Disability, Chronic Diseases and Access to Healthcare in Jamaica F Morris

ABSTRACT

Objective: To look at healthcare delivery for persons with disabilities in Jamaica. **Methods:** A quantitative survey of persons with disabilities using a systematic random sampling technique with respondents selected from the database of the Jamaica Council for Persons with Disabilities.

Results: Participants included 1014 persons with disabilities. The results showed that persons with disabilities were regular users of the public health system and that the major chronic illnesses identified among respondents were diabetes mellitus, mental illness and hypertension. **Conclusion:** Persons with disabilities are regular users of the public health system and so efforts must be made to consistently educate these individuals about ways to maximize use of this service.

Keywords: Chronic diseases, health Systems, Jamaica, persons with disabilities

Discapacidad, Enfermedades Crónicas y Acceso a la Salud en Jamaica F Morris

RESUMEN

Objetivo: Examinar la prestación de servicios de salud a las personas discapacitadas en Jamaica.

Métodos: Un estudio cuantitativo de las personas con discapacidad que utiliza una técnica de muestreo aleatorio sistemática con los encuestados seleccionados de la base de datos del Consejo de Jamaica para las Personas con Discapacidad.

Resultados: Los participantes incluyeron 1014 personas con discapacidad. Los resultados mostraron que las personas con discapacidad eran usuarios regulares del sistema de salud pública, y que las principales enfermedades crónicas identificadas entre los encuestados eran la diabetes mellitus, las enfermedades mentales y la hipertensión.

Conclusión: Las personas con discapacidad son usuarios regulares del sistema de salud pública, por lo que se deben hacer esfuerzos para educar sistemáticamente a estos individuos sobre las formas de maximizar el uso de este servicio.

Palabras clave: Enfermedades crónicas, sistemas de salud, Jamaica, personas con discapacidad

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INTRODUCTION

Chronic non-communicable diseases (CNCDs) brought about by modern lifestyle changes are some of the major health challenges faced by Jamaicans. Other priority areas for health include sexually related conditions such as HIV/AIDS and violence-related injuries and death (1).

Chronic non-communicable diseases include illnesses such as diabetes mellitus, hypertension, cancer, hyperlipidaemia, respiratory and cardiovascular diseases. Strokes and myocardial infarctions result from these illnesses and are of special concern. The World Health Organization declared that CNCDs are pandemic diseases, accounting for 63% of the 57 million deaths worldwide in 2008. It is projected that by 2030, approximately 80% of the CNCDs related deaths will occur in low- to middle-income countries (LMICs) such as Jamaica. When compared to high-income societies, mortality related to CNCDs occurs at a younger age in LMICs, with 29% of deaths occurring in patients 60 years or younger compared with 13% in high income countries (2).

Unplanned urbanization, along with unhealthy diets, sedentary lifestyles, social drug-use of tobacco and alcohol, have contributed to the emergence of CNCDs as a major public health issue in LMICs. In 2010, the Statistical Institute of Jamaica documented the increasing role of CNCDs in mortality rates (3). Among the general population, Persons with Disabilities (PwDs) are extremely susceptible to these diseases as the nature of their impairment can lead to the development of non-communicable diseases (NCDs). In addition to compromising their health status NCDs can add to the living expenses of this vulnerable group.

In 2007, Jamaica signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which, while it does not specifically provide a definition of "disability," stated that "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (4). The UNCRPD clearly indicated that PwDs must have a "long-term" impairment to attain that classification. The World Report on Disability through the International Classification of Functioning (ICF) provided another perspective on disability, which they defined as, "... the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with

a health condition) and that individual's contextual factors (environmental and personal factors)" (5). This definition coincides in part with that of the UNCRPD although a further examination of the report revealed the following: "The disability experience resulting from the interaction of health conditions, personal fac-tors, and environmental factors varies greatly. Persons with disabilities are diverse and heterogeneous, while stereotypical views of disability emphasize wheelchair users and a few other "classic" groups such as blind people and deaf people. Disability encompasses the child born with a congenital condition such as cerebral palsy or the young soldier who loses his leg to a landmine, or the middle-aged woman with severe arthritis, or the older person with dementia, among many others. Health conditions can be visible or invisible; temporary or long-term; static, episodic, or degenerating; painful or inconsequential" (6). Here disability is regarded as "short-term" and lends examination on the role of diseases in the aetiology of disability.

