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Is Disability Exclusion Associated with Experiencing an Unmet Need for Health Care?

Abstract (150 words)

Objective: Examine the association between disability exclusion and experiencing an unmet need for accessing health care.

Methods: The 2015 Survey of Disability Ageing and Carers was used to measure the prevalence of unmet needs for health care stratified by measures of exclusion. Log-Poisson models were fitted to examine the association between discrimination, avoidance and experiencing unmet needs for care.

Results: Approximately 10% of respondents reported unmet need to attend a GP, dentist or hospital and 25% reported unmet need to obtain to dental treatment. For those reporting an instance of discrimination in the last 12 months, the rates of experiencing unmet needs for healthcare was significantly higher (GP-29%, specialist-26%, dental -46%, hospital-18%). With controls included, discrimination or avoidance significantly increased the probability of reporting an unmet need for health care regardless of the context of previous experiences of exclusion.

Conclusion: Disability discrimination or avoidance is strongly associated with experiencing an unmet need for health care among older people with disabilities.

Keywords: Ageing, Disability, Discrimination, Health Care Access.

Impact Statement (50 words)

Disability discrimination and avoidance are strongly associated with reporting unmet needs for health care. , regardless of the context of previous experiences of exclusion. Addressing exclusion is important, in part, to reduce the likelihood of negative consequences of non-adherence to treatment regimes and deteriorating physical and mental health outcomes in later life.

Introduction

A considerable evidence base exists on the high levels of stigma facing people living with disabilities [1-3]. Australian studies have estimated population-level prevalence rates of disability discrimination (unfair treatment attributed to disability specifically) in the working age population (14%), in later life (4.5%) and across the full life course (9%) [4-6]. Levels of discrimination more generally (attributed to a range of characteristics, eg. nationality) are higher among older people with disabilities (15%), relative to their peers (9%) [7]. Moreover, recent research evidence suggests that as much as 1 in 4 older people with a disability avoid contexts or situations due specifically to their disabilities [4]. This may occur because of previous or anticipated experiences of discrimination, or accessibility barriers that prevent them from engaging in a range of situations or contexts, including accessing healthcare [5].

This is important as recent research has underscored the difficulties faced by those with chronic conditions and disabilities accessing healthcare in the Australian healthcare system. In particular, studies have underscored the importance of high out of pocket healthcare costs relative to income, contributing to avoidance of treatment [8 - 10]. For those experiencing poor health, it can have a deleterious impact on financial wellbeing due to withdrawal from the labour market alongside increased proportions of household expenditure being allocated to healthcare [11, 12]. Among older Australians specifically, barriers to healthcare have included problems with cost and financial constraints, but also with long waiting times and the unavailability of appointments, with the problem marked for those with multiple health conditions and disabilities [12]. For some, health literacy and language constraints may impose barriers to healthcare for older people and those living with a disability [13].

Although these studies have increased our knowledge about discrimination and barriers to health care experienced by people with disabilities, there is a paucity of Australian empirical evidence on experiences of disability discrimination and the likelihood of experiencing barriers to health care. For people with disabilities, barriers to healthcare include problems that are structural, financial and spatial in nature, as well as those that are personal and cultural – including stigma and discrimination [14-18]. Indeed, international studies show exposure to discrimination reported by people with disabilities is significantly associated with poor healthcare seeking behaviors, and barriers to healthcare [18-20]. These international studies on disabilities are consistent with a wide-ranging literature on how discrimination in its many guises is associated with deleterious health outcomes, including experiencing barriers to healthcare [21-23].

