as follows:

1. Women with a higher level of dependence on others experience sexual violence and neglect at a higher rate than women with a lower level of dependence. [61]
2. Some types of assistance will predict experiences of sexual violence/neglect at higher rates than others. [62]
3. These differences in experiences of sexual violence and neglect will persist when analyses are controlled for age and ethnicity.

177 women with physical disabilities were surveyed in 2000-2001 to identify the types of activities they needed assistance to complete and their experience of neglect and sexual violence. Tables of descriptive statistics are located in Appendix A. Data were standardized prior to analysis, and a summary variable of the total number of tasks where assistance was needed was calculated to serve as an indicator of dependence on others (variable name *ztotal*). Bivariate linear regression analyses were performed on the hypothesized relationships to identify those of significance. All hypotheses were tested at $\alpha = .05$ level of significance.

RESULTS

The results of the primary hypothesis indicate that women with a higher level of dependence on others did not experience violence at a significantly higher rate [$t\ (1,171) = -.75$, $p = .457$], but did experience neglect at a significantly higher rate than women with a lower level of dependence [$t\ (1,170) = 2.14$, $p = .033$]. These results persisted when the regression was controlled for age and ethnicity (Appendix B).

Analyses performed on the variables 'home maintenance,' 'assistance taking medication,' and 'neglect'. Results of the analysis indicate that women who needed assistance with home maintenance reported neglect at a significantly higher rate than those who did not need assistance [$t\ (1,172) = 2.16$, $p = .032$]. Women who needed

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[61] H_0: $\mu_{\text{higher dependence}} = \mu_{\text{lower dependence}}$, where μ refers to the average violence or neglect experienced
H_A: $\mu_{\text{higher dependence}} \neq \mu_{\text{lower dependence}}$

[62] H_0: $\mu_{\text{type of assistance}} = \mu_{\text{other types of assistance}}$, where μ refers to the average violence or neglect experienced
H_A: $\mu_{\text{type of assistance}} \neq \mu_{\text{other types of assistance}}$

assistance taking medication also reported neglect at a significantly higher rate than those who did not need assistance taking medication [t (1,174) = 2.07, p = .04], These results persisted when controlled for age and ethnicity (Appendix C).

Women who needed assistance getting in and out of bed also experienced neglect at a higher rate than those who did not need assistance, though this was only significant at the $\alpha = .10$ level of significance [t (1,173) = 1.95, p = 0.053]. These results persisted when controlled for age and ethnicity (Appendix D).

DISCUSSION

The findings of this study indicate that women who reported needing assistance on a higher number of tasks experienced neglect at a higher rate than women who needed assistance on fewer tasks. More specifically, women who needed assistance maintaining their home, taking medication, and getting in and out of bed reported neglect at higher rates than women who needed assistance on other tasks.

The results of this research are consistent with several studies which found high prevalence rates of maltreatment and neglect in people with disabilities (Sullivan & Knitson, 2000; Findley, Plummer, & McMahon, 2015). Findings of the present study contrast a number of previous studies, however, as this study did not identify a linear relationship between one's level of dependence and experiences of sexual violence (Brownridge, 2006; Erwin, 2000; Martin et. al, 2006;). Previous studies did not attempt to draw a relation between level of dependence and rate of abuse and neglect.

Several, but not all, tasks that rely on a certain threshold of mobility were found to be associated with higher levels of neglect. The extent of neglect experienced by the women (e.g. withholding of care, manipulation) is unclear. Future research may explore the relationship between mobility and abuse and neglect.

LIMITATIONS

The external validity of this study is limited in a number of ways. This study's small pool of participants exclusively consisted of women with physical disabilities, and did not include women with intellectual or cognitive disabilities. The experiences between these two populations may differ significantly. Women with intellectual or cognitive disabilities may perceive power dynamics and experience exploitation in a more pronounced way due to economic dependence, and may experience higher levels of control imposed on their daily lives from others (Benedet & Grant, 2014). Additionally, these findings are not generalizable to men or people who identify as LGBTQ+ with disabilities, as these populations may have unique experiences and considerations.