According to the most recent World Bank/WHO Report on PwDs, there are over one billion individuals or approximately 15–19% of the world's population living with some form of disability (7). This is a significant number for such a vulnerable, minority group. Accordingly, any country serious about improving its social capital for marginal groups will make concrete attempts at improvements.

The emergence of CNCDs and their aetiologic roles in various complications such as stroke is arguably a major cause of concern for disability and morbidity among adults worldwide. The result can affect short and long-term disability, particularly physical disability. Governmental responsibility for this population of PwDs can be costly for rehabilitative systems, mobility and accessibility. Direct and indirect medical costs, will likely also increase in the future.

In neighboring Latin America, the epidemiological changes and financial consequences of NCDs is also of concern. Hypertension, a chronic disease, was evaluated in Mexico from 2010–2012. Statistics showed a 24% increase in government's financial requirements through direct and indirect health costs with the total cost of hypertension in 2011 projected to be US\$5 733 350.291, inclusive of direct costs of US\$2 718 280.941 and indirect costs of US\$3 015 009.350 (8).

Public health costs of CNCDs, and its consequent complications are unsustainable for governments in LMICs. To mitigate these occurrences, the WHO advocates revision in planning, organization, and the allocation of resources, particularly in the area of health promotion, education and prevention, along with a recommendation for increased research in and surveillance of CNCDs (9).

It is within this context that this research was developed as it sought to generate new data on the subject of disability and public healthcare in Jamaica.

SUBJECTS AND METHODS

THE RESEARCH

Based on the nature of their disability, PwDs must access public or private healthcare systems (10). How these systems are sensitized or prepared to treat this group is important for social inclusion as citizens. Accordingly, an assessment of the healthcare system in Jamaica was made within the context of a socio-economic study conducted in 2015 by the Jamaica Council for Persons with Disabilities (JCPD) (11).

Respondents were among 1014 PwDs across Jamaica selected from a database of approximately 30 000 male and females with physical and intellectual disabilities (11). Health related issues as they specifically addressed NCDs were extracted, analysed and recommendations for improved service to PwDs were presented.

Analysis of Findings from Research

THE POPULATION

An analysis of the data showed that the majority of PwDs resided in rural Jamaica (57%), with the larg-est segment located in the southern corridor of the Island from Kingston to St Elizabeth. One-third of the respondents were over 60 years while another one third were below 30 years. Only one per cent of respondents was validated in the Disability Registry database as epileptic. we the researcher attributes this to respondents being uncertain whether this was considered a disability.

Approximately 52% of respondents were male with over 50% indicating they had both physical and multiple disabilities. Based on the high levels of crime in Jamaica, where males are major participants and/or victims of criminal violence, it is not unreasonable to anticipate high levels of physical disabilities (13). Seventy per cent of the sampled population were single.

Physical disabilities formed the largest segment of the population reviewed for this study with more than half reporting multiple disabilities. Contributory factors to these impairments included violence, motor vehicle accidents, and chronic diseases such as diabetes mellitus and strokes. These findings have profound implications for infrastructural development in Jamaica, since most public facilities have not been designed and constructed with the requisite accessibility features and therefore present accessibility challenges for this population. Restrictions or impediments to resources affect the upward mobility of any Jamaican and are an obstacle to growth and development.

Approximately one-third of the sampled population indicated that their disability was congenital, while twothirds indicated that it was acquired. While over 70% of respondents had domestic-related accidents/incidents, violent accidents/incidents remained low at 5%; with only 5.6% indicating having had an incident/accident which resulted in their having to seek medical attention.