The concept of unmet needs for healthcare is a useful measure to gauge into different dimensions of barriers to healthcare in disability research. An unmet need for healthcare arises when an individual did not receive care when needed, or when the care received was not adequate or suitable for the health conditions [24]. An unmet need can thus manifest in different forms. Allin et al [25] proposed that it can occur when an individual did not realise that healthcare is needed (*unperceived unmet need*); when the individual recognizes that care is needed but chooses not to seek care (*subjective, chosen unmet need*); when the individual recognizes the need of care but does not access it because of barriers outside of their control, such as costs, travel costs, or other forms of infrastructure/physical barriers (*subjective, not-chosen unmet need*); when the individual perceives a need of care but receive treatment seen as inadequate by clinicians (*subjective, clinical-validated unmet need*); or when an individual perceived a need for care but

received treatment that she/he deems as suitable (*subjective unmet expectations*) [p466]. Population level studies aiming to estimate the prevalence of unmet needs for healthcare has used a widely used instrument of self-reported/subjective unmet needs, drawn from a yes/no question in national and cross-country surveys phrased along the line of: "Was there a time in the last 12 months when you needed health care but did not receive it?" [24, 26, 27]. Studies suggest that adults with disabilities are more likely to report unmet needs than non-disabled adult highlighting concerns pertaining to health inequalities [24, 26, 28]. Higher levels of unmet needs among persons with disabilities relative to those without is associated with new health problems and accelerated ageing [29].

In this paper, we seek to answer two questions regarding disability exclusion and self-reported unmet needs for healthcare among older Australians living with a disability (aged 55 and over). Firstly, how does the prevalence of reporting an unmet need for health care at different points in the health care system (GP, specialists, dental and hospital services) differ by respondents' exposure to disability discrimination or disability avoidance. Second, with controls for background demographic, economic and health factors, does exposure to discrimination or avoidance remain associated with experiencing an unmet need for health care?

Methods

Data

To answer these questions, we draw upon unit record data from the 2015 Survey of Disability, Ageing and Carers (SDAC) conducted by the Australian Bureau of Statistics (ABS) between July and December 2015. The survey collected information from persons living in private dwellings,

in self-care retirement villages and in cared accommodation. The modules measuring disability exclusion were collected in the household component of the survey – which the ABS defined as including those living in both private dwellings and self-care retirement villages. Approximately 25,555 households fully responded to SDAC, with a response rate of 80%. The module on disability exclusion were only collected from persons living with a disability in private house households. Herein we restrict our sample to those aged 55 and over. As noted elsewhere, the age group 55-59 presents a unique turning point in disability prevalence in Australia [30-31]. From this point in the age distribution, the age-sex specific prevalence of disability significantly exceeds the population average. Moreover, this age cutoff is commonly used in Australian studies of ageing, as it represents a point at which many Australians can access private superannuation and retire should they have the desire and means [30].

The ABS collect these data under the *Census and Statistics Act 1905* and confidentialised data for this study were made available through the ABS and Universities Australia agreement. Ethics approval for this project was granted by the Melbourne School of Population and Global Health Human Ethics Advisory Group (HEAG) – Ethics ID: 1953686.1.

Measurement of Disability

The ABS definition of disability is "any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months" [31]. The measurement of disability used by the ABS follows the World Health Organisation's international classification of functioning, disability and health [32]. This framework views disability as not just based on the presence of a health condition, but also upon the condition restricting activities in an

ongoing manner. The definition is operationalised using over 100 questions, conducted face-to-face in the household component of the survey.

Measurement of Exclusion

Operationalisation of disability exclusion is available in SDAC through the concepts of discrimination and avoidance. The measure of discrimination is based on response to the question "In the last 12 months do you feel that you have experienced discrimination or have been treated unfairly by others because of your condition/s?" The measurement of avoidance is based on response to the question "In the last 12 months have you avoided situations because of your condition(s)?" Respondents answering yes to these questions were asked about the source or context of discrimination and avoidance. In this study, we define three contexts of avoidance or discrimination: 1. Any context, 2. A healthcare context, 3. Any context excluding health care. Further information on this measure is detailed elsewhere in this volume [5].

Measurement of Unmet Needs for Health Care

Separate modules measuring unmet needs for health care were included in SDAC for General Practitioner (GP) services (module 16.2), medical specialists (module 16.4), dental (module 16.5) and hospital admissions (module 16.7). The content of each module is different; however, a similar question is used to measure experiencing an unmet need for care at each. For example, in the medical specialist module, respondents were asked "Since last year, has there been any time you needed to go to a medical specialist but didn't?" Similarly, in the hospital module, respondents were asked "Since last year, has there been any time you needed to go to hospital but didn't?". The broader measures in each module enable a disaggregation of three important groups: 1. Those not

requiring care at each point-of-care, 2. Those requiring care and who received it, 3. Those requiring care and did not receive it. For calculations of prevalence of unmet needs for care, as well as the regression models, the relevant populations are groups 2 and 3, with the later group defined as experiencing an unmet need for care.

