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Utilizing the China Health and Retirement Longitudinal Study (CHARLS) to Understand the Aging of People Living in the Community with Intellectual and Developmental Disabilities

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Abstract

There remain challenges in understanding the aging lives of people with intellectual and developmental disabilities. Method: A cross-sectional comparison of people with and without I/DD was created using China Health and Retirement Longitudinal Study (CHARLS). A definition of I/DD was established, three samples were created: those with an assigned/described intellectual and developmental disability prior to age 22 years; those with similar impairments at and after age 22 years; and those in the population without an assigned/described impairment. Findings: Those with I/DD appeared to have greater health needs on initial analysis. People with an impairment similar to I/DD but occurring after age 22 years had the same or greater needs in subsequent analyses. Both groups had greater needs than those with no identified disability. Discussion: There must be greater efforts to discover those with I/DD who are already in existing datasets, greater attention to the full range of lives led by people with I/DD and inclusion of data from a broader range of countries.

Keywords

Intellectual Disability, Developmental Disability, Aging, China

1. Introduction

For the general population much of what we know about health and aging is drawn from longitudinal studies. Countries around the world also share a desire to gather data on people with intellectual and developmental disabilities (I/DD), as they age, and to seek insights to support quality health care, social inclusion, meaningful occupation, choice, self-direction, family support and engagement, and avoidance of institutionalization [1]-[7]. In the emerging data from administrative datasets and population surveys, aging people with IDD are between 1% and 2% of the population of persons who are aging and as compared with older adults in the general population [4] [8] have been found to have:

- Elevated rates of unhealthy lifestyles [9] [10] to include unhealthy weight gain, obesity, cardiovascular disease (CVD), and CVD-related mortality among those living independently [11].
- Higher levels of polypharmacy and excess polypharmacy [12] [13].
- An elevated level of missing teeth with little replacement e.g., with dentures and poor dental hygiene in general [14].
- Females having poorer health than males as they age [15].
- Sedentary lifestyles and a reduced likelihood to achieve levels of physical activity that will positively affect health [16].
- Higher rates of chronic conditions such as dementia [17] [18].
- Earlier onset of menopause for women with I/DD with increased risks for dementia and early mortality [19].
- Increased pain, sarcopenia, osteoporosis, and arthritis [20] [21].
- Greater levels of co-occurring mental health concerns [10].

An additional concern is that much of what is known and reported is drawn from U.S., European and Australian data [8]. The data of other nations is under-represented. There is also often under-representation of adults with milder levels of life-long cognitive impairment as most I/DD studies draw heavily, if not exclusively, from individuals who are receiving formal services. To the extent that people with milder forms of I/DD are more likely to have the opportunity to live a life similar to the general population, finding information on this group offers an opportunity to confirm or dispute this idea. For all people with I/DD there are the additional challenges of differences in definitions of I/DD and in study sampling frames such as use of community household and voting registers where people with I/DD tend to be under-represented or simply not included [8].

Defining Intellectual and Developmental Disabilities

Intellectual Disability (ID) is defined by the World Health Organization as “a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)…that may result in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends…also and crucially on the extent to which environmental factors support the child’s full participation and inclusion in society…includes children with autism who have intellectual impairments. It also encompasses children who have been placed in

institutions because of perceived disabilities or family rejection and who consequently acquire developmental delays and psychological problems."
http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability. Definitions, country by country, of intellectual disabilities often vary and the measurement required for such a diagnosis varies further.

Impairments in intellectual functions central to ID are also classified within WHO's International Classification of Functioning, Disability and Health (ICF) in disability rather than health terms. The American Association on Intellectual and Developmental Disabilities (AAIDD) by focusing mainly on functioning, adaptive behavior and support needs supports the ICF conceptual model seeing ID as a disability with "significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18" [22]. In the U.S., ID is a subset of Developmental Disability (DD) defined as:

- A severe, chronic disability in an individual 5 years of age or older
- Onset before 22 years of age
- Results in substantial functional limitations in three or more areas of life activity (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent learning, economic self-sufficiency) [23]

There is also continued use in some jurisdictions of "learning disabilities" defined as a condition that affects the way a person learns new things in any area of life, and affects the way a person understands information and how they communicate. This often means difficulty understanding new or complex information, learning new skills and coping independently.
https://www.nhs.uk/conditions/learning-disabilities/. Again, the measures required to establish these diagnoses vary. These varying definitions and measurement approaches illustrate one of the epidemiological challenges—who represents a "case." And the picture is further complicated when differences are reported in health and quality of life by levels of cognitive and functional disability [8].

