

A Comparative Analysis of Four Disability/Functional Limitation Modules in the 2003 Joint Canada/United States Survey of Health

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KEY WORDS: International comparison, disability, functional limitation, HUI, Restriction of activities, joint Canada/United States survey

Introduction

Theoretical models of disability clearly demonstrate that disability is a multidimensional concept influenced not only by the physical or mental limitations an individual experiences, but also by the social and physical environment in which the individual lives and works (WHO, 2003; Brandt & Pope, 1997). For this reason, measurement of disability in a population survey is very difficult. It is influenced by the survey instrument and data collection methods used, and also by the conceptual component of disability that the instrument addresses.

International comparisons of the prevalence of disability have suffered from all these problems; the multidimensionality of the concept, the variety of characteristics of the survey instrument and the mode of data collection. In addition, such comparisons are strongly influenced by the social understanding and definition of disability within the individual cultures, the use and meaning of language in translation and the stigma associated with disability that prevents open indications of problems.

The Joint Canada/US Survey of Health (JCUSH) represents the first time the same survey was conducted by two national statistical agencies to measure the health of both Canadian and US citizens, using standardized methodology (Gentleman et al., 2003). Included in the instrument were four question sets used by either Canada or the United States to identify the disabled population in their respective countries. This paper, using those four approaches to measuring disability, compares disability and functional limitation in both countries, based on the four different modules.

We compare the overall age-standardized prevalence rates of disability/functional limitation derived by the four modules, and then

explore whether they produce consistent differentials across countries. We also examined how the measures vary by important socio-demographic dimensions such as age, race, sex, education and income. These are important first steps in the discussion as to whether and how the questionnaires across countries can be brought closer in disability measurement.

Methodology

The JCUSH is a unique population health survey conducted jointly by Statistics Canada and the U.S. National Center for Health Statistics of the U.S. Centers for Disease Control and Prevention between November 2002 and June 2003. Because it was conducted in the same manner in both countries, it provides a degree of comparability never before possible. As a result, meaningful comparisons can be made between Canada and the United States in health and disability. The target population included residents of both countries aged 18 or over living in private dwellings. For more information on the JCUSH data, see the JCUSH analytic report (Sanmartin et al., 2004) that was released with the microdata.

The objectives of the JCUSH are three-fold. The first objective was to produce highly comparable data on the Canadian and American populations on core indicators, including health care, functional status, health status and risk factors, that is unaffected by the difference in data collection methodology. Secondly, it was to influence content of the respective countries health surveys for greater comparability. Last but not least, it was to develop a model for successful collaboration towards standardizing concepts. This paper will focus on the first objective, related to comparing disability status between Canada and the United States.

All respondents in JCUSH were asked all the questions in the four disability modules. The order of placement of the four modules was randomized. Results reported here are for adults aged 18 and over, a total of 5,100 in the United

States and 3,100 in Canada. For age-standardization of the overall prevalence for all 4 measures, the US 2000 standard population aged 18 and above was used (Klein and Schoenbaum, 2001).

The socio-demographic dimensions such as age (18-44,45-64,65+), sex (male, female), education (less than high school, high school graduation, some college, college graduation) and race (white, non-white) are self-explanatory. For income quintiles, respondents in Canada and the U.S. were separately ranked according to the adjusted household income and were assigned a quintile group such that the weighted count of each quintile group contained approximately one-fifth of the population reporting household income. Q1 represents the quintile with lowest income, while Q5 is the quintile with the highest income.

To fully account for the design effects of the survey, SUDAAN using Taylor linearization was used as the appropriate software to calculate point estimates and confidence intervals.