Statistical Tests

To examine differences in the prevalence of unmet needs for care by exposure to discrimination and avoidance, we present weighted tests of proportions. To model the association between discrimination, avoidance and unmet needs for health care, we fit modified log-Poisson models [33]. This technique utilises a Poisson variance and log link function with a robust variance-covariance matrix of estimators, optimised by maximum likelihood [33]. Using the raw modified log-Poisson coefficients, we calculated prevalence ratios (PR) which measured the change in the probability of experiencing an unmet need for care given a change in exposure to discrimination or avoidance, once all other factors in the model were controlled for. Control variables included age, sex, country of birth (Australia, English speaking countries, Non-English-speaking country), social marital status (married, separated/divorced, widowed, never married), region of residence (major cities, inner regional areas, other), household income decile and severity of disability (profound or severe, moderate or mild, no core limitations). Separate models were fitted for avoidance and discrimination within each point-of-of-care unmet need model (GP, specialist, dental and hospital). Moreover, we separate the source of discrimination into two components: within healthcare settings and all other settings. For avoidance models, we only include avoidance in general settings. We did not include a model examining the relationship between avoidance in

healthcare settings and unmet needs for healthcare as this is likely to be endogenous. We nonetheless present the descriptive statistics.

Results

Table 1 displays prevalence rates of experiencing an unmet need to care disaggregate by measures of exclusion, socio-economic and health characteristics. In this population of older Australians living with a disability, approximately 12% report an unmet need to GPs, 9% an unmet need to specialists, 26% an unmet need to dental care and 7% an unmet need to hospital services. Across each of these points-of-care, the likelihood of experiencing an unmet need to care is significantly higher for those reporting discrimination or avoidance. For example, 29% reporting discrimination reported an unmet need to GPs relative to 11% of those not reporting discrimination. Approximately 15% of those reporting avoidance reported an unmet need to specialist care relative to 7% of those not reporting avoidance.

Results in table 1 also disaggregate unmet needs for care disaggregated by whether previous instances of discrimination or avoidance occurred in healthcare contexts or other contexts or situations. With the exception of health context discrimination in hospital settings, any form of avoidance or discrimination has a heightened level of exposure to unmet needs for health care.

Apart from differing by these measures of exclusion, the descriptive statistics uncover a range of population sub-groups at a heightened risk of reporting unmet needs for care. Across all points-of-care, the prevalence of experiencing an unmet need reduces with age and only negligible

differences are observed by gender. Older persons who have been separated or divorced are more likely to report an unmet need relative to their married peers and high levels of education and household income appear to be protective against experiencing an unmet need to care particularly for dental services. For GP, dental and hospital services, those living with a severe or moderate disability are at a heightened risk of experiencing an unmet need to care, as are those living outside of cities or inner regional areas of Australia. These variations in unmet needs for care that we observe by socio-economic and health characteristics are important and need to be controlled for to determine whether disability exclusion is associated with experiencing an unmet need to care, or is simply confounded by some other characteristic.

Table 2 presents prevalence ratios estimated from the log-Poisson models for each point-of-care. Even with extensive controls for demographic, economic and disability severity, exposure to discrimination or avoidance (invariant to context) was associated with experiencing an unmet need for care at each point-of-care. For discrimination, prevalence ratios ranged from 1.37 $p<0.001$ for dental to 1.97 $p<0.001$ for specialists. Specifically, once controlling for all other factors in the model, exposure to discrimination increases the probability of experiencing an unmet need to specialist care by almost double (PR=1.97). For avoidance, prevalence ratios ranged from 1.36 $p<0.001$ for dental to 2.02 $p<0.001$ for G.Ps.

