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## Views of Disability in the US and Singapore

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#### Views of Disability in the U.S. and Singapore

Lois M. Verbrugge, Kalyani K. Mehta, and Ellen Wagenfeld-Heintz

#### Introduction

Countries of southeast and east Asia are demographically aging at rapid pace. Health and disability surveys from the U.S. and Europe are often consulted for questions that might be used with Asian older populations. Same or similar questions enhance international comparisons. But whether questions from Western surveys fit the way Asian people think about health and disability is uncertain. Indeed, whether the questions fit Western lay people's views may be uncertain as well. How do older persons define "disability"? What do "independence" and "dependence" mean to them? Do they like or dislike assistance for tasks? We conducted a small-scale project to study these issues among older Americans and Singaporeans. We find that older persons' views in the two cultural settings differ a great deal.

#### Background

Disability surveys proliferated in Western countries from the 1980's onward, and new surveys built on prior ones for their content and question wording. Replication across different samples and time points was a strong goal, so questions tended to be the same or very similar across surveys. U.S. and European surveys typically ask about health-related difficulties doing personal care (ADL) and household management (IADL) activities, and also basic physical, cognitive, and sensory actions. Two types of assistance for tasks are queried: personal help (someone else assists; includes hands-on, supervise, remind) and special equipment (aids and devices; may include structural modifications).

In the past decade, concerns have been raised about what disability questions really mean to respondents. Several lines of research are addressing this, ranging from small-sample

qualitative to large-scale quantitative approaches. Focus groups discuss disability, and key themes are then identified (LaPlante, 2004; Mullan, Wong, LeBlanc, Kaye, & LaPlante, 2001; see also Knodel, 1995). In-depth interviews probe individuals' interpretations of disability questions (Agree, Freedman, & Landsberg, 2004). Autobiographical writings show how persons with disability think about their lives and limitations (French, 1993; Williams, 2001). For large-scale surveys, disability prevalence rates are compared for variants of a question in a given survey, or for similar questions across several surveys (Freedman, 2000; Wiener, Hanley, Clark, & Van Nostrand, 1990). Researchers use the results from all of these approaches to design survey questions with known features, rather than assumed or guessed ones.

In research parlance, having personal assistance for a task is often called dependence or dependency, and not having personal assistance is independence (e.g., Elston, Koch, & Weissert, 1990; Fulton, Katz, Jack, & Hendershot, 1989). Sometimes, dependency includes equipment assistance. Disability is health-related difficulty doing a task on one's own (intrinsic disability; Verbrugge, 1990). Sometimes, the definition is health-related difficulty with assistance (actual disability, Verbrugge, 1990; residual disability, Agree, 1999). People's own definitions of independence, dependence, and disability may or may not match researchers'. Does independence mean not having personal help? Does dependence mean having it? Is assistance a welcome or unwelcome feature of daily life? Does disability mean difficulty doing tasks due to health? What are social criteria for defining someone as having disability?

Psychological and cross-cultural research offer cautions about assuming what disability research concepts mean to older people. First, independence and dependence may be distinct notions, not antonyms (Gignac & Cott, 1998). Also, they are not simply an objective feature, but have subjective meanings. Independence can imply personal autonomy, own residence or

decision-making, having choices and opportunities, psychological and mental fortitude, doing as much as possible on one's own, living the same way now as decades ago, and more.

Dependence can mean reliance on others, reciprocity among humans, trust in God, acceptance of karma, fate or destiny, and more. Thus, for example, a person may have ample help but feel very independent, or have no help but feel dependent on a higher being.

Second, in Asian societies, coresidence of older persons with their children is the norm (Hermalin, 2002; Kendig, Hashimoto, & Coppard, 1992; Phillips, 2000). Interdependence of family members day-to-day and across the years is expected. Older people often rely comfortably on their children for help with daily life tasks, housing, and financial support (Hitchcock, Hutchings, Stephenson, & Ward, 1998; Ingersoll-Dayton, Saengtienchai, Kespichayawattana, & Aungsuroch, 2001). Thus, questions about disability may be interpreted in unexpected ways by Asian samples, compared to Western ones (Jitapunkul, Kamolratanakul, & Ebrahim, 1994; Whyte & Ingstad, 1998).

Our research on these issues began with a pilot study in 2001 of U.S. older persons' attitudes about personal and equipment assistance (Boynton, 2001; Verbrugge & Boynton, 2002). When results were presented (Verbrugge) in Singapore, the audience noted many differences in Singaporean culture from Western notions of disability, assistance, and independence. We (Verbrugge and Mehta) subsequently designed this comparative study of older Americans and Singaporeans to explore such differences.

Three hypotheses for the study are based on the Singaporean tradition of coresidence and family interdependence, contrasted with the American ethos of self-reliance and own residence.

(H1): Older Singaporeans strongly prefer *personal assistance* over special equipment, while Americans prefer *equipment*.

(H2): Older Singaporeans view *independence* as doing the activities they wish, whether helped or not. *Dependence* means "to depend on others", and it is a welcome aspect of late life. Older Americans define independence as not having personal help; dependence is the opposite and very undesirable.

(H3): Older Americans and Singaporeans define *disability* as difficulty with activities due to health, and they agree on social indicators of a "person with disability".

#### Methods

Elderly cohorts in the U.S. and Singapore are historically very different. The U.S. cohort has lived in a society with educational emphasis, stable nationhood, and continued modernization. The Singapore cohort often had little or no education, experienced both foreign occupation and national independence, and saw their country transformed to a modern economy in just a few decades. Our goal was to choose older people with a current similarity, namely, those with functional problems and assistance, but living in the community.

