

The Medical, Functional and Social Challenges Faced by Older Adults with Intellectual Disability

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Abstract

Introduction: Little is known about the sociodemographic and clinical profile of older adults with intellectual disabilities (ID) in Singapore. We studied the sociodemographic and clinical profile of older adults with ID and investigated factors associated with caregiver availability and identity in this population. **Materials and Methods:** The study population involved all adults with ID aged ≥ 40 years receiving services from the Movement for the Intellectually Disabled of Singapore (MINDS), the largest such provider in Singapore. Information on sociodemographic and clinical profiles, functional status, and availability of caregivers were collected via interviewer-administered questionnaires from guardians of older adults with ID. Descriptive characteristics were computed and chi-square and logistic regression identified predictors of caregiver availability and identity. **Results:** Participation was 95% (227/239). There were differences in client age, gender, and caregiver availability between recipients of residential and non-residential services (all $P < 0.05$). Common comorbidities included hyperlipidaemia (17.6%), hypertension (15.9%), psychiatric diagnoses (16.3%) and epilepsy (10.6%). The majority were fully independent in basic activities of daily living, but only 21.1% were fully communicative. Only a small minority (9.4%) were exercising regularly. The majority (73.5%) of clients had a primary caregiver; almost equal proportions relied on either parents or siblings. Older client age was associated independently with the lack of a primary caregiver, independent of greater functional dependence and presence of medical comorbidities in the client. **Conclusion:** Older adults with ID have multiple medical, functional, and social issues. More can be done to support the care of this unique group of adults with special needs.

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Introduction

Older adults with intellectual disabilities (ID) and their caregivers are sometimes overlooked in the planning and delivery of health services;¹ and unfortunately, are sometimes exposed to various disparities in healthcare access and delivery.² In terms of their needs, however, older adults with ID face similar challenges and priorities compared to other older adults. Top causes of mortality amongst older adults with ID include cardiovascular disease, respiratory disease, and malignancy,^{3,4} while cardiovascular disease and mental disease account for significant morbidity.^{5,6} In general, older adults with ID have higher mortality compared with the rest of the older adult population.⁷ However, in societies undergoing demographic transitions,

both in Western countries^{8,9} as well as other urbanised Asian societies,^{10,11} better care has generally led to longer lifespans for adult patients with ID. This has created new demands in terms of medical needs. Unfortunately, there is a lack of information on the sociodemographic and clinical profile of older adults with ID in Singapore. Such information is needed to better plan health services to meet the needs of these patients and their caregivers.

In addition, there is a lack of information on the profile of caregivers for older adults with ID in Singapore. Given the unique challenges of providing care for older adults with ID, their caregivers play an often under-appreciated but vital role. In particular, given population ageing, there are valid

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concerns about the ability of older parent-carers to cope with the caregiving burden, given their own ageing and the ageing of their own son or daughter.^{12,13} Knowing whether parent-carers or sibling-carers predominate as caregivers for older adults with ID in Singapore would be useful to predict future challenges faced by caregivers, as the needs of these 2 groups of caregivers would be significantly different.¹⁴ More information on the average age of caregivers can also address concerns on whether caregiving burden is sustainable in the long term,¹⁵ and whether services such as respite care are necessary to relieve caregivers of older adults with ID.¹⁶

While the exact prevalence of ID in Singapore is unknown, estimates from other Asian countries suggest a prevalence of less than 1.3%.¹⁷ These numbers are comparable with Western studies.¹⁸ Services for the intellectually disabled are largely supported by voluntary welfare organisations. One such organisation is the Movement for the Intellectually Disabled of Singapore (MINDS), the largest organisation in Singapore catering to the needs of persons with moderate to severe ID in Singapore. Due to the varying needs of those with ID, services are provided in a wide range of settings, such as sheltered workshops, adult day activity centres, and residential homes.¹⁹ It is likely that clients in these different settings would have significant differences in clinical and sociodemographic profile;²⁰ however, there is currently a lack of such local data in the literature. Apart from a 2009 review that presented limited data suggesting a relatively high prevalence of mental health issues and physical health problems such as obesity (42.1%), high blood pressure (24.2%), and high blood cholesterol (16%), amongst older adults with ID in Asia,¹⁷ there is little information on medical issues amongst older adults with ID in Singapore. Similarly, nothing is known about the profile of caregivers locally. Although studies done in other urbanised Asian societies like Taiwan suggest that sociodemographic factors, such as caregiver employment and caregiver age,^{21,22} are important predictors of caregiver burden, locally a lack of information about such sociodemographic characteristics makes it difficult to estimate the potential caregiver burden for older adults with ID in Singapore. Hence, the objectives of our study were 2-fold: to obtain a picture of the sociodemographic profile of older adult Singaporean patients with ID, as well as their caregivers; and furthermore, to study the factors associated with caregiver availability and caregiver identity for older adults with ID in Singapore. We hope that this will provide greater insights into the challenges faced by this segment of the population, as well as their caregivers, with regard to health needs and health services.