Disability measures

Of the four sets of questions, two are taken from Canadian survey instruments and two are taken from survey instruments used in the United States. The Canadian sets include the Restricted Activity Screener (RAS) taken from the Canadian Community Health Survey (CCHS) (Statistics Canada, 2003) and the Health Utilities Index (HUI) (Torrance et al., 1995), also taken from the CCHS. The screener is a restriction of activities question set and provides a scaled response. The HUI is a comprehensive health status and health-related quality of life measure designed for population health surveys. It has a multi-attribute health status classification system and a multi-attribute utility function. These permit the calculation of a single summary score generic health-related quality of life measure usually between 0 and 1, the latter being full health.

The U.S. measures are both taken from the National Health Interview Survey (NHIS) (Botman, et al., 2000) One set identifies persons who have limitations in various types of activities and forms of social participation (APL). The second set focuses on Limitations in Physical Functioning (PFL) and provides scaled response options.

For the purpose of this analysis, dichotomous variables were constructed reflecting disability/functional limitation as present or absent. Table 1 and Appendix A show the various measures and how they were coded.

Canadian Restriction of Activities (RAS)

RAS is a new set of inclusive screening questions originally developed by Statistics Canada to filter in more of the potentially disabled population. In other words, the objective of this measure was to include persons with all types and levels of disability for follow-up questioning in post-censal surveys such as the Participation and Activity Limitation Survey (Statistics Canada, 2002). As seen in Table 1, this measure combines questions about physical limitations with questions about reduced activity at home, at school, at work or in other activities caused by a physical, mental or health problem expected to last 6 months or more. It consists of five questions which focused on the frequencies of occurrence of

- difficulty with physical activities;
- reduction of activities at home;
- reduction of activities at school;
- reduction of activities at work; and
- reduction in other activities.

The levels of response include ‘never’, ‘sometimes’ and ‘often’. ‘Often’ was used to define disability in this analysis.

Health Utilities Index adapted to reflect disability (d-HUI)

The 8 dimensions of functioning in the classification system of HUI (vision, hearing, speech, mobility, dexterity, emotion, cognition and pain) were used to define disability. Each dimension has five to six levels ranging from fully functional to severely impaired (see Appendix A). The usual HUI therefore enables us to classify a respondent into one of the 972,000 theoretical health states. In this analysis, the d-HUI (which means dichotomized HUI as compared to a usual HUI score) construct reflects only response categories possibly associated with limitation or disability in each dimension. The limitation thresholds in each dimension coded as disability are as follows:

- Vision (problem seeing not corrected);
- Hearing (problem hearing in a group, not corrected);
- Speech (partially understood by strangers);
- Mobility (problem, no aid required);
- Dexterity (problem, no help required);
- Emotion (somewhat unhappy);
- Cognition (very forgetful/great deal of difficulty thinking);
- Pain (prevents a few activities).

Activity and Participation Limitations (APL)

These questions from the U.S. NHIS focus on limitations associated with physical, mental or emotional problems. In a set of seven questions, 4 are related to self care or working, two ask about self definition or definition by others as disabled and one very general question refers to limitation in any activity. Only five of the seven questions were used for this analysis (see Table 1). The questions about self definition or definition by others as disabled were not included since they were related to identity rather than actual limitations in activity or participation. The response categories for the questions were 'yes' or 'no'. If any component had a 'yes' response, then the respondent was identified as disabled on this measure.

Physical Functioning Limitations (PFL)

This set of questions, also from the NHIS, is based on indicators of difficulty in performing basic physical actions without the use of special equipment. Response categories range over 5 responses extending from 'no difficulty' to 'cannot do'. The question set is made up of 14 questions, nine of which were used for this measure. The number of questions used was restricted to those dealing with physical functioning. The question on moving furniture was not used since it has been found that about one quarter to one third of respondents reporting that problem have no other physical functioning problems. The use of that question artificially inflates the numbers identified with disability (Rasch et al., forthcoming). Also questions reflecting social participation activities were not used since they reflected contextual conditions and choice as well as physical functioning limitations. Responses indicating that the

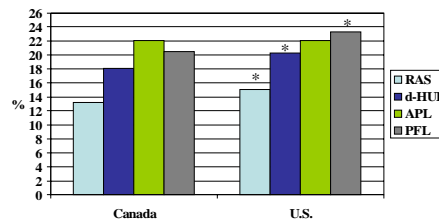
individual found the action 'somewhat' or 'very difficult' or that they 'cannot do' them were considered to represent disability.

