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## Association between perceived discrimination and healthcare-seeking behavior in people with a disability

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### ABSTRACT

**Background:** Experiences of discrimination lead people from vulnerable groups to avoid medical healthcare. It is yet to be known if such experiences affect people with disabilities (PWD) in the same manner.

**Objectives:** To determine the association between perceived discrimination and healthcare-seeking behavior in people with disabilities and to explore differences of this association across disability types.

**Methods:** We performed a cross-sectional study with data from a national survey of people with disabilities. Perceived discrimination and care-seeking behavior were measured as self-reports from the survey. Dependence for daily life activities, possession of health insurance, and other disability-related variables were included and considered as confounders. We used Poisson regression models and techniques for multistage sampling in the analyses. A stratified analysis was used to explore effects of discrimination across types of disability.

**Results:** Most of PWD were 65 years or older (67.1%). Prevalence of healthcare seeking was 78.8% in those who perceived discrimination, and 86.1% in those who did not. After adjusting for potential confounders, the probability of not seeking care was higher in people who reported perceived discrimination (adjusted PR = 1.15; 95%CI: 1.04–1.28). In a stratified analysis, significant effects of discrimination were found in people with communication disability (adjusted PR = 1.34, 95%CI: 1.07–1.67) and with physical disability (adjusted PR = 1.17, 95%CI: 1.03–1.34).

**Conclusions:** People with disabilities that perceive discrimination are less likely to seek healthcare. This association was higher for people with communication and physical disabilities. These results provide evidence to institutions who attempt to tackle discrimination.

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## 1. Introduction

Discrimination is defined as unequal treatment of individuals based on certain characteristics. Examples of discrimination include racism, sexism, and religious discrimination and are commonly manifested as verbal abuse or physical attacks.<sup>1</sup> Previous research has shown that discriminatory experiences have a negative effect on many aspects of a person's health.<sup>2,3</sup> For example, people who report experiences of discrimination are more likely to have depressive symptoms or alcohol consumption problems.<sup>4–6</sup> Moreover, the perception of discrimination prevents people from going to places where they perceive discrimination to occur, such as

workplaces, group meetings, and hospital or other clinical care centers.<sup>7–9</sup>

Healthcare seeking behaviors are considered important determinants of health as reports have shown that average self-reported health is higher among people who seek healthcare services compared with people who do not.<sup>10</sup> Discriminated groups like African-Americans or certain religious groups are more likely to refrain from seeking medical attention or underutilize medical services than non-discriminated groups, leading to worse health outcomes.<sup>6,11</sup>

Disability discrimination is also a concerning issue. The experience of acquiring a disability can affect people's perception of themselves and their capacities, and experiences of discrimination due to their condition are often reported<sup>12</sup> and linked to a decreased acceptance of their disability, development of depressive symptoms and abuse.<sup>13</sup>

PWD require more frequent healthcare visits compared to

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others, but it remains to be seen if they experience discrimination differently from other discriminated groups. In addition, while prior studies have shown that PWD were more likely to refrain from seeking medical treatment due to discrimination, the scope of these studies has been limited to the clinical setting and did not consider experiences outside of healthcare institutions. Furthermore, these studies did not differentiate between different types of disabilities.<sup>11,14</sup>

We aim to analyze data from a national disability survey done in Peru to determine the association between perceived discrimination and healthcare-seeking behaviors among PWD and to compare this association among various types of disabilities. Results from the survey will help identify patterns of healthcare access for PWD, and can be used to develop strategies for combating discrimination.

## 2. Methods

### 2.1. Study design and location

We performed a secondary analysis using data from the Specialized National Disability Survey, (ENEDIS, by its Spanish acronym) from Peru.<sup>15</sup> This survey was conducted between 2012 and 2013, by the Peruvian Institute of Statistics and Informatics in order to identify the prevalence and types of disability nationwide and to analyze the healthcare needs of PWD.

### 2.2. Participant's selection

The ENEDIS classified 37,524 people with at least one disability, as defined by the Washington group on Disability Statistics criteria.<sup>16</sup> Types of disability assessed were physical disability, visual disability, hearing disability, communication disability and cognitive disability. Despite self-care disability is also included in the Washington criteria; it was not included in ENEDIS.