Community dwellers aged 70+ with elder-care services were recruited for interview. The U.S. sample was residents of assisted living facilities. The Singapore sample was people with day-care services at community centers. Multiservice centers are a common type of elder-care in Singapore, available weekdays for a participation fee; seniors socialize, play games, have meals together, exercise, and get physiotherapy. Completed interviews were obtained from 34 persons in the U.S. and 30 in Singapore. The U.S interviews were at the respondent's residence, and the Singapore interviews were at the community centers. Singapore interviews were conducted in Mandarin, Malay, or English; no respondent required Tamil.

The questionnaire started with sociodemographic and health items. We then asked about disability: difficulty doing tasks on one's own due to health or aging (8 ADLs, 5 IADLs, 9 physical limitations) For each task, respondents were asked if they receive personal help and/or equipment help, and who the personal helpers are. We asked about help for every task in order to capture situations where help has resolved intrinsic disability. Opinions about assistance were queried: how R (respondent) feels about personal help and special equipment; who should help if personal help is needed, and why; if R sometimes receives help that is not needed or requested, and if so, how s/he feels about it. Independence was next: how R defines it; self-rated independence; which type of assistance best maintains a sense of independence, and why. Similar questions were asked about dependence: how R defines it; self-rated dependence; which type of assistance makes R feel most dependent, and why. Lastly, we asked R to define disability; whether s/he is a person with disability, and why or why not; their society's views and physical barriers about disability; and typical indicators of a person with disability. Table footnotes show question wordings.

After fieldwork was completed, Singapore interviews conducted in Chinese or Malay had their open-ended items translated into English. Open-ended items in all 64 interviews were read by editors, code classifications were developed, and answers were coded into themes.

The open-ended items had multiple mentions. After coding each mention, we generated "any mention" variables by scanning across mentions for a given theme, scoring 1 if present, else 0.

We conducted quantitative and qualitative analyses of the data. Tests of differences between the U.S. and Singapore samples were computed using Chi-square or ANOVA, as appropriate. Significance levels are \*\*\*  $P \le .001$ , \*\*  $P \le .01$ , \*\*  $P \le .05$ , \$\phi\$  $P \le .10$ , ns P > .10. Separate from the quantitative work, one author (Wagenfeld-Heintz) conducted qualitative analyses of open-ended items, identifying themes within each country and comparing across

them. We present quantitative results supplemented by the qualitative ones, with example quotations. We use abbreviations for United States (US), Singapore (SG), and respondent (R). After describing sample characteristics, we adopt present tense for the results: attitudes about assistance, independence, dependence, definition of disability, and societal views and barriers.

#### **Results**

#### Sociodemographic, Health, and Disability Characteristics

The Americans were mostly white females, widowed, and living alone; average age was 83.9 (Table 1). The majority of Singaporeans were females; one third were males. Over 40% of the Singapore seniors were married; average age was 76.3; the majority were Chinese. All lived with others in HDB flats (high-rise housing built by the Singapore government). Education and income levels were higher for the American sample. This reflects cultural differences about schooling when the two cohorts were young, and some economic selectivity (assisted-living residence is private-pay housing for middle and higher income persons, and HDB residence is mainly middle and low income families). The groups had similar numbers of medical conditions (m 7.6 US, 6.9 SG, ns). Singaporeans said health problems affect their daily tasks more (m 2.8 US, 3.4 SG, \*). Numbers of disabilities were slightly higher in Singapore, but the difference is nonsignificant (8.2 US, 9.6 SG, ns).

#### Assistance for Tasks

U.S. and Singapore seniors have similar numbers of assisted tasks, of tasks with personal help, and of tasks with equipment help (<u>Table 2</u>). The percent of assisted tasks that get personal help is similar in both countries (67.6% US, 70.5% SG, ns), and so is the percent having equipment help (39.0% US, 37.1% SG, ns).

Table 1. Sociodemographic, Health, and Disability Characteristics, US and Singapore Samples<sup>a</sup>

Number of cases	<u>US</u> 34	Singapore 30	significance
Females	79.4%	63.3%	ns
$Age^{b}(\underline{m})$	83.9	76.3	***
Majority race/ethnicity <sup>c</sup>	94.1%	70.0%	(*)
Nonmarried	82.4%	56.7%	(*)
Household size (including R; <u>m</u> )	1.4	4.1	***
Formal education completed (years; <u>m</u> )	14.9	4.1	***
Low income <sup>d</sup>	50.0%	96.7%	***
No. of medical conditions <sup>e</sup> ( <u>m</u> ) How much medical conditions affect ability	7.6	6.9	ns
to do daily tasks <sup>f</sup> ( <u>m</u> )	2.8	3.4	*
No. of disabilities <sup>g</sup> ( <u>m</u> )	8.2	9.6	ns
Degree of difficulty for disabilities <sup>g</sup> ( <u>m</u> )	2.2	2.7	*

a \*\*\*  $P \le .001$ , \*\*  $P \le .01$ , \*  $P \le .05$ , \$\phi P \le .10\$, ns P > .10. Parentheses indicate Chi-square is approximate, due to half or more cells with n<5. Not applicable (Inap) responses deleted. Frequency distributions have colon after title and % after just first category; they sum to 100.0%.

b Singapore sample has one person age 65 due to initial uncertainty; kept in analyses.

c US: majority is white, minority is black. SG: majority is Chinese, minority is Malay or Indian.

d US: <\$40,000 per year. SG: <\$18,000 per year (US\$10,800).

e Respondents were asked if a physician or health care provider has diagnosed them for 18 medical conditions and "anything else" [specify].

