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Original Article

The Application of Network Scale Up Method on Estimating the Prevalence of Some Disabilities in the Southeast of Iran

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ARTICLE INFORMATION

ABSTRACT

Background: More than a billion people have some form of disabilities worldwide. Persons living with a disability have many needs (including physically, mentally, and socially needs). Estimating the size of disabled population is a challenge in health systems. An innovative indirect method to estimate the size of populations is network scale up (NSU) having widely used for hidden populations. The method is based-on the social network of individuals. We assessed the capability of NSU to estimate persons living with a disability being a middle population (neither non-hidden nor hidden populations) in the Southeast of Iran (Kerman City, southeast Iran).

Methods: A total of 3052 of Kermanian people over 20 year old were interviewed by simple random sampling. We asked them whether they knew acquaintances with complete blindness, severe visual impairment, deafness, severe hearing impairment, limb defects, and mental retardation, if yes; we wanted them to count them.

Results: Based on the network scale up method, the prevalence of the populations was estimated at 5.21/1000 in Kerman City where severe visual impairment was 1.35, mental retardation was 1.039, severe hearing impairment was 1.005, limb defects was 0.78, deafness was 0.59, and complete blindness was 0.56 (per 1000 inhabitants).

Conclusions: The results were not exactly comparable to previous studies using different methods such as surveys. Although the method has some limitations, considering its easiness and cost-effectiveness, modified NSU could be used when direct methods are not practicable.

Introduction

Disability is a complex multidimensional condition which encompasses different types of impairments and limitations. The World Health Survey (WHS) has reported that more than 780 million people over 15 yr of age are living with a disability[1]. In Regional Office for the Eastern Mediterranean (EMRO), the prevalence of all types of disabilities varies considerably across countries, from 0.8% in Bahrain to 16.3% in Tunisia (based on WHS)[2]. The Ministry of Health and Medical Education (*MOHME*), Iran determined the prevalence of the population living with a disability 17.8/1000 in Iran (a middle-income country located in EMRO with a population of more than 76 million)[3].

Some forms of disabilities are more dominant. Over half of persons living with a disability (645 million) are suffering from visual impairment and blindness, deafness and hearing loss[4]. Besides, mental retardation and losing limbs are noteworthy among low- and middle-income countries, since they carry substantial burden for instance, in 2000, about 28800 mentally retarded persons in Iran[5]. On the other hand,

surveys indicated that the number of persons living with the disabilities increased in Iran (for example visual impairment from 2.6% in 2006 to 4.04% in 2011)[6,7].

People living with a disability are "middle population", neither hidden nor non-hidden, because some of them are stigmatized by the general population like unilateral hearing loss[8,9]. In addition, generating an acceptable profile of different types of disabilities is point of concern to allocate sufficient resources and determine priorities. Methods to estimate the size of populations such as population based surveys are costly and prone to different types of systematic errors[10,11]. Therefore, it is usually difficult to list the priority of various disabilities based on the size and severity[12]. Compared to such methods, indirect methods included capture-recapture, multiplier, and Network Scale Up (NSU) are alternative approaches using to estimate the size of sub-populations[13]. However, capture-recapture and multiplier methods rely on some assumptions being difficult to meet,

NSU is more applicable, easier, and cost-effective to estimate the size of many sub-populations[11,14].

The NSU works based on the social network of members of a society. In this method, the frequency of subpopulations of interest is assessed in the social network of a sample from the general population. The logic behind NSU method is very easy using the frequencies in the social network of population as estimation for the frequencies in the general population[13].

The NSU method has been widely used to investigate the size of hidden populations such as injected drug users (IDUs), female sex workers (FSWs), men who have sex with men (MSMs)[11, 17,18]. It was also used to estimate non-hidden population[18], but no documents included the "middle populations", like persons living with a disability.

Therefore, in this study we aimed to describe the application of NSU in estimating the size of population of persons living with a disability and to explore whether the method is useful for such populations or not.

Methods

A cross sectional study was conducted in Kerman city (in the southeast of Iran), with a population around 700,000. Four trained interviewers were approached 3052 persons through simple random sampling from March 2012 to July 2012; interviewees had to be more than 20 years and have lived in the Kerman at least in the past five years. Having taken verbal consent, data were collected through face-to-face interviews in various locations (in crowed places such as parks and streets, but not hospitals and clinics). Only pedestrians who were alone were approached.

The questions of interview had two parts; the first part was about main demographic variables such as age, sex, and education of subjects in the second part, we asked the participants whether they knew any disabled person or not, if yes, they should count them by sex. Before the conducting second part of interview, the definition of active social network was explained to subjects clearly; the definition was "people whom you know and who know you, in appearance or by name, and you can interact personally by telephone or e-mail over the last two years"[14,18].

There are two methods in estimating social network (C): the known population size and summation method[13]. In a separate study using known population size, the average size of active social network (C) of the Iranian population was computed 308 people[10].