Results

Country Differences

Age standardized disability prevalence estimates show that the Canadian Restriction of Activities screener provided the lowest rates of prevalence (13.2 % in Canada and 15.1% in the U.S.) when compared to the other measures. The highest level of prevalence in the U.S. was the estimate of physical functioning limitations, 23.3%. The highest level of prevalence estimate among the Canadian population was the estimate provided by the activity and participation measure, 22.1%. Three of the four measures revealed statistically different estimates between Canada and the U.S. with all three estimates higher in the U.S. (see Figure 1).

Figure 1: Age standardized disability estimates based on 4 modules, Canada and U.S., JCUSH



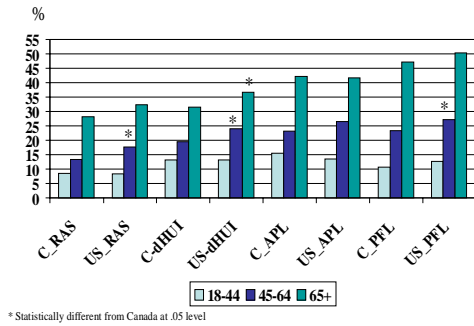
* Statistically different from Canada at .05 level

Examination of the association between age, race and sex and disability prevalence shows where some of the differences between the two countries may come from. While all the age specific estimates for each of the measures show the expected relationship with age, lower rates among the youngest group and highest rates among the oldest age groups, there are some indications that country differences occur among the middle aged group. Prevalence rates estimated for three of the question modules indicate higher rates of disability among persons ages 45 to 64 in the U.S. This is true for the RAS measure, the d-HUI measure and the PFL measure all of which indicate higher prevalence rates in the U.S. (see figure 2). In addition, the d-HUI measure shows a significant difference

between the U.S. and Canada in the prevalence estimates among those aged 65 and over (36.7% and 31.6%, respectively).

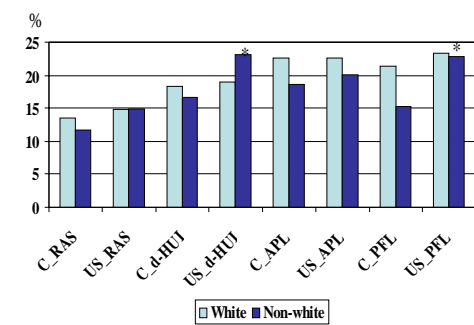
Among nonwhites and among women, the d-HUI measure and the PFL measure (as well as RAS for females only) also show significant differences in prevalence rates between countries (see figures 3 and 4). In both cases, American minorities and women have higher prevalence rates than their Canadian counterparts. Comparisons by racial groups can only be considered for whites since the makeup and characteristics of the nonwhite component of the populations differ considerably between Canada and the United States.

Figure 2: Age Differences by 4 modules, Canada and U.S, JCUSH



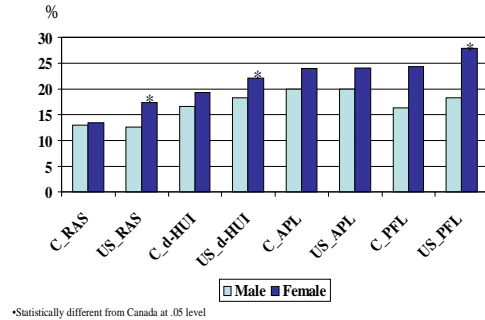
* Statistically different from Canada at .05 level