 $f \ \ Ordinal \ categories \ scored \ 1=not \ at \ all, \ 2=a \ little, \ 3=somewhat, \ 4=quite \ a \ bit, \ 5=very \ much.$ 

g "Because of health or aging, how much difficulty do you have [doing task] on your own? Would you say: no difficulty, some difficulty, a lot of difficulty, unable to do?" (scored 0-3).

Table 2. Personal and Equipment Assistance, US and Singapore a,b

	US	Singapore	significance
Number of tasks with			<del></del>
Personal help only (m)	5.0	5.1	ns
Equipment help only (m)	2.6	2.7	ns
Both personal and equipment help (m)	0.7	0.8	ns
Personal help total ( <u>m</u> )	5.7	5.9	ns
Equipment help total (m)	3.3	3.6	ns
Percent of assisted tasks that have <sup>c</sup>			
Personal help	67.6%	70.5%	ns
Equipment help	39.0%	37.1%	ns
Personal helpers for tasks: <sup>d</sup>			
Spouse	2.5%	28.5%	***
Children	15.9	38.0	
Grandchildren	3.0	5.0	
Sibling or other relative	2.5	0.0	
Friend or neighbor	2.5	1.0	
Maid	0.0	25.5	
Other	7.5	2.0	
Professional	66.1	0.0	

a See Table 1, footnote a.

b "What kind of help do you receiving in [doing task]? Do you receive no help, help from another person, help from special equipment, or both personal and equipment help?" (asked for each task except if R doesn't do it for nonhealth reasons).

c Personal help = personal only, or both; equipment help = equipment only, or both.

d All mentions for the 22 tasks.

But the kinds of personal helpers differ greatly. The U.S. seniors rely mainly on professional staff at their assisted-living facility (66.1% of all mentions), and relatively little on their children (15.9%). Staff are the key helpers for ADLs, home-based IADLs (medications and light housework), and physical limitations. Children help only with away-from-home activities and managing finances. By contrast, Singaporeans have help mostly from their children and spouse (66.5% of all mentions) and household maid (25.5%). Spouse and maid are the main helpers for ADLs, and children are the key helpers for all other tasks. Increasingly, maids are being employed for senior care in Singapore; they are usually live-in and treated as household members.

How do seniors feel about having personal help for tasks? We organized responses into positive, negative, and neutral themes. In both countries, the majority state positive features of personal help (67.7% US, 63.3% SG, ns) (Table 3) [1]. (Brackets signal quotations below.) But about half the seniors state negative ones (45.2% US, 50.0% SG, ns) [2]. Singaporeans often give a positive opinion first, then a negative one. Help has dual aspects; they are grateful for it, but worried about being a burden on others [3]. Neutral feelings about personal help (simply accept it because it's needed) are uncommon in both countries (19.4% US, 23.3% SG).

[1] US06: "It makes me feel quite good, because there's someone to do it for me, and I don't have to do it myself if I can't." and SG44: "Very happy and very grateful." [2] SG51: "Feel frustrated and no choice. I used to be OK, but now I need to depend on my children for help." and US07: "It makes me feel inadequate. I have always done things myself. It's not very pleasant to ask people to help you." [3] SG57: "(My wife) is kindhearted and takes good care of me. But on the other hand, I feel sad and lost, because it is the husband who should look after the family. Sometimes I feel useless."

Table 3. Attitudes about Personal and Equipment Assistance, US and Singapore<sup>a,b</sup>

	US	Singapore	significance
How personal help for tasks makes R feel <sup>c,d</sup>			_
Positive feeling	67.7%	63.3%	ns
Negative feeling	45.2%	50.0%	ns
Neutral feeling	19.4%	23.3%	ns
How equipment help for tasks makes R feel <sup>c,d</sup>			
Positive feeling	63.0%	80.0%	ns
Negative feeling	25.9%	55.0%	ф
Neutral feeling	37.0%	30.0%	ns
If need personal assistance, who should help:			
Spouse, child, or grandchild	17.2%	86.7%	***
Other relative, friend, neighbor	6.8	3.3	
Maid (SG) or other person (US)	13.8	10.0	
Professional	62.2	0.0	
Why (main reason):			
Availability	38.0%	56.6%	*
Obligation	17.2	26.7	
Expertise	20.7	0.0	
No other option/don't need help yet	24.1	16.7	
If R ever receives help when doesn't need or ask (yes) How such help makes R feel <sup>d</sup>	47.1%	53.3%	ns
Positive feeling	39.1%	93.8%	**
Negative feeling	43.5%	3.1%	**
Neutral feeling	17.4%	3.1%	ф

a See Table 1, footnote a.

b "How does receiving help with daily tasks from other people make you feel?" (4 mentions). "How does using special equipment to help with daily tasks make you feel?" (4 mentions). "If you need help with daily tasks from someone, who do you think should be the person to help you?"; "Why?" (2 mentions). "Do you ever receive help when you don't need it or don't ask for it?"; if yes, "How does that make you feel?" (2 mentions).

c Among users of personal help (equipment help).

d Percent who state this theme in any mention.