Finally, the size of following disabilities was identified: complete blindness, severe visual impairment, deafness, severe hearing impairment, limb defects, and mental retardation. The full definitions of these disabilities were explained to respondents (Table 1). Prevalence of the disabilities is then calculated by dividing the number of the summation of the known disabled people in 2012 by the size of Kerman City population (722,484 based on national census in 2011).

Statistical analysis

The NSU method assumes that the prevalence of a specific group in the network of a random sample of respondents is proportional to that of the target population. For example, assume a population T with size t, and a subpopulation E with size e. If, on average, members of T know m subjects in e , then the proportionality $m/C=e/t$ seems reasonable, where C corresponds to the average number of people known by members of T. Aggregating the replies of all respondents, the basic formula to estimate the size of groups is (Equation 1):

$$\hat{e}_j = (t * \sum m_{ij}) / \sum c_i \ (m \text{ summing over the subjects}) \ (1)$$

Here i and j stands for respondent and disability type, and t is the total population of Kerman city (according to the latest official census in 2011: 722,484).

Table 1: Definitions of disabilities

Type of disability	Definitions
Complete blindness	Who is quite unable to see
Severe visual impairment	Who needs others despite using glass or should use white stick
Deafness	Who was deaf and contact with sign language
Severe hearing impairment	Who has to use earphone.
Limb defects	Who has amputated hand, foot, or both
Mental retardation	Who experience mental health conditions or intellectual impairments

Ethical consideration

Results

A total of 3023 (out of 3052 respondents) with mean (SD) age 33.21 (10.35) years were analyzed. Proportion of male and female subjects was equal at about 50%. Nearly two third of the participants were married, and about half of them had less than 12 years formal education (Table 2). Overall, 9700 disabled people were reported by interviewees. This gave the prevalence of disability at 5.21 per 1000 of Kerman City.

Among the assessed disabilities, severe visual impairment and complete blindness had the maximum and minimum frequencies (1.35 and 0.56/1000, respectively) (Figure 1). Following that, severe hearing impairment and mental retardation were the most prevalent disabilities (1.039 and 1.005/1000 inhabitants). We found that the frequency of complete blindness and deafness were almost equal (410 and 427 people).

Table 2: Demographic characteristics of respondents

Variables	Number (%)
Gender	
Male	1499 (49.5)
Female	1524 (50.5)
Marital Status	
Single	1019 (33.7)
Married	1920 (63.5)
Divorce/Widow	84 (2.8)
Formal Education (yr)	
<12	1493 (49.4)
12-16	1415 (46.8)
>16	117 (3.8)
Response Rate	3023 (99.0)

Discussion

By modifying of the NSU, this method could be an alternative method to estimate some types of disabilities, neither hidden nor non-hidden population (middle population), where indirect methods are not practicable. Our findings showed that 5.21 per 1000 Kermanian inhabitants were living with a disability including complete blindness, severe visual impairment, deafness, severe hearing impairment, limb defects, and mental retardation. In addition, the most common forms of disabilities were severe visual impairment followed by mental retardation.
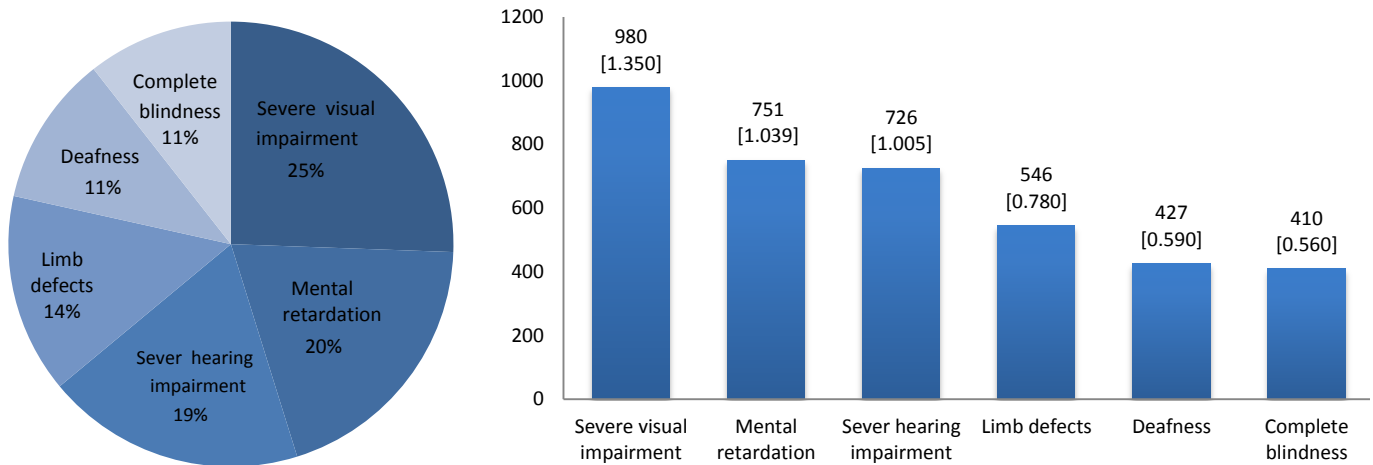