Among those surveyed, we selected only individuals aged 18 years or older who have had an injury or symptom in the last six months ( $n = 24,252$ ). People who reported not needing medical assistance for their symptoms or injuries ( $n = 1808$ ) and those with uncompleted questionnaires ( $n = 31$ ) were excluded. After exclusion, 22,413 individuals met the inclusion criteria and were included in the final analysis.

### 2.3. Sampling procedures

The sample for the survey was obtained following a two-step probability sampling. In the first step, clusters of residential blocks (primary sampling units) were randomly selected from each testing location, both urban and rural cities. After selection of clusters, a census of all included households (secondary sampling units) was conducted to find PWD and collect information about their demographic characteristics. Finally, people who reported having a disability were asked to complete a survey about the characteristics of their disabilities, access to healthcare, and social relationships. If a PWD was unable to respond or was under 18 years old (legal adult age in Peru), a family member or legal tutor was allowed to complete the survey on their behalf.

## 2.4. Variables

### 2.4.1. Perceived discrimination

Perceived discrimination was measured by two questions from the survey: First, individuals answered the question "Have you ever felt treated differently due to your limitations?" (Yes/No); those who answered "yes" were asked to respond in which ways they felt they had been treated differently. Possible answers to the second

question were: "They respect me or help me", "They are over-protective", "They neglect me or ignore me", "They feel nervous around me" and "They attack me physically or verbally."

An affirmative answer to the first question and choosing one of the last three options in the second question was considered as perceived discrimination. Even though the first two choices are also considered forms of discrimination, we are restricting this study to negatively-perceived discrimination.<sup>3</sup>

### 2.4.2. Healthcare-seeking behaviors

In order to measure healthcare-seeking behaviors, participants were asked: "In the last six months, where did you go to attend the symptom or injury you have suffered from?" Possible answers were: public or private hospitals, primary care centers, independent health practitioners, or nowhere. We dichotomized all answers into "Yes" if participants marked any option that involved seeking healthcare and "No", if they answered "nowhere". In our analysis, we coded "Yes" as Zero and "No" as One as we wanted our outcome to be not seeking healthcare.

### 2.4.3. Other variables

We included demographic characteristics like sex, age, marital status (married/not married), educational level (no education/primary/secondary/superior), and socioeconomic status (by tertiles of deprivation index).<sup>17</sup>

Self-reported dependence on another person for daily activities (yes/no), having health insurance (yes/no), self-report of having a chronic disease (yes/no) and area of residence (rural/urban) were also included as they were considered potential confounders.<sup>11</sup> Self-report of dependence was based on the question: "Does your limitation makes you depend on another person?" We considered as "Yes" to those who report dependency on activities like eating, dressing, grooming and transfers.<sup>18</sup> Self-report of chronic diseases included medical conditions as hypertension, severe anemia, asthma, lung emphysema, diabetes, hyperthyroidism, burns sequelae and chronic kidney disease. In the same way, those who reported having any of this conditions were considered as "Yes". Self-report of chronic conditions has been used in other studies.<sup>19</sup>

We also used variables related to disability, including type (physical/visual/hearing/communication/cognitive), severity (mild/moderate/severe) and origin of disability (congenital/acquired) in order to explore differences in the association between perceived discrimination and healthcare-seeking behavior.

### 2.4.4. Data analysis

All analyses were performed using Stata 13 for Windows (StataCorp, College Station, TX, USA). Categorical variables were presented as percentages and continuous variables were presented as means and standard deviations. We used Chi-squared hypothesis tests to analyze primary associations. For multiple variable analysis we used Poisson log regression to calculate prevalence ratios and 95% confidence intervals (95%CI).<sup>20</sup>

We generated three models in the regression analysis. Our first regression analysis presents a model of perceived discrimination and healthcare-seeking behavior adjusted by demographic characteristics. Our second analysis presents a model adjusted only for disability-related variables. Finally, we present a model adjusted for all variables, which was also calculated for each type of disability. All analyses were completed with cluster sampling techniques.<sup>21</sup>

According to previous studies,<sup>11</sup> interactions of perceived discrimination with socioeconomic status and sex were tested within the Poisson regression models. Missing data for regression models were discarded through automatic list-wise deletion.

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