How do seniors feel about having equipment help for tasks? The majority of both groups state something positive about using equipment (63.0% US, 80.0% SG, ns) [1]. Respondents often say they were initially reluctant, but gradually grew to like it. Seniors in both countries say that equipment gives them security at home and in public. However, Singaporeans often state negative feelings about equipment (55.0% SG, 25.9% US  $\phi$ ), fearing they lose selfworth or self-identity when using it [2]. Neutral feelings about equipment (simply accept it because it's needed) are least common (37.0% US, 30.0% SG, ns) [3].

[1] SG40: "At first, I hardly accepted it. But later I became used to it. Now we are good friends and always go together." and US17: "It makes me feel good. I can go anywhere I want. ..In the summer, I can go around the house several times." [2] SG58: "Every time when I see the wheelchair, I feel I have no face. I blame my legs." [3] US36: "It makes me feel old, but I need it." and SG59: "Everybody will become old. There is one day when you have to use special equipment. This is natural."

Who *should* help if they need it? Almost all Singaporeans name family members (spouse, child, grandchild; 86.7%), else a maid (10.0%). By contrast, Americans name professionals (62.2%), and much less often, their family (spouse, child, grandchild; 17.2%) or "other" (people hired for specific services; 13.8%). In both countries, availability is the main reason for the top choice (38.0% US, 56.6% SG). Singaporeans usually give two reasons, citing both availability and filial obligations/family reciprocity [1]. Americans say the professional staff are available, are obligated due to payment, or have expertise [2]. When the Americans prefer family members, it is because of trust and intimacy.

[1] SG66: "Children, because they are staying with me and all of them have grown up and are independent. Since they are the closest to me, they should help me. I've always taken care of them since young." [2] US09: "I'm paying for them, and it's their job."

About half the seniors say they sometimes get help when they don't need or request it (47.1% US, 53.3% SG, ns). Gignac and Cott (1998) call this imposed dependence, and our data show it often occurs. How do people feel about such help? Almost all the Singaporeans

say something positive (93.8% SG, 39.1% US, \*\*). They view it as kindness, with no implications for their own self-esteem [1]. Americans see some positive features of unsolicited help, but often feel uncomfortable or accept it grudgingly (43.5% US, 3.1% SG, \*\*) [2].

[1] SG62: "I feel relieved and happy that someone is willing to help." and SG41: "I don't feel inferior. Others' help doesn't make me feel self-abased. Others want to help you and of course, you should thank them." [2] US25: "I'm not mad, but I just think they're kind of telling you that you aren't doing it right." and US03: "Sometimes it's difficult to stop people. Nobody helps me very long when I don't want them to."

#### Independence

What is "independence"? There are three themes: doing activities on one's own, maintaining personal autonomy, and having help/lost autonomy (independence defined by its opposite). Singaporeans uniformly define independence as doing activities on one's own, without personal help (96.7% SG), and Americans also rank this first (67.6% US, \*\*) [1] (Table 4). In both countries, nearly half the seniors say independence is personal autonomy (47.1% US, 43.3% SG). Americans are emphatic about being in charge of their lives -- having their own residence, finances, decision-making, and thoughts [2]. Singaporeans discuss autonomy in a very different way, emphasizing positive psychological attributes that help when old [3]. Lastly, Singaporeans often define independence by what it is not (43.3% SG, 20.6% US, φ).

[1] SG61: When you can do things on your own, like a normal person." and US10: "It's caring for yourself rather than other people (doing so)." [2] US13: "To make my own decisions." and US32: "To be able to take care of myself, get up when I want, watch tv when I want. It's very important to me to have my freedom of choice." [3] SG45: "The stronger your willpower and perseverance, the more independent you can be. So in terms of independence, you should internalize the idea." and SG46: "When you are not able to handle some daily tasks (on your own), you don't need to be worried; you should be optimistic. The more optimistic you are, the better you'll be able to maintain independence."

Table 4. Independence, US and Singapore<sup>a,b</sup>

	US	Singapore	<u>significance</u>
Definition of independence <sup>c</sup>			
Doing activities on one's own/no help from others	67.6%	96.7%	**
Maintaining personal autonomy	47.1%	43.3%	ns
Defined by absence (have help, lost abilities/autonomy)	20.6%	43.3%	ф
Rating of own independence:			
Not at all independent	0.0%	6.7%	(φ)
A little	14.7	13.3	
Somewhat	32.3	33.3	
Very	32.4	46.7	
Totally independent	20.6	0.0	
What kind of help is best for independence:			
Friends or neighbors	12.1%	0.0%	ns
Family	24.3	33.3	
Professionals	21.2	46.7	
Special equipment	18.2	20.0	
Don't know	24.2	0.0	

a See Table 1, footnote a.

b "Nowadays, people often talk about the importance of independence as they age. What does it mean to you to be independent?" (4 mentions). "How would you rate your own level of independence? Would you say you are not at all independent, a little, somewhat, very, or totally independent?" "What kind of help do you feel is best for maintaining a sense of independence: help from friends or neighbors, from family, from professionals, or special equipment?"; "Why?" (4 mentions).

c Percent who state this theme in any mention.

Singaporeans rate their own independence lower than Americans do ( $\phi$ ). No Singapore seniors feel they are "totally independent", compared to 20.6% of the Americans.

Asked what type of help is best for maintaining independence, nearly half the Singapore seniors name professionals (46.7%). They say physiotherapy and exercises help people regain function [1]. Family is ranked next (33.3%), chosen because of mutual understanding and emotional bonds [2]. Equipment ranks third (20.0%), liked for its ease of use [3]. The Americans give mixed responses; family members are appreciated for their emotional closeness, professionals are trusted for their ability, and equipment is liked because it enhances mobility and self-sufficiency. Qualitative analyses show that they seldom feel that any type of assistance increases independence, but equipment receives more enthusiasm than personal help [4].