In addition, the data analyzed was collected in 2000-2001, and just 100 of the 177 participants reported having experienced sexual violence or neglect at least once. This sample is small and prone to self-selection bias due to the sampling method used in the original study (which consisted of sending letters and flyers to disability advocacy

organizations, submitting announcements to newsletters, and sending informational mailings to physical therapists and domestic abuse programs). It is also generally understood that relying on self-reporting by participants to gather data on sensitive topics results in systematic underestimation the true magnitude of prevalence (Garcia & Gustavson, 1997). This may explain why the findings of this study did not identify a relationship between level of dependence and experiences of sexual violence (type II error), as women may hesitate to report experiences due to fear of retaliation or associated stigma. Due to recent increases in discussions surrounding sexual assault (as a result of the #MeToo Movement) and increased visibility and inclusion of people with disabilities, more women may be willing to disclose their experiences of violence and neglect today compared to 2000-2001. Replication of this study may result in a larger sample size, as well as increased willingness among participants to disclose experiences of violence and neglect.

Finally, and perhaps most importantly, this study assumes that one's need for assistance in completing certain tasks is a proxy for their level of dependence on others. In reality, autonomy is a complex indicator and may exist as a spectrum. Due to unexplored confounding factors, people with disabilities who have a low level of dependence on others may remain more susceptible to violence or neglect compared to the nondisabled population. Omitted variables unrelated to dependence may account for increased risk of assault or neglect, such as living environment during childhood, family history of domestic violence, previous experiences of violence, cumulative exposure to violence over the lifetime, level of education regarding preventative interventions, and informal institutions/normative frameworks in the cultural context (Dabby & Poore, 2007; INSPQ, 2019).

POLICY IMPLICATIONS AND CONCLUSION

Despite these limitations, the findings of this study offer insight into several research and policy implications for people with disabilities. This study may help inform future educational and preventative programming meant to protect people with disabilities from sexual violence and neglect. This may include:

- human-centered awareness trainings for personal care assistants or family members who serve in this role.
- trainings oriented toward individuals with disabilities themselves, to include educational programming on signs of neglect and abuse, as well as actions they may take if they are victimized
- internal accountability improvements in institutions that provide patient care

Once an instance of abuse or neglect occurs, it is essential that the survivor has access to the resources they need. While one's level of dependence on others may put an individual at elevated risk of violence and neglect, it may also act as an additional barrier

to seeking safety following an instance of abuse. Many nondisabled survivors of violence endure long periods of abuse before ever seeking help due to many existing barriers, including (but not limited to) stigma, isolation from others, and financial dependence on their spouse. These barriers may be heightened for people with disabilities living in abusive settings, who may be unable to escape their circumstance due to limited physical mobility, unique verbal abilities, and limited access to healthcare (Barrett, O'Day, Roche, Lepidus Carlson, 2009; Saxton et. al, 2001). Prevention measures aside, ensuring that people with disabilities have the means to escape from an abusive environment without enduring further harm should be paramount.

Future revisions to disability policy may include:

- introduction of disability awareness or sensitivity training for responders to domestic violence situations (including EMTs and law enforcement officers)
- instruction of appropriate communication with people with disabilities
- implementation of human-centered approaches that keep survivors in control of their circumstances

Additionally, centers for survivors of domestic violence may not presently be able to accomodate the needs of people with disabilities (i.e. purchasing of equipment, accessible lodging, and disability-related medical services) due to scarce resources (Chang et. al, 2004). Future policy revisions might consider taking steps to:

- increase funding appropriations to emergency shelters for the purchasing of equipment and medical services
- increase the number of ADA-compliant emergency shelters

In conclusion, while visibility and acknowledgement of sexual violence and disability have increased over recent decades, these gains have occurred slowly and research into their overlap is exceedingly scarce in academia. This study attempted to explain one relationship between intersecting identities and compounding experiences of injustice. Ableism, or discrimination against people with disabilities, can take many forms and may not be immediately recognized. Ableism is often unconsciously perpetrated by well-intentioned, nondisabled people in their language and behaviors. To combat ableism, advocacy must at its core ensure that the inclusion of individuals with disabilities is prioritized, and that their voices are not overshadowed by able-bodied advocates. Future research must thoroughly explore the needs of people with concurrent identities in order to push policymakers and legislators to effectively serve all people.

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APPENDIX A

```
. tab AGE
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AGE	Freq.	Percent	Cum.
20-29	14	7.91	7.91
30-34	13	7.34	15.25
35-39	28	15.82	31.07
40-44	34	19.21	50.28
45-49	22	12.43	62.71
50-54	31	17.51	80.23
55-59	19	10.73	90.96
60+	15	8.47	99.44
Unknown	1	0.56	100.00
Total	177	100.00	

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. tab ETHNIC
```

ETHNICITY	Freq.	Percent	Cum.
Caucasian	139	78.53	78.53
African American	28	15.82	94.35
Other	10	5.65	100.00
Total	177	100.00	