Results in table 3 present prevalence ratios (PR) from separate log-Poisson models which disaggregate the source of discrimination attributed to health care or other settings, and exclusion attributed to avoidance in general settings. For the discrimination models, exposure to discrimination significantly increased the probability of experiencing an unmet need for care from

GPs, specialists and dental care. Confirming the descriptive statistics displayed earlier in Table 1, discrimination in other settings is associated with an unmet need to hospital care (PR=1.89 $p<0.001$), but the effect is not significant for exposure to discrimination in healthcare settings ($p>0.1$). Avoidance in general settings is also associated with unmet need for care at each point-of-care.

Discussion

Motivated by international evidence on the association between exposure to disability discrimination and experiencing an unmet need for healthcare, we sought to examine (1.) whether the prevalence of experiencing an unmet need to health care at different points in the healthcare system differed by exposure to disability exclusion? and (2.) With controls for economic, demographic and health characteristics included, does exposure to disability exclusion increase the likelihood of experiencing an unmet need for care.

Mirroring prior international studies, we find that both discrimination and avoidance due to disability is strongly associated with experiencing an unmet need to healthcare, and that this differed along points in the health care system. This finding is important as people with disabilities have a high reliance on health care and other services and experiencing an unmet need for care may lead to higher rates of treatment discontinuation, suboptimal therapeutic care and increased patient safety concerns resulting in worsening health [34]. Moreover, exposure to discrimination in a healthcare setting specifically may lead to deleterious health outcomes. Longitudinal evidence from the US Health and Retirement Survey shows that about 1 in 5 persons aged over 50

experienced some form of healthcare discrimination and that frequent exposure to discrimination was strongly associated with new or worsening disabilities over a 4-year time period [35] .

This raises the question of how does disability discrimination within healthcare contexts may manifest? Drainoni et al (2006), posit that cultural barriers to healthcare among people with disabilities may be related to insufficient knowledge and misconceptions about people with disabilities, insensitivity and disrespect, failure to take patients and caregivers seriously and a reluctance or unwillingness to provide care [18]. In their examination of people in the UK with intellectual disabilities, they cite discrimination manifesting as substandard care and problems with staff attitudes, knowledge and behaviour [20]. In the Australian context, responses to a 2009 enquiry underscored "that many in health and allied health sector receive very little training regarding disability and therefore have little understanding of the health needs of people with disabilities. More disturbingly, some argued that myths and misconceptions regarding disability are affecting clinical decision and compromising quality of care… submission argued that despite their training, health professionals hold the same beliefs and misconceptions about disability as the rest of the community" [36, p 32-33]. This fact and its deleterious impacts have been demonstrated in response to racial discrimination. This in turn has resulted in the development of principles, training and curricula to improve the cultural safety of care [37, 38]. These measures can be further strengthened through the addition of cultural safety to professional standards [39. 40]. A similar raft of measures is required to improve the understanding of disability by health professional and ensure that the rights of people with disabilities are not compromised in seeking the healthcare that is vital to their well being.

However, our results further show that experiencing discrimination and avoidance in non-health care contexts is also associated with unmet needs for care. This supports earlier studies suggesting association between perceived discrimination in non-healthcare settings on the one hand, and underutilization of medical and mental health care on the other [41, 42]. One potential explanation for this result is the notion of 'label avoidance'. Experiencing discrimination in everyday settings has been linked to 'label avoidance' which involves the active avoidance of contexts around service use such as social services, medical treatment, and education and workplaces. This is a direct result of a fear of public consequences of being labelled [1]. This result also underscores the significant levels of disability stigma in Australia generally [36].

Interestingly, we did not find a significant association between perceived disability discrimination within healthcare contexts with unmet needs to hospital services in our sample. This finding is consistent with the finding elsewhere in this special feature showing that avoidance of healthcare due to disability had a significantly lower prevalence rate than discrimination in healthcare settings – indicating that some people with disabilities have no option but to expose themselves to contexts in which they may experience discrimination to attend to their healthcare [5]. Moreover, hospital visits by their nature, are generally more acute, rather than chronic. Unmet needs are less likely to manifest given that accessing hospital services has an urgent and unexpected nature. Conversely, accessing primary care – through a GP for example - is more routine and less unexpected. While unmet needs for hospital services for acute medical conditions may be associated with more severe health consequences relative to unmet needs associated with primary care, the cumulative impact of unmet needs for primary care and dental services, for example suboptimal management of a chronic condition, also has the potential to manifest in poorer health outcomes [43].