[1] SG41: "Because of their help, my legs are getting better and better, and I am less dependent on others."

[2] SG48: "Help from family, because family members are insiders and are supposed to help each other.

Peace in the family will make it prosper, won't it?" [3] SG60: "We don't have to feel ill at ease (with equipment); it doesn't complain and does what it is supposed to do." [4] US20: "Because I can use the equipment independently. I don't have to rely on someone else to use it for me."

#### Dependence

What is "dependence"? There are five themes: needing help from others, difficulty doing activities one used to do easily, loss of own decision-making, negative feelings, and positive/neutral feelings. For Singaporeans, the key criterion is needing personal help (63.3%); activity problems that prompt help are usually mentioned at the same time (53.3%) (Table 5) [1]. For Americans, the same two criteria rank at the top: needing help (42.4%, φ) and activity difficulties (36.4%, ns) [2]. Both groups express some strong negative feelings about dependence (36.4% US, 26.7%SG, ns) [3]. Positive views are voiced when dependence connotes social bonds among humans [4].

[1] SG56: "You are not able to eat and get dressed on your own; you have to depend on the maid's help. You are financially dependent on your children; you have no savings on your own. You use a walker or other equipment, and you have to exercise your limbs under the guidance of a physiotherapist." [2] US25: "To have somebody else help me with things I once upon a time could do for myself." [3] SG66: "It makes you feel somewhat useless." and US15: "It means that I'm not fit; if I have to depend on someone, I figure I'm a cripple or ashamed." [4] US12: "I need help. Everyone needs help." and SG42: "In society, people depend on each other to work, so humans are dependent beings. We have to remember that."

Singaporeans rate themselves as more dependent than Americans, especially in the category "very dependent" (24.1% SG, 9.1% US).

Asked what type of help makes them feel most dependent, Singaporeans name family first (50.0%), and equipment next (40.0%) [1]. Equipment has negative connotations for self-identity or self-esteem [2]. Americans have mixed responses about what makes them feel most dependent; there is no typical opinion. When they say equipment causes high dependence (24.2%), they simply mean that the device is always needed [3].

[1] SG43: "I feel this will burden the family and trouble them. ..I feel frustrated; if only I could be independent!" [2] SG47: "When you have to depend on special equipment, you will feel guilty. You may think that you haven't done well in terms of healthcare." [3] US34: I couldn't do anything without my walker, going from here even to the bathroom. I take that with me all the time."

Table 5. Dependence, US and Singapore<sup>a,b</sup>

	<u>US</u>	Singapore	significance
Definition of dependence <sup>c</sup>			
Need/have help from others	42.4%	63.3%	ф
Difficulty doing activities	36.4%	53.3%	ns
Loss of decision-making	18.2%	30.0%	ns
Negative feelings	36.4%	26.7%	ns
Positive/neutral feelings	18.2%	10.0%	(ns)
Rating of own dependence:			
Not at all dependent	12.1%	6.9%	ns
A little	36.4	34.5	
Somewhat	39.4	34.5	
Very	9.1	24.1	
Totally dependent	3.0	0.0	
What kind of help makes R feel most dependent:			
Friends or neighbors	27.3%	10.0%	**
Family	12.1	50.0	
Professionals	15.2	0.0	
Special equipment	24.2	40.0	
Don't know	21.2	0.0	

a See Table 1, footnote a.

b "People sometimes worry about being dependent. What does it mean to you to be dependent?" (4 mentions). "How would you rate your own level of dependence? Would you say you are not at all dependent, a little, somewhat, very, or totally dependent?" "What kind of help does or would make you feel most dependent: help from friends or neighbors, from family, from professionals, or special equipment?"; "Why?" (4 mentions).

c Percent who state this theme in any mention.

#### Definition of Disability

"When you think of someone with a disability, what comes to mind?" Four themes occur: limitations in activities and abilities, making adaptations and having assistance, negative feelings (disability is sad, tragic, depressing), and positive feelings (admiration for how people cope). The majority of American and Singapore seniors mention difficulty with activities/abilities (56.2% US, 73.3% SG, ns) (Table 6). Both groups emphasize physical limitations; Americans sometimes include cognitive ones [1]. Singaporeans often add that disability is a hard personal situation for individuals (63.3% SG, 28.1% US, \*\*) and requires adaptations and assistance (46.7% SG, 21.9% US, \*). Positive statements are uncommon (12.5% US, 13.3% SG, ns).

[1] SG61: "People who cannot walk and need wheelchair."; US21: "That they're not able to do something."; and US14: "Unable to walk and talk. Inability to express oneself. Inability to physically take care of self. Inability to think clearly."

We asked about public criteria for disability: "Do you consider a person to have disability if he or she has [problem]?" Sixteen problems were stated, including mobility/sight/hearing limitations, medical conditions, and personal assistance for ADLs/IADLs. The Singaporeans choose fewer criteria than the Americans do (m 7.0 SG, 12.3 US, \*\*\*). They focus on severe mobility and sensory problems (cannot walk/wheelchair 93.3%, blind 86.7%, deaf 76.7%; also toileting assistance, 76.7%). This is a "traditional" view of disability. In contrast, the Americans choose all 16 problems more often (12 significant differences; 7 \*\*\*, 1 \*\*, 3 \*, 1 ф). Nine problems are chosen by the great majority (≥75%) of Americans, compared to just 4 so often in Singapore. Americans universally think inability to walk, see, or hear (100.0%, 100.0%, 97.0%) and assistance for eating, bathing, and toileting (100.0%, 93.9%, 90.0%) are disability criteria.