There are also differences in approaches to the classification of severity of disability. Learning disabilities are described as being mild, moderate or severe and profound with someone described as a person with profound and multiple learning disabilities (PMLD) when there is more than one disability, with the most significant being a learning disability and the persons needing help from someone else with most daily living skills areas
https://www.nhs.uk/conditions/learning-disabilities/. Other published reports rely on DSM-4 and DSM-5 severity levels (mild, moderate, severe, and profound). There are further studies where severity is based on adaptive functioning in the conceptual, social, and practical domains, or on the basis of cognitive skills and the distribution of IQ scores, as used in the International Statistical Classification of Diseases and Related Health Problems (ICD-10) [24]. Reports using

ICD-11 criteria are beginning to appear. As much as definitions have been different based upon the version of the classification system used, a larger issue is that independently established levels of I/DD are not usually reported in available datasets, nor the basis on which they were assessed, and there are individuals where there has been no formal assessment of severity [8].

Finding ways to reconcile these many differences becomes important if use of available data is to be maximized as does the inclusion of data from other countries. If achieved, there may be improved approaches to examining different patterns of aging among people with I/DD of different etiologies, differences across levels of I/DD and differences from the general population including of multi-morbidity patterns and their consequences for older age [25] (McCarron *et al.*, 2014). The report here is of an effort to 1) identify and test the feasibility for use of additional already established datasets such as the China Health and Retirement Longitudinal Study (CHARLS) and 2) determine if a sample of persons with milder forms on I/DD might emerge capable of being compared with the larger general population.

2. Method

A cross-sectional comparison was created using China Health and Retirement Longitudinal Study to better understand the aging lives of people with I/DD as compared to the lives of others in China.

The CHARLS Baseline Survey

The China Health and Retirement Longitudinal Study (CHARLS) using similar questions to the Health and Retirement Survey (HRS) in the US, the England Longitudinal Study of Aging (ELSA), and the Survey of Health, Ageing, and Retirement in Europe (SHARE) provides extensive demographic, socioeconomic, physical health and psychological health (and cognition) data. In 2011-12 baseline data was collected on a nationally representative survey that included one person per household who was 45 years of age or older and their spouses (totaling 17,708 individuals) living in 10,287 households in 450 villages/urban communities in 150 counties/districts in 28 of China's 30 provinces excluding Tibet. The response rate for the survey was over 80% (94% in rural areas and 69% in urban areas). Significant health issues were immediately highlighted with 31.8% reporting having poor health; 38.1% reporting a disability, defined as having any difficulty completing basic daily activities on their own; 23.8% requiring assistance with basic daily activities; and 33.4% experiencing bodily pain. Forty percent reported elevated levels of depressive symptoms. Physical examinations completed as part of the data collection confirmed 10.7% those over age 45 years were underweight; 28.0% were overweight, and 4.5% were obese with 54.0% reported a diagnosis of hypertension. Women as they aged were more likely to report a need for assistance with basic daily activities, and that they experienced higher levels (as compared to men) of bodily pain, overweight, cognitive decline and hypertension but also a higher life expectancy. One possible explanation is that nearly half of elderly men (46.8%) were current smokers, and the percentage was higher (58.3%) for men aged 45 to 59 [26].

Sample of People with a Developmental Disability

Although not specifically targeted in the recruitment of subjects, two questions on the baseline CHARLS survey permitted people with an I/DD to be identified. Those questions were:

1) Do you have one of the following disabilities: Response included a) Physical Disabilities; b) Brain damage/mental retardation; c) Vision problem; d) Hearing problem; and e) Speech impediment.

2) In what year did you become disabled?

(Note: wording is as found in the baseline survey)

Utilizing the response of brain damage/mental retardation and birth year and year in which having a disability was noted as beginning, seventy-six individuals were identified as presenting with a diagnosis of brain damage/mental retardation (wording used in survey) prior to age 22 (*i.e.* the cut off age for defining a developmental disability). These individuals are hereafter described as presenting as a person with an intellectual and developmental disability (I/DD) (n = 76). There was also a group of 428 individuals describing themselves in terms of health and functioning similar to a person with I/DD, hereafter described as having similar impairment, but occurring at or after age 22 years.