We further found that the prevalence of experiencing an unmet need for healthcare differed considerably by points in the health care system, but was highest in dental care. For those reporting an instance of discrimination and/or avoidance in any context in the last 12 months, the rates of experiencing an unmet need for dental care were significantly higher that those who did not report disability exclusion.

In Australia, although primary care, pharmaceuticals and hospital services are subsidised through universal health care, dental services are not. It is estimated that annually, over 2 million Australians reported avoiding or delaying dental care due to the cost [43]. Of those who did attend a dentist, a fifth reported that cost prevented them from following the treatment recommendations [44]. Access to dental care is particularly problematic for Australians with a disability on lower incomes, as shown by the strongly significant effects of income in our analysis. People on lower-incomes generally have poorer oral health and poor oral health is associated with health problems such as diabetes and cardiovascular disease. Poor oral health is also costly [43]. Left untreated, people with poor oral health end up using services and experiencing ill health that would have been prevented with earlier intervention. Indeed, the AIHW estimated that in 2016-17 over 70,000 hospitalisations for dental conditions could have been prevented with earlier treatment [45]. Our findings provide strong evidence that unmet needs for dental care is particularly problematic for older Australians living with a disability, and that this accumulates with an experience of disability discrimination.

Independent of measures of exclusion, we found variation in unmet needs for healthcare by demographic, economic and health characteristics. The association between experiencing disability exclusion and unmet needs for care weakens by age. This finding can be explained through the concept of immortal time bias [46]. Due to the cross-sectional survey design, death cannot occur. This is compounded by the fact that people who have unfettered access to health care will likely live longer and be healthier. However, a robust conclusion on the association between perceived discrimination/avoidance, age, and unmet needs for health care cannot be ascertained, given the cross-sectional nature of the data set where observations are censored by higher rates of mortality in later life. As expected, severity of disability moderates the effect of perceived discrimination on unmet needs for health care.

Limitations

Interpretation of our findings needs to be balanced by the limitations of the data and analysis. Firstly, the measures of exclusion are all self-reported and may be subject to bias due to (1.) recall over a 12-month period, (2.) some respondents may feel uncomfortable disclosing instances of exclusion, (3.) not all measures of perceived discrimination may be actual discrimination. Moreover, the SDAC modules on discrimination only includes persons living in private dwellings. Further data collections would be necessary to examine the generalizability of these findings presented herein to individuals living in cared accommodation and other institutions (non-private dwellings).

Furthermore, the discrimination and avoidance questions were asked of those who responded to personal interview (n=6533). An additional (n=661) were people living with a disability in households, but interviews were conducted by a proxy and therefore the ABS did not ask the

discrimination or avoidance modules. The ABS note that proxy interviews in the household component were used for "those incapable of answering for themselves due to illness, impairment, injury or language problems" [31]. This raises the question of due to the omission of this population, does it bias our measures of exclusion downwards; and thus weaken the observed association with experiencing an unmet need for healthcare? A further limitation of our analyses is the inability to consider the barriers facing older Aboriginal and Torres Strait Islander people living with disabilities. Unfortunately, the flag indicating Aboriginal status is not released in the SDAC RADL microdata.

Conclusion

Among older Australians with disabilities, exposure to discrimination or engaging in avoidance behaviours in any context was associated with reporting an unmet need for care from GPs, medical specialists, hospitals and dentists. The unmet needs for dental services were particularly acute for people with disabilities, with this problem exacerbated by exposure to discrimination. The potential consequence to these unmet needs is limited access to care, poor health and worsening health inequities. More generally, from a health service perspective, adjustments need to be made to address disability exclusion. With the forecast growth in the number of older Australian with profound disabilities considerable over the next 20 years, addressing broader challenges on social exclusion is paramount from a health services perspective in an ageing Australia. Ensuring equal healthcare access without fear of discrimination (in any context) is key to protecting the health of older people with disabilities and enabling participation in all aspects of economic and community life in Australia.

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