Table 6. Definition of Disability, US and Singapore<sup>a,b</sup>

	<u>US</u>	Singapore	significance	
Definition of disability <sup>c</sup>				
Limitations in activities and abilities	56.2%	73.3%	ns	
Adaptations and assistance	21.9%	46.7%	*	
Negative feelings (sad, tragic, depressing)	28.1%	63.3%	**	
Positive feelings (admire how people cope)	12.5%	13.3%	ns	
No. of criteria for "person with disability" (m)	12.3	7.0	***	
If R thinks s/he is a person with disability:				
Yes	48.5%	43.3%	ns	
No	51.5	56.7		
If yes, why? <sup>c</sup>				
Difficulty in specific activities	75.0%	84.6%	(ns)	
Impairments or functional limitations	56.2%	46.2%	ns	
Use personal or equipment assistance	18.8%	38.5%	(ns)	
If no, why not? <sup>c</sup>				
Not disabled by own definition	52.9%	23.5%	ф	
Can still do stated activity	41.2%	88.2%	Ψ **	
Don't need assistance	11.8%	0.0%	(ns)	
Don't need assistance	11.070	0.070	(115)	

a See Table 1, footnote a.

b "When you think of someone with a disability, what comes to mind?" (4 mentions). "Do you consider a person to have disability if he or she: has difficulty walking or uses a cane or walker; can't walk or uses a wheelchair; wears glasses most of the time; is blind; is hard of hearing or wears a hearing aid; is totally deaf; has high blood pressure; has heart disease; has diabetes; has depression; has schizophrenia; needs assistance to eat; needs assistance bathing; needs assistance using the toilet; needs assistance with housework because of health; is unable to drive because of health?" (16 problems). "Do you consider yourself to be a person with disability?"; if yes, "Why?" (3 mentions); if no, "Why not?" (3 mentions).

c Percent who state this theme in any mention.

Asked if they consider themselves a "person with disability", similar percents of the Americans and Singaporeans say yes (48.5% US, 43.3% SG, ns). Both groups give the same *reasons for yes:* difficulty with specific activities they used to do (75.0% US, 84.6% SG, ns) or having certain impairments/functional limitations (56.2% US, 46.2% SG, ns) [1]. But *reasons for no* differ sharply. The U.S seniors often say they don't fit the definition (52.9% US, 23.5% SG; φ) [2]. Singapore seniors mention activities they can still do as the rationale for saying no (88.2% SG, 41.2% US, \*\*) [3].

[1] US02: "Because I can compare myself with a year ago, and I am in very different shape. Balance isn't good." and SG42: "Yes, because I cannot walk. ..I am physically disabled, but I am mentally OK." [2] US03: "Cause I don't have any." and US33: "I'm just getting older." [3] SG46: "No; I'm still able to walk and go out. And I'm still able to come to this center and chat with my friends. I'm still able to take a bus, though I move slowly." and SG52 (having rehabilitation due to a stroke): "My eyes can see; my ears can hear; I can walk and sing. There is no reason why I have to consider myself to be a person with disability."

#### Societal Views and Barriers

How are people with disability viewed by society? We organized responses into three themes: positive (people are kind, attitudes/access are improving), negative (disabled people do not have enough support or empathy), and equivocal (some people treat them well, others don't). The Singapore seniors are much more positive about societal treatment of persons with disability than the American seniors are (73.3% SG, 43.3% US, \*) (Table 7) [1]. They note how important religious and charitable organizations are in helping Singapore's elderly. The Americans state negative aspects of society much more often (63.3% US, 30.0% SG, \*\*) [2].

[1] SG52: "Society is concerned with the disabled, helping them. ..They are regarded as members of this society and aren't excluded. They can study if they want, they can work if there are job opportunities." and SG53: "Most people have a loving and compassionate heart. They help the disabled on their own initiative."

[2] US02: "They are viewed as below the level of most people." and US18: They're not treated the way they want to be treated, or how society thinks they ought to be treated."

What physical barriers are encountered by people with disability? Singaporeans *universally* mention public access problems in buildings, walkways, and public transportation (100.0% SG, 51.6% US, \*\*\*). Buildings have too many steps, overhead bridges that cross roads have steep steps, tile floors are slippery, traffic lights are timed too short to walk across the road, metro ticketing gates are narrow, elevator landings do not exist at all floors (older HDB flats), and more [1]. In contrast to Singaporeans' voluble and highly critical answers, the Americans give shorter and less-focused ones. They cite fewer problems, mostly with stairs and vehicle entry/exit [2]. They think society is working to remove physical barriers, more than Singaporeans do (19.4% US, 3.6% SG,  $\phi$ ).

[1] SG40: "The escalators in (metro) stations are too fast; there are no lifts, too. ...Many places are inaccessible; many things, such as visiting an exhibition and going shopping, I'm unable to do" and SG55: "The disabled are fearful of crossing streets and roads. Vehicles move fast; green traffic lights last a short time. The steps of overhead bridges are steep. There is no special seat for the disabled person in the church." [2] US20: "Stairs. Even ramps can be very difficult for a person who is breathless. I've heard people talk about doorways too narrow for their (wheelchair/scooter)."