Materials and Methods

The study population involved all adult clients aged 40 years and above who received services in MINDS. At the time of our study, MINDS had 239 adult clients aged ≥ 40 years as of 31 December 2010 who were recipients of various services (out of a total of approximately 1300 adults with ID under its care). The main types of services that MINDS provides include residential services, Employment Development Centres (EDCs) and Training Development Centres (TDCs). The EDCs serve individuals who have some degree of independence in daily living skills and promote the integration of adults with ID into society through programmes focused on empowering the vocational ability of their clients. The TDCs, on the other hand, serve adults with ID who require higher levels of support, and have their focus training in activities of daily living skills, community living skills, and social/recreational skills. MINDS also runs residential services that provide respite, short-term or long-term care for ID adults.¹⁹ Hence, within our study population, we had a mix of both community-dwelling and institutionalised clients. We used age ≥ 40 years as the cut-off in this study. Similar studies on adults with ID have used such a cut-off, largely because of the increased morbidity of chronic disease beyond this age.²⁰ From July to November 2011, the guardians of all MINDS clients aged ≥ 40 years were approached to seek consent for participation in the study. We collected baseline information about the client and primary caregiver (if present), such as sociodemographic data, medical history and functional history, via interviewer-administered standardised questionnaires that were administered to the guardian. As caregiver availability was a key outcome variable, having a primary caregiver was defined as having available a main person, aged 21 years and above, living with the client and actually providing care for the client. Information on other health behaviours, such as tobacco/alcohol consumption and physical activity was also collected. Ethics approval was obtained from the National University of Singapore (NUS) Institutional Review Board, informed consent was sought from the guardians of participants, and participation was voluntary. Assent from participants themselves was attempted but most of participants were unable to provide it.

Statistical Analysis

Descriptive statistics were computed for the study population. In the first part of the analysis, focused on the profile of older adult clients with ID and their caregivers, we compared sociodemographic characteristics of the older adult clients with ID (age ≥ 40 years) and their caregivers (if they had caregivers), stratifying the analysis by the type of service they were utilising (EDCs, TDCs or residential services) and using chi-square test to compare the

proportions. In this analysis, a small number of older adult clients ($n=2$) were using ≥ 1 type of service from MINDS; as the number was small and it was not possible to distinguish the principal type of service utilised, we excluded them from this particular analysis. We then compared the clinical profile and functional status of older adult clients with ID, again stratified by type of service being received and using chi-square test, and again excluding those using ≥ 1 type of service ($n=2$). In the next part of our analysis, focused on caregivers for older adults with ID in Singapore, we first determined factors associated with caregiver availability amongst Singaporean adult clients with ID, aged ≥ 40 years, using chi-square and logistic regression. We then identified sociodemographic and clinical predictors of caregiver identity (i.e. having a parent vs having a sibling as caregiver) amongst carers for older adults with ID, again using chi-square and logistic regression. In this particular analysis, in addition to excluding those without caregivers, we also excluded clients who identified a person other than their parents or siblings ('Others') as their primary caregiver. The rationale was that the numbers of those who had 'Others' as their primary caregiver were small ($n=19$) and the composition of this group was extremely heterogenous, with caregivers linked to the client by a variety of factors (e.g. blood relations, by marriage e.g. sisters-in-law, or by friendship with clients' parents/relatives). Thus, including them in the analysis as a separate category would not be meaningful. The criterion for initial entry of variables into all multivariate models was $P < 0.2$ on univariate analysis and we presented the most parsimonious model. All statistical analysis was performed using SPSS (Version 18.0, USA) and statistical significance was set at $P < 0.05$.

Results

Overall participation was 95% (227/239); participation rate amongst those receiving EDC services was 97.2% (142/146); 83.3% (15/18) amongst those receiving TDC services and 90.7% (68/75) amongst those receiving residential services.