The two groups were compared to each other and to the larger CHARLS sample (n = 15,635), using t-tests and chi square tests as appropriate. As may be seen in **Table 1**, the group with I/DD tended to be younger than the other two groups and were somewhat more likely to have less education or to report being illiterate. There was also a non-significant trend towards being more likely to be male. They were less likely to be married than those without reported I/DD or similar impairment but those most likely not to be married were those with similar impairments on or after age 22 years. Matched samples for comparison purposes were then established.

Matching Strategy: Propensity score matching is a method of generating a single score based on observed covariates in order to match participants in one group in an observational study with participants in a second or third group. A propensity score matching approach was used to create groups of subjects with otherwise similar characteristics among those with an assigned/described intellectual and developmental disability (I/DD), prior to age 22 years, and at and after age 22 years and those in the population without an assigned/described impairment similar to an I/DD, at any age [27]. Using the variables of age, gender, urban/rural residency and education level, propensity score matching was completed in STATA13 using the “psmatching” command. Nearest neighbor matching without replacement was used based on a greedy matching algorithm with a caliper of 0.15 of the standard deviation of the logit of the propensity score (to reduce potential imbalances among matches). Given that several covariates

Table 1. Sample characteristics by status of intellectual and developmental disabilities (I/DD) status with weight (N = 16,106).

	People had I/DD before 22 yrs	People had Similar Impairment on 22 yrs and above	People had no reported I/DD	Total	p-value
N	76	395	15,635	16,106	
% with weight	0.5%	2.4%	97.1%		
Demographics					
Age (yrs.) (mean ± SD)	55.2 ± 7.5	63.6 ± 12.5	59.5 ± 10.3	59.5 ± 10.4	<0.001
Gender (female)	40.9%	50.8%	51.9%	51.8%	0.249
Marital Status	78.7%	75.6%	85.7%	85.4%	<0.001
Urban	80.4%	87.9%	85.4%	85.4%	0.433
Education Level					
No formal education illiterate	36.3%	32.4%	25.6%	25.8%	0.077
Primary School	39.5%	37.2%	37.9%	37.9%	
Middle School	9.6%	21.6%	21.4%	21.3%	
High School	9.3%	5.3%	8.6%	8.5%	
Vocational School, College and above	5.2%	3.6%	6.5%	6.5%	
Health Conditions					
Self-rated health (mean ± SD)	3.36 ± 0.9	3.62 ± 0.9	2.93 ± 0.9	2.96 ± 0.9	<0.001
Hypertension	13.9%	43.0%	24.8%	25.2%	<0.001
High-cholesterol	9.0%	17.3%	9.8%	9.9%	<0.001
Diabetes	2.3%	10.8%	6.0%	6.1%	<0.01
Cancer	1.8%	2.7%	0.8%	0.9%	<0.001
Lung disease	19.3%	13.6%	9.8%	10.0%	<0.01
Heart disease	12.1%	17.7%	11.6%	11.7%	<0.01
Stroke	3.9%	15.5%	2.3%	2.6%	<0.001
Kidney disease	5.6%	9.0%	6.1%	6.2%	0.072
Digestive disease	28.9%	32.0%	20.6%	20.9%	<0.001
Arthritis	37.8%	37.5%	31.2%	31.3%	<0.05
Dementia	4.1%	20.6%	1.2%	1.7%	<0.001
Emotional problem	27.5%	15.0%	1.1%	1.5%	<0.001
Smoke now	45.5%	34.5%	30.0%	30.1%	<0.05
Smoke ever	51.5%	46.0%	38.9%	39.1%	<0.01
Drink now	25.0%	27.8%	31.2%	31.1%	0.277
Drink ever	35.9%	44.1%	38.7%	38.8%	0.164
ADL limitations	26.2%	49.2%	14.4%	15.3%	<0.001
IADL limitations	57.3%	62.7%	19.1%	20.3%	<0.001

were represented, a single propensity score was generated which can be viewed as the absolute difference between individuals in each group. A dataset of 228 matched participants was then generated. The characteristics on which the three groups were matched were then examined and no significant differences were found. Again, comparisons were conducted using t-tests and chi square tests as appropriate.

3. Findings

Across the three matched groups, ADL and IADL limitations were greatest for the group with impairments on or after age 22 years, but those who reported I/DD also report greater limitations than those without reported I/DD or similar impairment. In terms of chronic conditions: those who reported I/DD also reported.