Table 7. Societal Views and Barriers for Disability, US and Singapore<sup>a,b</sup>

	US	Singapore	<u>significance</u>
How people with disability are viewed by society <sup>c</sup>		<del></del>	
Positive aspects (kindness and improving attitudes)	43.3%	73.3%	*
Negative aspects (not enough support or empathy)	63.3%	30.0%	**
Equivocal (attitudes vary in society)	23.3%	36.7%	ns
Physical barriers encountered by people with disability <sup>c</sup>			
Access problems outside home	51.6%	100.0%	***
Society has too many physical barriers	12.9%	0.0%	(*)
Mental and psychological troubles	25.8%	0.0%	(**)
Physical limitations	19.4%	0.0%	(*)
Personal care (ADL) problems	19.4%	0.0%	(*)
Must make adaptations or get help from others	12.9%	0.0%	(*)
Society is removing physical barriers	19.4%	3.6%	(φ)
Social barriers faced by people with disability <sup>c</sup>			
Social prejudice and embarrassment	34.5%	10.3%	*
Social barriers are largely gone	17.2%	6.9%	(ns)
People try to help those with disabilities	37.9%	37.9%	ns
People with disabilities have social troubles	24.1%	72.4%	***
Limited opportunities	8.8%	40.0%	**
Equivocal (attitudes vary in society)	6.9%	0.0%	(ns)

a See Table 1, footnote a.

b "Government leaders and policy makers are now working to improve the quality of life for persons with disability. How do think people with disability are viewed by our society?" (4 mentions). "What types of physical barriers do you think people with disability encounter in our society?" (4 mentions). "What types of social barriers do you think people with disability face in our society?" (4 mentions).

c Percent who state this theme in any mention.

What social barriers are faced by people with disability? The American seniors are more likely to say that social prejudice and public embarrassment persist (34.5% US, 10.3% SG, \*). On the other hand, some think society has removed social barriers (17.2% US, 6.9% SG, ns). Both groups say the public is helpful to persons with disabilities (37.9% US, 37.9% SG, ns). The most striking result is Singaporeans' expressions of empathy for disabled people's communication troubles, social isolation, and depression (72.4% SG, 24.1% US, \*\*\*) [1], and their concern about reduced social opportunities for disabled persons of all ages [2].

[1] SG48: "I think they may feel lonely because they are homebound most of the time, and there seems to be so much time to kill. Moreover, the disabled may have difficulty interacting and communicating with others." [2] SG49: "Difficult to get married because of their disability. They have the right to get married and enjoy family life. So government should help them to realize their dreams."

#### **Discussion**

The American and Singapore seniors differ in views of assistance, independence, dependence, and disability, far more often than they agree. Despite our small samples, many differences are statistically significant, even at  $P \le .01$  and  $P \le .001$ . We note key features of each group of older persons, and then the differences between them.

Singapore seniors usually live with one of their children, and receive help from family (coresident/nearby children and children's spouses) on a daily basis. Care and respect for older kin is a traditional, and still strong, feature of all three major ethnic groups in Singapore, especially the Chinese community. Four themes emerge for the older Singaporeans we interviewed: (1) They are *ambivalent* about the family help that occurs in their everyday lives. They appreciate and expect assistance, but feel it reduces their independence. Ambivalence also applies to special equipment; it helps them get about, but they fear losing face (public respect). Help from nonkin (friends and neighbors) is uniformly disliked because it creates a social debt that may be difficult to repay. In contrast, family

help involves longterm reciprocal ties, so help at one time is returned at another. (See Mehta, Osman, & Lee, 1995, for complementary results from a focus-group study.) (2) Singaporeans' independence criterion of "no help" runs squarely against the facts of kin coresidence and routine help. This juxtaposition of wish versus reality is likely a key reason for self-ratings of lower independence and higher dependence, compared to the Americans. Despite little cultural awareness of what more late-life autonomy might be like, Singaporeans often vividly state their wishes for it. (3) Singaporeans think having disability is a very difficult situation for seniors in their country. Although citizens are helpful one-on-one, societal buttresses are lacking --especially access for transportations, walkways, and buildings. (4) Throughout the interviews, Singaporeans discuss basic human feelings and motivations more than the Americans do. They talk about the importance of psychological strengths such as optimism, confidence, and peace of mind when older and disabled, and they say religious beliefs are valuable. Concerning their own limitations, they mention sadness, loss of self-worth, and worry about being a burden on their children. They express great empathy for persons with disability in their society, and say most Singaporeans are kind when encountering them. This helps explain their own gratitude, rather than affront, about receiving unrequested help.

The American seniors are living on their own, with professional help close at hand. Three themes emerge: (1) They are dedicated to a *sense of freedom*. They insist on doing what they can by themselves and staying in charge of daily life. Personal help is avoided whenever possible. If it is needed, assisted-living staff are preferred over children or friends. Equipment is viewed less negatively than personal help. (2) The Americans are able to *match their goals with their living situation*. Assisted-living residence is usually carefully chosen over other options, to maximize privacy but offer ready access to care. Residents do remain in charge. This is probably a key reason for the Americans' high self-ratings of

independence, and low ratings of dependence. (3) The older Americans are critical of social views and physical barriers for persons with disability, but report *societal progress* in relieving those problems.