Figure 3: Race differences by 4 modules, Canada and U.S, JCUSH



* Statistically different from Canada at .05 level

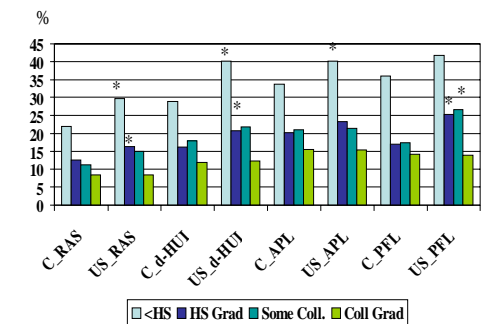
Figure 4: Sex differences by 4 modules, Canada and U.S, JCUSH



* Statistically different from Canada at .05 level

Socio-economic resources are also a source of differences in disability prevalence between the two countries. Figures 5 and 6 demonstrate the association of education and income with prevalence estimated from the four measures. The U.S. has significantly higher prevalence of disability among those with less than a high school education and even those with only a high school education compared to Canada when using the RAS measure and the d-HUI measure. Prevalence rates among those with middle levels of education (high school graduate or some college) are significantly higher in the U.S. when disability is measured by the PFL measure. Prevalence of disability, as measured by the APL (reflecting activity and participation) are significantly higher in the U.S. than in Canada for those with the lowest levels of education. Note that this is the only time we are able to detect any statistical difference using the APL measure.

Figure 5: Education differences by 4 modules, Canada and U.S, JCUSH



* Statistically different from Canada at .05 level

Income has its greatest association with disability prevalence estimates at the level with lowest income (Q1). Among persons reporting lowest levels of income, more are estimated to have a disability in the U.S. when using the RAS module, the d-HUI module and the PFL module. However, when using the d-HUI measure of disability, the U.S. has a lower estimate of disability prevalence than Canada at the highest income level. Income does not seem to influence differences in disability prevalence estimates when using the APL module for measurement.

Figure 6: Income Differences by 4 modules, Canada and U.S

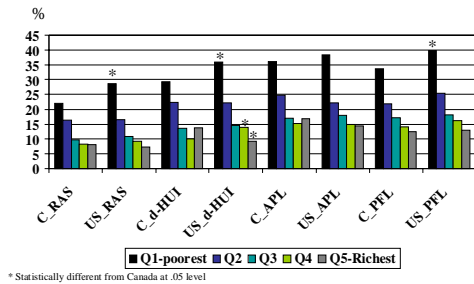


Figure 7 Disability consistency analysis using d-HUI as indicator to predict APL, JCUSH

		APL	
		Yes	No
d-HUI	Yes	12%	7%
	No	9%	72%

Discussion and Conclusion

These 4 different measures are related to one another, but they also clearly capture different aspects of disability. While RAS and APL were measuring more about performance, d-HUI and PFL were focused more on individual capacity as interpreted by the individual’s assessment of his/her level of difficulty performing those functions as opposed to a standardized assessment.

The RAS measure yields the lowest level of disability as the definition used in this study is quite stringent. The person has to respond ‘often’ to any of the 5 questions to be included as being disabled. The use of the ‘sometimes’ response as the threshold for indication of disability would yield much higher rates.

The APL-based measure is the one measure that consistently showed no overall statistical difference between countries and in all dimensions, except for those with the lowest education. It would be interesting to understand why this was so.

The other 3 measures produce generally consistent cross-country differentials, both for overall and by socio-demographic dimensions such as age, sex, income, education.

An important aspect of future research is to better understand the similarities and differences of the four measures so as to understand how the questionnaires across countries can be more compatible in disability measurement. It would also be of interest to examine the 4 measures based on a better understanding of the severity of disability.

Relationship Among Measures

With four measures of disability available in one dataset, JCUSH can be used to answer questions regarding the relationship among measures as follows:

- how well do the health or functioning measures predict activity or participation limitation?
- how well does the activity measure predict those who are experiencing health/functional limitations or pain problems?