Sociodemographic Profile of Older Adults with ID in Singapore and Their Caregivers

The sociodemographic profile of older adults with ID in our study population is detailed in Table 1, stratified by the type of service being received. The median age of this population was 46 years (interquartile range (IQR), 42 to 52). As expected, participants receiving residential services tended to be older, female, and lack a primary caregiver, compared to those receiving non-residential services (EDCs and TDCs). The median age of caregivers was 66 years (IQR, 55 to 72). Roughly equal numbers of clients

depended on their parents (46.1%, 77/167) or siblings (42.5%, 71/167) as their primary caregiver, and a smaller number ($n=19$) identified other individuals/relations as their primary caregiver. A much higher proportion of clients receiving residential services had siblings, as opposed to parents, as their primary caregiver. Correspondingly, their caregivers were also of younger ages (median age of caregiver = 58 years, IQR = 51 to 67) compared with those receiving non-residential services; caregivers for older adult clients with ID staying in residential services also tended to be currently working, compared to those receiving non-residential services in which the majority of carers were either retired, or unemployed. Of note, higher proportions of those receiving residential services had caregivers staying in smaller (1- to 3-room) public housing flats, a significant marker of socioeconomic status in Singapore.

The medical history and functional status of older adult clients with ID are detailed in Table 2, again stratified by the type of service received. Some of the common diseases in the study population were: hyperlipidaemia (17.6%, 40/227); mental disease (16.3%, 37/227); hypertension (15.9%, 36/227) and epilepsy (10.6%, 24/227). There were some differences in clinical profiles of clients receiving various services, likely because particular medical conditions made clients less suited for certain services. For example, the proportions of clients with epilepsy were roughly similar amongst those in TDCs and residential services (about 20%) but much less in EDCs (5.6%); whereas the proportions of clients with mental disease were the highest amongst those receiving residential services (38.2%). In this population, in terms of health behaviour, rates of smoking and alcohol consumption were generally low (only 4.4% (10/227) had smoked before, with 2.2% (5/227) currently smoking; none had a history of alcohol consumption). However, notably, in terms of exercise, excluding residents utilising residential services (whose exercise schedule was actively managed by the residential homes and involved regular opportunities for exercise), only 9.4% (15/159) of older adults with ID staying at home were exercising regularly, even though the majority of study participants were able to walk independently. In terms of communication, only 21.1% (48/227) were fully communicative. Unsurprisingly, those receiving residential services tended to be more dependent in terms of their functional status and in carrying out activities of daily living.

Caregiver Availability and Identity Amongst Older Adults with ID in Singapore

In this population of older adult clients with ID, the majority had a primary caregiver (73.5%, 167/227). Factors associated with having a primary caregiver are listed in Table 3 (univariate analysis) and Table 5 (multivariate analysis).

Table 1. Sociodemographic Characteristics of Adult clients (Age ≥ 40 Years) at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 227), and Their Caregivers (n = 167); Stratified by Type of Service Received

Characteristics	n (%)				P Value†
	Total*	Employment Development Centres (n = 142)	Training Development Centres (n = 15)	Residential Services (n = 68)	
Clients (n = 227)*					
Age					
40 to 49 years	146 (64.3)	104 (73.2)	8 (53.3)	32 (47.1)	
50 to 59 years	71 (31.3)	35 (24.6)	7 (46.7)	29 (42.6)	0.001
≥ 60 years	10 (4.4)	3 (2.1)	(0.0)	7 (10.3)	
Gender					
Male	110 (48.5)	79 (55.6)	8 (53.3)	23 (33.8)	0.012
Female	117 (51.5)	63 (44.4)	7 (46.7)	45 (66.2)	
Ethnicity					
Non-Chinese	37 (16.3)	24 (16.9)	1 (6.7)	11 (16.2)	0.589
Chinese	190 (83.7)	118 (83.1)	14 (93.3)	57 (83.8)	
Has caregiver					
No	60 (26.4)	29 (20.4)	3 (20.0)	28 (41.2)	0.005
Yes	167 (73.5)	113 (79.6)	12 (80.0)	40 (58.8)	
Main Caregiver (n = 167)*					
Identity of Main Caregiver					
Parent	77 (46.1)	62 (54.9)	6 (50.0)	9 (22.5)	
Sibling	71 (42.5)	35 (31.0)	6 (50.0)	28 (70.0)	<0.001
Others	19 (11.4)	16 (14.2)	0 (0.0)	3 (7.5)	
Age of Caregiver					
40 to 59 years	61 (36.5)	34 (30.1)	5 (41.7)	21 (52.5)	0.037
≥ 60 years	106 (63.5)	79 (69.9)	7 (58.3)	19 (47.5)	
Current Marital Status of Caregiver					
Not married	80 (47.9)	49 (43.4)	6 (50.0)	24 (60.0)	0.192
Married	87 (52.1)	64 (56.6)	6 (50.0)	16 (40.0)	
Housing Type					
HDB 1 to 3 room	55 (32.9)	31 (27.4)	2 (16.7)	22 (55.0)	
HDB 4 to 5 room	87 (52.1)	59 (52.2)	9 (75.0)	17 (42.5)	0.003
Private property	25 (15.0)	23 (20.4)	1 (8.3)	1 (2.5)	
Current Employment Status of Caregiver					
Not employed	98 (58.7)	75 (66.4)	8 (66.7)	13 (32.5)	
Employed	69 (41.3)	38 (33.6)	4 (33.3)	27 (67.5)	0.001
Monthly Household Income					
<\$899	52 (31.1)	37 (32.7)	2 (16.7)	12 (30.0)	
between \$900 and \$2499	54 (32.3)	32 (28.3)	2 (16.7)	19 (47.5)	0.033
>\$2500	61 (36.5)	44 (38.9)	8 (66.7)	9 (22.5)	