The main differences between the U.S. and Singapore seniors relate to personal help and to societal views and indicators of disability. First, Singaporeans cannot extricate themselves from personal help, due to coresidence with children. They accept and appreciate help, but wish they had more privacy and control. Seeming contradictions in their answers about assistance and (in)dependence are in fact sensible compromises. By contrast, the Americans have chosen a residential setting that avoids personal help from kin and permits sparing use of professional help. They maintain own residence, finances, and decision-making as much as possible. In sum, older Singaporeans live in a culture of interdependence, while older Americans live in a culture of individual independence. Second, Singaporeans express deep personal sympathy for *people with disabilities*, and say the general public is kind towards them. The Americans are more critical of society's treatment, saying progress has been made for persons with disabilities, but much remains to be done. The two groups also differ in popular indicators of disability in their society. Singaporeans name wheelchair use, blindness, and deafness as the main signs of disability, while Americans choose many more criteria. In sum, one group speaks with "old-fashioned" compassionate heart, and the other with "modern" cognitive attitudes.

Our two hypotheses about assistance, independence, and dependence were not on target, but the hypothesis about disability was more so. For H1 & H2: The sharp cross-country contrasts expected for type-of-assistance preferences, and definitions of independence, do not occur. Positive and negative aspects of personal/equipment assistance are voiced by both groups. Definitions of independence are similar for both countries, and definitions of dependence are diverse within each country. Singapore seniors are more positive about

dependence than Americans are, as expected. What the hypotheses missed is the ability of Singaporeans to make psychological compromises, that is, to have daily and often unwanted help, but to tolerate and accept it. For H3: Definitions of disability are the same in both countries, as expected. But Americans choose more public indicators of disability than Singaporeans do.

This study put demographic definitions of disability, independence, and dependence to real-life test. In both countries, *disability* is defined as difficulty doing activities on one's own, which aligns with contemporary research definitions. Contrary to research practice, *independence and dependence* have diverse definitions, and are not simple opposites. For both Singaporeans and Americans, independence can mean not having personal help for tasks or autonomy in daily life (maintaining own residence, finances, decision-making).

Dependence means receiving help for tasks, needing that help, loss of autonomy for decisions, depending on others for daily life and financial support, relying on others, or altruism. It is telling that during the interviews, respondents had no trouble answering separate questionnaire sections about the two topics, one right after the other. In fact, demographic literature is slowly dropping the terms "independence" and "dependence", in recognition of their psychological content. Straightforward terms like "human help", "personal help", "assistance from others", and "no human or equipment help" are replacing them (e.g., Spillman, 2004).

In the psychological literature, Gignac and Cott (1998) have pointed out that independence and dependence can be quite different notions. Their conceptual scheme for the concepts hinges on personal assistance needed or not needed, and received or not received. But their underlying theorizing goes far beyond that, covering many subjective aspects of independence and dependence. Since that important paper, Gignac and colleagues have shifted toward the Baltes model of "selective optimization with compensation" as a way

to blend more fully the behavioral and psychological aspects of independence/dependence (Baltes & Baltes, 1990; Falter, Gignac, & Cott, 2003; Gignac, Cott, & Badley, 2000, 2002).

In this study, we explored definitions and feelings of independence and dependence without a prior conceptual scheme. The data show that behavioral features are important: need/receipt of help, manifest autonomy, and maintenance/loss of abilities. Subjective ones are just as important: reciprocity, self-esteem, feeling in charge, psychological strengths, self-identity, religious beliefs, and views of human goodness. In sum, objective and subjective aspects routinely factor into what independence and dependence mean to individuals.

Lastly, we note our work to choose a suitable sampling design. We wanted persons who were community dwelling but had senior care. The senior-care criterion gave good chances that respondents have well-formed opinions about assistance, independence, and disability. We operationalized "senior care" by a contemporary and popular approach in each society: assisted-living residence in the U.S., and day-care centers in Singapore. Although we did not know in advance how the samples would differ for disability, they had similar levels of disability and assistance. This was propitious since the small sample sizes allowed only bivariate analyses (between-country differences with no control variables). Both samples had ethnic/race diversity. They differed in education and income statuses due to cohort histories and some selectivity. Socioeconomic differences are an unavoidable aspect of studies that compare current cohorts of seniors in Western and Asian societies.

#### Conclusion

Singapore and American seniors' experiences of disability and assistance differ greatly. Singaporeans come to terms with the cultural imperative of coresidence with their children and daily help from them. They appreciate the instrumental and emotional benefits, but worry about being a burden, and yearn for more personal freedom. Americans in assisted-

living residence insist on that freedom. They rely very little on their children for help, preferring professional staff when necessary. By maintaining their own abode, they keep a distinct boundary between private life and needed services.

In both countries, notions of independence and dependence are varied and have emotional content. Independence means not having personal help for tasks, or personal autonomy. Seniors in both countries like independence, and the Americans are more successful in achieving it. Dependence is a more complex notion. Receiving personal help for tasks and loss of autonomy are often mentioned, but so are reliance on others in late life and human altruism. Both groups see pluses and minuses of dependence, and Singapore seniors accept it as an inevitable feature of late life. The diversity and richness of responses have led us to conclude that independence and dependence should always be treated as psychological concepts, not demographic ones.

American seniors' broad criteria for a person with disability fit contemporary government policies. Although the Singapore government is promulgating a public view of disability similar to the U.S., it has not penetrated the perspectives of older Singaporeans themselves.

Researchers who conduct cross-cultural studies encounter difficult issues about standardization, validity, and comparability (Keith, Fry, Blascock, Ikels, Dickerson-Putnam, Hapending, et al., 1994). Replicating questions closely across cultural settings appeals to researchers, but does it make good sense to respondents? This pilot study suggests that using the same or similar closed-ended questions in large-scale surveys will capture weakly the different disability experiences of older persons across societies. Open-ended questions and small-scale studies are a necessary adjunct, not for "cultural flavor", but to permit veridical profiles and interpretations in each place.

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