Thirty per cent indicated they had illnesses that caused them to seek medical attention. The duration of sickness varied as 141 respondents (46.69%) had illnesses that lasted under one week, 139 persons (46.03%) were incapacitated between one to four weeks, and 22 persons stated that their illness lasted over four weeks.

Two hundred and fifteen persons (72.88%) were unable to carry out activities for under one week; 67 persons (22.71%) indicated they were unable to carry out activities between one to four weeks, and 13 (4.41%) of respondents were unable to carry out activities for over four weeks. The vast majority of respondents (7 from 10) had mild illnesses and this affected their activity for one-week. Three out of ten persons had moderate to serious illnesses that incapacitated them for over two weeks. This synchronized with those who indicated that they visited a medical professional during their period of illness.

Approximately a third of the respondents indicated that they visited a doctor, nurse, pharmacist, midwife, normal healer or any other health practitioner during the period of the study when compared to a half (47.9%) who had not done so.

Of the 316 persons who visited a medical practitioner, 98.75% stated that they visited one to six times in the past four weeks. Two persons (0.63%) stated that they visited a health practitioner between seven and 21 times in the past four weeks, while another two respondents stated that they visited a health practitioner over 22 times in the past four weeks.

Of the respondents who indicated that they visited a health professional during the period of the research (331), approximately two-thirds (62.84%) said that they went to a public hospital. Conversely, less than 10% (31) indicated that they visited a private hospital. Since most persons in the study (91%) were unemployed, it would be reasonable that they would access healthcare at the public hospitals.

The average waiting time for PwDs at the public hospital was four hours with a maximum of 24 hours and a minimum of one hour. Persons who visited a private hospital reported significantly different experiences. Their average waiting time was 1.5 hours with a minimum of one hour and a maximum of four hours.

Respondents indicated that they spent an average of J\$2955 with a minimum of J\$0.99 and maximum of J\$15 000. Respondents who visited the private hospitals spent on average J\$23 029.41, with a minimum of J\$1000 and a maximum of J\$293 000. Fees indicate that PwDs who visited the public hospitals were paying relatively low sums. This is despite the fact that a "no user fee" policy was in place to benefit the most vulnerable as the major beneficiaries. In comparison, fees charged at private hospitals are significantly higher. Accordingly, matters of health cost must be communicated to all PwDs.

Of the 331 respondents who indicated they visited a health practitioner, 74 (22.05%) of respondents stated they visited a Public Health/Maternity centre versus 75 who visited a private facility. Waiting time at the public facility averaged 3.5 hours with a minimum of one-hour and a maximum of 12 hours. Conversely, PwDs who visited the private facility waited an average of two hours, with a minimum of one hour and a maximum of six hours. Persons who visited the private health/maternity centres had 50% less waiting time. This trend is similar to the different in waiting time between both facilities.

Respondents indicated that they spent an average of J\$1413.50, and a maximum of J\$2600, at public health/ maternity centres during the period under study. Conversely, those who visited private health/maternity centres indicated that they spent an average of J\$4207; a minimum of J\$500 and a maximum of J\$36 000. Twenty-nine (2.86%) respondents who visited some other health facility stated they had to wait an average of 4.5 hours, a minimum of one-hour and a maximum of 14 hours. These respondents also indicated that they spent an average of J\$2370, *ie*, a minimum of J\$200 and a maximum of J\$5000.

Respondents who indicated that they had a recent bout of illness but did not visit a health facility indicated that they could not afford it (9.01%). Just over a quarter (27.93%) indicated that they were not ill enough. While a significant number of respondents indicated that they did not visit a health facility during their illness (52.25%), the researcher suggests part of the reason possibly stemmed from pride. Although poor, most PwDs would not want to highlight their inability to afford healthcare.