Figure 1: Left chart (Pie chart): the composition of different types of disabilities (assuming that multi-disabled people were not count); right chart: the frequency and [prevalence*1000] of disabilities in Kerman city based on the results of network scale up method

All previous surveys about visual impairment and complete blindness in Iran have indicated considerably higher estimation than the NSU (visual impairment: 1.2%–4.4% vs. 0.56%; complete blindness: 0.13%–1.2% vs. 0.093%)[21,22]. It seems that the overestimation related to the sample population which the participants were almost all recruited from specialty clinics where trained examiners confirmed the disabilities with distinct definitions.

A survey about the epidemiology of deafness and hearing impairments in the North-west of Iran showed higher prevalence of deafness and lower one of hearing impairments than our estimation using the NSU method (deafness: 0.43% vs. 0.097%; hearing impairment: 0.71% vs. 0.165%, respectively)[3]. Part of the discrepancy might be due to geographic area. Furthermore, NSU assumed that all people know everything about their networks' member while those had unilateral deafness or hearing impairment might conceal their condition (transmission effect). Nevertheless, comparing NSU and official figures of deafness and severe hearing impairment was interesting, the NSU value about deafness was very close to the official report (0.11% vs. 0.09%) and sever hearing impairment of the NSU was as equal as official report (0.16%)[24]. This proximity might, because interviewers in both were neither being professional (for example audiometrist) nor using medical instruments to diagnose these disabilities; only self-reporting was considered.

Another disability was mental retardation underestimated (0.17%) in comparison with previous studies (0.42–4.4%) and statistical center of Iran (0.39%)[24]. The difference partly caused by different subpopulations. Previous studies used various criteria to diagnose mentally retard people like DSM-VI criteria. Even though the NSU estimated the size of a subpopulation in the general population, there were not especial criteria that people could definitely confirm mental retardation.

We only compared the finding of defect limb population to annual report of *MOHME*; however, the team tried to seek any other evidence in the country. Comparing NSU and MOHME report clarified that NSU underestimated limb defects population (0.07% vs. 0.52%). This discrepancy might be, because of respondents did not count congenital malformation (Aplasia); they only enumerated those having amputated limb such as diabetic people. Surely even their close friends could hardly detect people with mild problem or who had aplastic fingers (especially toes). In addition, interviewers only asked about accident-related limb defects population. We suggest that questionnaire of NSU should differentiate between congenital and acquired limb deficiencies with questions like "what made him/her to not have a finger?", this makes respondents to ratiocinate and to measure all of them.

The discrepancies among the results were due to the sensitivity of registry systems to detect and collect cases is not completely efficient because many cases do not recourse or they are in middle/high level socioeconomic status demanding for financial aids serving by state welfare organization of the country.

Next, all previous studies were surveys, in which professionals evaluated participants with distinct definitions. As a result, the sensitivity of detecting persons living with the disability was much higher than NSU because self-reporting is the approach that NSU uses to detect the populations. Another problem was that people suffered from unilateral severe hearing impairment or have had internal earphone might not be identified by even their close friends which NSU studies call it as "estimation effect".

Previous studies using NSU corroborated that some of respondents do not have willing to report all of people of the subgroup of interest[24]. Although interviewers tried to deduce the subpopulations, some values were underestimated.

Limitations of this study almost are due to violation of three assumptions of NSU. The first one is that all members of the general population (*t*) had the same chance of knowing

member of the subgroup (*e*). Bias occurring in the first assumption is called "barrier effect", because social and physical barriers like race, location of work, and residency perform different network size. It means that some respondents know more people living with a disability like those working in health delivery system. Second, NSU assumes respondents have perfect knowledge about contacts, but actually it cannot happen thoroughly. This is termed "transmission effect". Third, assumption is that respondents can accurately recall the number of contacts living with a disability (known as recall bias). Although recall bias is unavoidable[24], interviewers helped respondents by asking detailed questions.

A considerable body of evidence now exists indicating that using NSU to estimate the size of middle populations such as people living with a disability, may not be applicable, but distinct populations like those suffer from alopecia areata or cutaneous leishmaniasis could be tested.

Even though the study showed different results, NSU could be modified by decreasing the target population like people working in health delivery systems. On the other hand, easiness and simplicity of NSU and also estimating many populations in a project is an acceptable reason to use it along with the other national projects.

Conclusions

It seems that NSU with some modifications could be an alternative method to estimate some types of disabilities, neither hidden nor non-hidden, while indirect methods are not practicable. Totally, questions about the accuracy and reliability of the NSU in non-hidden populations remain.

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Conflict of interest statement

The authors have no conflicts of interest to declare.

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