Figure 7 provides a simple example of such disability consistency analysis. It examines how well we can predict disability in terms of APL by knowing one’s d-HUI score. Some 84% of the JCUSH respondents had consistent responses (12% disabled and 72% not disabled). Further analysis shows that the 9% who were not disabled in terms of d-HUI were only mildly disabled in terms of APL. This kind of analysis can be done by country to see if there is a cross-country difference.

Finally, there is also a need to conduct a comparison of individual items used in measuring disability, where appropriate. Such a comparison could provide information on question wording interpretation.

Acknowledgement: Funding for the survey was provided by the U.S. Centers for Disease Control and Prevention's National Center for Health Statistics, The Robert Wood Johnson Foundation, Statistics Canada, and the Canadian Institutes for Health Research.

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Table 1: Construction and comparison of 4 disability/functional limitation modules, JCUSH

	Restriction of activities screener (RAS)	Health utilities index (d-HUI)	Activity and participation limitation (APL)	Physical functional limitation (PFL)
Domain	Limitation in daily activities	Functioning in 8 areas	Limitation in activities:	Functioning in
Questions used	activities in general at home at school at work other activities	vision hearing speech mobility dexterity emotion cognition Pain	personal care handling routine needs working at job kind/amount of work any activities	walking climbing standing sitting stooping reaching grasping lifting
Criterion	Limitation caused by a physical, mental or health problem expected to last 6 months or more.	Questions about day-to-day health, but not about illness like colds that affect people for short periods of time.	Restriction caused by a physical, mental or emotional problem	Difficulties due to a health problem; functioning without special equipment.
Categories	Never Sometimes Often	(mostly) Yes No	Yes No	Not at all difficult Only a little difficult Somewhat difficult Very difficult Cannot do at all
Definition of problem	Respond 'often' to any of 5 questions	See appendix A	'Yes' to any one of five questions	'Somewhat difficult' to any of 8 questions

Appendix A: Health Utilities Index*

Vision (Level 3)

1. No visual problems
2. Problems corrected by lenses (distance, close, or both)
3. Problems seeing distance – not corrected
4. Problems seeing close – not corrected
5. Problem seeing close and distance – not corrected
6. No sight at all

Hearing (Level 4)

1. No hearing problems
2. Problem hearing in group – corrected
3. Problem hearing in group and individual – corrected
4. Problem hearing in group – not corrected
5. Problem hearing in group and individual – individual corrected
6. Cannot hear

Speech (Level 2)

1. No speech problems
2. Partially understood by strangers
3. Partially understood by friends
4. Not understood by strangers
5. Not understood by friends

Mobility (getting Around) (Level 2)

1. No mobility problems
2. Problem – no aid required
3. Problem – requires mechanical support
4. Problem – requires wheelchair
5. Problem – requires help from people
6. Cannot walk

Dexterity (hands and fingers) (Level 2)

1. No dexterity problems
2. Dexterity problem – no help required
3. Dexterity problem – require special equipment
4. Dexterity problem – requires help with some tasks
5. Dexterity problem – requires help with most tasks
6. Dexterity problem – requires help with all tasks

Emotion (feelings) (Level 3)

1. Happy and interested in life
2. Somewhat happy
3. Somewhat unhappy
4. Very unhappy
5. So unhappy that life is not worthwhile

Cognition (memory and thinking) (Level 5)

1. No cognitive problems
2. A little difficulty thinking
3. Somewhat forgetful
4. Somewhat forgetful / a little difficulty thinking
5. Very forgetful / great deal of difficulty thinking
6. Unable to remember and / or to think

Pain and Discomfort (Level 3)

1. No pain or discomfort
2. Pain - does not prevent activity
3. Pain prevents a few activities
4. Pain prevents some activities
5. Pain prevents most activities

***limitation thresholds are stated in parenthesis**