When asked about their source of medication for recent illnesses, over a third of these respondents (38.30%) indicated public pharmacies and just under two-thirds (61.70%) indicated private pharmacies. The greater proportion of PwDs who used private pharmacies could possibly attribute their decision to do so because of the long wait at public hospitals or unavailability of the medication. Respondents indicated that they spent an average of J\$2439.12, *ie*, a maximum of J\$8000, on medication at a public source. This is in comparison to an average of J\$4587.71, *ie*, a minimum of J\$2.00 and a maximum of J\$193 000.00 at a private source.

A significant proportion (73.96%) of respondents indicated having health insurance. This does not corroborate with their employment record. Of the 750 persons who stated that they had insurance, only 215 persons identified the sources as private entities (7.20%), to include: NI Gold (2.56%), NHF/JADEP (7.00%), and other (4.44%).

Respondents were asked to rate the state of their health. Approximately three-quarters indicated that they enjoyed fair to very good health, while approximately one-fifth indicated that they had poor to very poor health. Persons with disabilities apparently enjoyed reasonably good health but this can be further improved through major public education programmes to sensitize them about public health facilities and available benefits.

Respondents indicated that chronic diseases included: asthma (7.10%), diabetes mellitus (14.50%), mental illness (16.17%), hypertension (22.88%) and arthritis (9.76%). Management of these illnesses require physical activities which could be impeded by the particular disability.

Nine out of the ten respondents (88%) did not smoke while less than one out of ten (7.5%) smoked. Most of the PwDs heeded the "no smoking" campaigns and this was extremely encouraging. It shows that consistent public education campaigns can in fact yield positive results.

RECOMMENDATIONS

The following recommendations arise from this research:

1. There is need for consistent public education programmes to sensitize PwDs to the availability of public health facilities and encourage their use, especially if personal finances are an issue. Public education programmes should also be directed at health professionals so that they can demonstrate greater sensitivity when relating with PwDs.

- 2. Health professionals should be trained on how to relate to PwDs. For example, public health facilities should have an individual trained in Sign Language.
- 3. Women of child-bearing age should be educated on the need for a healthy diet, exercise, and regular visits to the clinic, especially when pregnant.
- 4. Special mechanisms should be in place at public hospitals to accommodate PwDs, such as a special phone line to expedite service and reduce waiting time. Additionally, healthcare facilities should develop a system to remind PwDs of scheduled appointments. A mobile unit could also visit communities with resident PwDs to offer medical support.
- 5. Parents of children with disabilities such as Downs Syndrome should be allowed to claim these children on their health insurance for life. These children are often prone to chronic conditions and they are unlikely to attain employment due to stigma and discrimination, especially if the condition is severe. There is need also for progressive policies to assist with their basic healthcare needs.
- 6. In the context of a "no user fee" policy, PwDs should be exempt from paying fees at public health facilities. Over 91% of these individuals are unemployed and possibly their employability may be due to societal prejudices.
- 7. Services offered to PwDs through the National Health Fund should be expanded to include equipment/assistive aids such as prosthesis and hearing aids. These are critical for the treatment and rehabilitation of persons with specific types of disabilities.

CONCLUSION

The issue of quality healthcare is of fundamental importance to any society because it forms an axiological part of the indexation which determines the quality of life for its citizens. Access to quality healthcare, types of diseases affecting citizens and the nature of the service to patients are quintessential for analysis and understanding, but even more so for persons who fall within vulnerable groups. Some of these individuals are prone to chronic diseases and are unable to cope with the ensuing economic challenges. Therefore, it is imperative for mechanisms to be in place to monitor their health status.

It is within this context that this research sought to assess the situation of PwDs who access the health services in Jamaica. The data, extracted from a socioeconomic study conducted among 1014 PwDs from the database of the Jamaica Council for Persons with Disabilities, confirmed the significance of this empirical work. It is important that policymakers also pay attention to these findings in order to improve the service delivery and well-being of PwDs within Jamaica.

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