- the lowest levels of hypertension and high cholesterol, diabetes and kidney disease (a non-significant difference);
- rates of lung disease and emotional problems higher than for any other group;
- rates of cancer, heart disease (non-significant), stroke (non-significant), arthritis, and dementia higher than for those without reported I/DD or similar impairment, but significantly lower than what was reported by the group with impairments on or after age 22 years;
- Digestive disease was significantly higher in the group with I/DD and the group with impairments on or after age 22 years as compared with those without reported I/DD or similar impairment.

Finally, for those without reported I/DD, or similar impairment, self-rated health was poorer than reports from the other two groups. Rates of smoking now and smoking ever were significantly higher for the group with reported I/DD. Rates for drinking alcohol now or ever were similar for the three groups.

When these findings are re-examined across the three matched groups, (see Table 2) the lower reported rates of marriage for the group with reported I/DD and the poorer self-rating of health by those without reported I/DD, or similar impairment were confirmed. This was also true of lower hypertension for those with reported I/DD but not compared to those without reported I/DD, or similar impairment. Higher rates of emotional problems as compared to both groups were also confirmed and rates of dementia were now comparable for the groups with I/DD and the group with impairments on or after age 22 years, with both significantly higher than for those without reported I/DD, or similar impairment. For most chronic conditions where there were significant differences, rates were highest for the group with impairments on or after age 22 years. Rates of smoking now and smoking ever were no longer significantly higher for the group with reported I/DD. Rates for drinking alcohol now or ever remained similar for the three groups.

Table 2. Comparison of people with I/DD before 22 years old, people with similar impairments on or after age 22 and people after 22 years old and population no reported I/DD or similar impairments.

	People had I/DD before 22 yrs. (n = 76)	**People had Similar Impairment on 22 yrs and above (n = 76)**	**People had no reported I/DD (n = 76)**	**p-value***
	% (n)	**% (n)**	**% (n)**	
Demographics				
Age (yrs.) (mean ± SD)	55.7 ± 7.3	56.0 ± 7.3	55.8 ± 7.3	0.962
Gender (female)	47.4 (36)	48.7 (37)	46.1 (35)	0.949
Marital Status	82.9 (63)	92.1 (70)	93.4 (71)	0.070
Urban	88.2 (67)	92.1 (70)	89.5 (68)	0.713
Education Level				0.957
No formal education illiterate	38.2 (29)	36.8 (28)	38.2 (29)	
Primary School	43.4 (33)	46.1 (35)	43.4 (33)	
Middle School	10.5 (8)	13.2 (10)	10.5 (8)	
High School	5.3 (4)	4.0 (3)	5.3 (4)	
Vocational School, College and above	2.6 (2)	0 (0)	2.6 (2)	
Health Conditions				
Self-rated health (mean ± SD)	3.3 ± 0.9	3.6 ± 0.9	3.1 ± 0.7	<0.01
Hypertension	15.8 (12)	44.7 (34)	17.1 (13)	<0.001
High-cholesterol	9.2 (7)	9.2 (7)	6.6 (5)	0.795
Diabetes	2.6 (2)	6.6 (5)	4.0 (3)	0.481
Cancer	2.6 (2)	6.6 (5)	0 (0)	0.061
Lung disease	17.1 (13)	10.5 (8)	9.2 (7)	0.283
Heart disease	11.8 (9)	15.8 (12)	7.9 (6)	0.322
Stroke	5.3 (4)	6.6 (5)	2.63 (2)	0.512
Kidney disease	6.6 (5)	6.6 (5)	13.6 (10)	0.254
Digestive disease	27.6 (21)	35.5 (27)	23.7 (18)	0.261
Arthritis	43.4 (33)	48.7 (37)	42.1 (32)	0.689
Dementia	5.3 (4)	5.3 (4)	0 (0)	0.126
Emotional problem	23.7 (18)	17.1 (13)	0 (0)	<0.001
Smoke now	39.5 (30)	30.3 (23)	39.5 (30)	0.395
Smoke ever	44.7 (34)	43.4 (33)	44.7 (34))	0.982
Drink now	27.6 (21)	30.3 (23)	31.6 (24)	0.864
Drink ever	34.2 (26)	44.7 (34)	38.2 (29)	0.405
ADL	27.6 (21)	42.1 (32)	10.5 (8)	<0.001
IADL	54.0 (41)	57.9 (44)	11.8 (9)	<0.001

4. Discussion

There were both encouraging and concerning findings about the health of those with IDD including that they had the lowest levels of hypertension and high cholesterol, diabetes and kidney disease, although the differences were statistically non-significant. Findings of higher rates of emotional problems, arthritis, digestive issues, and dementia were consistent with reports for other populations of people with I/DD [28]. Yet the lives of these individuals were different from other reports with higher levels of education and marriage. Further work is needed in developing similar and larger samples of persons with I/DD with lower levels of impairment than usually reported in such studies and their lives better explored.