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. tab DISABIL2
```

TYPE OF DISABILITY-2	Freq.	Percent	Cum.
None	113	63.84	63.84
Stroke	1	0.56	64.41
Multiple sclerosis	1	0.56	64.97
Visual impairment	5	2.82	67.80
Traumatic brain injury	7	3.95	71.75
Hearing impairment	6	3.39	75.14
Spinal cord injury	3	1.69	76.84
Arthritis	14	7.91	84.75
Other	27	15.25	100.00
Total	177	100.00	

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. tab MULTIDIS
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MULTIPLE DISABILITY	Freq.	Percent	Cum.
No	117	66.10	66.10
Yes	60	33.90	100.00
Total	177	100.00	

APPENDIX B

```
. regress zneglect ztotal

      Source |       SS           df       MS      Number of obs   =       171
-------------+----------------------------------   F(1, 169)       =      4.60
       Model |  4.4716523         1  4.4716523    Prob > F        =    0.0334
    Residual |   164.3599       169  .972543788   R-squared       =    0.0265
-------------+----------------------------------   Adj R-squared   =    0.0207
       Total | 168.831552       170  .993126779   Root MSE        =    .98618

------------------------------------------------------------------------------
    zneglect |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
      ztotal |   .1635329   .0762651     2.14   0.033      .012978    .3140878
       _cons |   -.006302   .0754198    -0.08   0.934    -.1551882    .1425842
------------------------------------------------------------------------------
```

```
. regress zneglect ztotal zage zethnicity

      Source |       SS           df       MS      Number of obs   =       171
-------------+----------------------------------   F(3, 167)       =      1.59
       Model | 4.68894668         3  1.56298223   Prob > F        =    0.1937
    Residual | 164.142606       167  .982889855   R-squared       =    0.0278
-------------+----------------------------------   Adj R-squared   =    0.0103
       Total | 168.831552       170  .993126779   Root MSE        =    .99141

------------------------------------------------------------------------------
    zneglect |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
      ztotal |   .1649107   .0772631     2.13   0.034     .0123724    .3174491
        zage |   .0060609   .0765733     0.08   0.937    -.1451155    .1572373
  zethnicity |   .0357217   .0761638     0.47   0.640    -.1146463    .1860897
       _cons |  -.0060546   .0758286    -0.08   0.936    -.1557608    .1436517
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APPENDIX C

```
. reg zneglect zhomemain

      Source |       SS       df       MS              Number of obs =     174
-------------+------------------------------           F(1, 172)     =    4.66
       Model |  4.54224685     1  4.54224685           Prob > F      =  0.0322
    Residual |  167.552273   172  .974141123           R-squared     =  0.0264
-------------+------------------------------           Adj R-squared =  0.0207
       Total |   172.09452   173  .994766012           Root MSE      =  .98699

------------------------------------------------------------------------------
   zneglect |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
  zhomemain |   .1621115    .075074     2.16   0.032     .0139266    .3102964
      _cons |  -.0047264   .0748246    -0.06   0.950    -.1524192    .1429664
------------------------------------------------------------------------------


. reg zneglect zmedications

      Source |       SS       df       MS              Number of obs =     175
-------------+------------------------------           F(1, 173)     =    4.30
       Model |  4.18313737     1  4.18313737           Prob > F      =  0.0396
    Residual |   168.26007   173  .972601563           R-squared     =  0.0243
-------------+------------------------------           Adj R-squared =  0.0186
       Total |  172.443208   174  .991052918           Root MSE      =  .98621

------------------------------------------------------------------------------
    zneglect |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
zmedications |   .1576331   .0760088     2.07   0.040     .0076091     .307657
       _cons |  -.0067945   .0745585    -0.09   0.927     -.153956    .1403669
------------------------------------------------------------------------------
```

APPENDIX D

```
. reg zneglect zbed

      Source |       SS           df       MS      Number of obs   =       175
-------------+----------------------------------   F(1, 173)       =      3.79
       Model |  3.69345772         1  3.69345772   Prob > F        =    0.0533
    Residual |   168.74975       173  .975432081   R-squared       =    0.0214
-------------+----------------------------------   Adj R-squared   =    0.0158
       Total |  172.443208       174  .991052918   Root MSE        =    .98764

------------------------------------------------------------------------------
    zneglect |      Coef.   Std. Err.      t    P>|t|     [95% Conf. Interval]
-------------+----------------------------------------------------------------
        zbed |   .1490637   .0766044     1.95   0.053    -.0021359    .3002634
       _cons |  -.0065947   .0746697    -0.09   0.930    -.1539757    .1407863
------------------------------------------------------------------------------
```