To best realize the potential for understanding and supporting the lives of people with I/DD, it is important that greater standardization occurs in the definition of intellectual and developmental disabilities. The need to further reconcile developmental disabilities and learning disabilities with intellectual disabilities, as well as addressing continuing concerns about standardization of interpretations of levels of disability, means this will be difficult. It would also be helpful if identifiers for a better defined I/DD were added to more national datasets and if the samples selected better included people with I/DD living in out-of-home settings and/or presenting with milder forms of I/DD. Perhaps the move to ICD-11 classifications is advancing standardization [29].

The greatest opportunity for standardization is in administrative datasets and in disability-based population surveys [30] (Friedman *et al.*, 2018). At the very least researchers and administrators of these resources and related studies must take the responsibility of routinely and consistently providing in their studies and report the definition of I/DD utilized, as well as definitions of levels of I/DD if reported. This should extend to also reporting data by sex and age preferably using consistent or easily converted categories of age [28] [30]. As has been previously stated, additional efforts to facilitate making datasets publicly available, in formats that are easily analyzed and with codes to easily identify subpopulations will increase the ability to use such data effectively and for the benefit of people with I/DD [31].

The findings here demonstrate that assumptions that people with I/DD are not present in large household based surveys are not necessarily true. The findings highlight that the lives and health concerns of people with I/DD, particularly those with milder levels of impairment, may not be as dramatically different from others in the population as has been previously reported (see for example, [17] [18]). There are findings elsewhere that people with I/DD have lower levels of smoking [18]. This was not true here and encourages caution in describing protective or risk factors, such as rates of smoking, found in one study as true for all populations of people with I/DD. Identification here that people with later onset impairment had similar health needs to those with I/DD raises that joint advocacy for changes in service provision is also possible. The realization that the need for more tailored services will positively effect a much larger proportion of a population may encourage legislators and policymakers to ensure greater provision of such services.

People with I/DD as they embark upon aging are usually viewed as disadvantaged as compared to other groups, by their needs and their earlier experiences in personal development, accessing quality health care and lifestyles, engagement with social networks and participation in employment/meaningful activities. The group here initially looks less unlike at least some of their peers. This needs further exploration. Further research may also build better understanding of life transitions for the group identified in CHARLS. Economic constraints and the caring cultures of the nation in which people with I/DD live further shape individual life experiences and present challenges for existing and emerging service systems [8]. These all influence quality of life opportunities for people with I/DD as they age and it will be important to understand what is similar and what is different for those aging in China. Continued follow-up through CHARLS may offer new insights both for people with I/DD in China and may suggest new and additional questions for other national longitudinal studies of aging.

There are many limitations in this study, not least the small sample size, need to construct a definition of I/DD, reliance on self-report diagnoses, and a limited understanding of the lives of a group that is largely hidden in most countries, persons with a mild I/DD who otherwise are living somewhat similar lives to others in the community. The methodological limitations are similar to those in most longitudinal studies of aging which also over-rely on self-report. The construction of a definition of I/DD, however, had the benefit of highlighting people with I/DD who are not often considered and of also locating a second group with similar but late onset needs adding to our understanding of aging. Finally, a desire that all persons with I/DD have the opportunity to live community lives will only benefit from greater understanding of the lives of people with I/DD who are and were already present in the community.

The use of propensity score matching in this study permitted comparisons between three groups: people with I/DD before 22 years old, people with similar impairments on or after age 22 and people with no reported I/DD or similar impairments. Some differences between groups in the initial uncontrolled comparison disappeared when matching occurred suggesting that unbalanced designs and inattention to demographic characteristics may have the unintended consequence of exaggerating differences. Future comparative research should consider these concerns.

Preparation for aging is a lifelong task for everyone, but remains often not considered or addressed for people with I/DD. In addition, the absence of people with I/DD from the data policy makers utilizes for decision-making compounds problems. There must be greater efforts to include people with I/DD in those data collections but there must also be greater efforts to discover those who are already there, greater attention to the full range of lives led by people with I/DD and inclusion of data from a broader range of countries.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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