*As 2 adults MINDS clients (aged ≥ 40 years) were receiving more than one type of service from MINDS, they were excluded from the chi-square analysis in this table.

†P value calculated using chi-square test.

Table 2. Medical History and Functional Status of Adult Clients (Age ≥40 Years) at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 227); Stratified by Type of Service Received

Characteristics of Clients (n = 227)*	n (%)				P Value†
	Total*	Employment Development Centres	Training Development Centres	Residential Services	
Principal Diagnosis for Intellectual Disability					
Down's syndrome	63 (27.8)	41 (28.9)	3 (20.0)	17 (25.0)	
Cerebral palsy	22 (9.7)	6 (4.2)	0 (0.0)	16 (23.5)	
High fever	16 (7.0)	11 (7.7)	3 (20.0)	2 (2.9)	
Epilepsy	11 (4.8)	7 (4.9)	3 (20.0)	2 (2.9)	<0.001
Global developmental delay	15 (6.6)	15 (10.6)	0 (0.0)	0 (0.0)	
Others‡	19 (8.4)	6 (4.2)	0 (0.0)	7 (10.3)	
Unknown cause	81 (35.7)	52 (36.6)	5 (33.3)	24 (35.3)	
Known Medical History§					
Hypertension	36 (15.9)	27 (19.0)	4 (26.7)	4 (5.9)	0.023
Diabetes mellitus	17 (7.5)	11 (7.7)	1 (6.7)	4 (5.9)	0.884
Hyperlipidaemia	40 (17.6)	30 (21.1)	0 (0.0)	9 (13.2)	0.068
Congenital heart disease	11 (4.8)	5 (3.5)	1 (6.7)	5 (7.4)	0.458
Thyroid disease	10 (4.4)	2 (1.4)	2 (13.3)	6 (8.8)	0.011
Epilepsy	24 (10.6)	8 (5.6)	3 (20.0)	13 (19.1)	0.006
Asthma	5 (2.2)	3 (2.1)	0 (0.0)	2 (2.9)	0.775
Dermatological condition	17 (7.5)	9 (6.3)	1 (6.7)	7 (10.3)	0.592
Psychiatric diagnosis (excluding mental retardation)	37 (16.3)	8 (5.6)	3 (20.0)	26 (38.2)	<0.001
Ear, nose and throat problems	8 (3.5)	0 (0.0)	2 (13.3)	6 (8.8)	0.001
Eye problems	9 (4.0)	4 (2.8)	0 (0.0)	5 (7.4)	0.209
Gout	4 (1.8)	2 (1.4)	0 (0.0)	2 (2.9)	0.635
Gastrointestinal diseases	14 (6.2)	6 (4.2)	1 (6.7)	7 (10.3)	0.234
Lifestyle History					
Smoked before					
No	217 (95.6)	133 (93.7)	14 (93.3)	68 (100.0)	0.104
Yes	10 (4.4)	9 (6.3)	1 (6.7)	0 (0.0)	
Regular exercise (>30 min/day, >5 days a week) 					
No	144 (90.6)	130 (91.5)	12 (80.0)	NA	0.007
Yes	15 (9.4)	12 (8.5)	3 (20.0)	NA	
Mobility Status					
Walks independently	196 (86.3)	137 (96.5)	15 (100.0)	42 (61.8)	
Limited mobility (e.g. uses assistive devices)	27 (11.9)	2 (1.4)	0 (0.0)	25 (36.8)	<0.001
Wheelchair bound or immobile	4 (1.8)	3 (2.1)	0 (0.0)	1 (1.5)	
Communication Abilities					
Fully communicative (verbally)	48 (21.1)	43 (30.3)	1 (6.7)	4 (5.9)	
Limited verbal communication	148 (65.2)	87 (61.3)	14 (93.3)	45 (66.2)	<0.001
Non-verbal communication/non-communicative	31 (13.7)	12 (8.5)	0 (0.0)	19 (27.9)	
Activities of Daily Living					
Feeding					
Feeding independently	194 (85.5)	134 (94.4)	14 (93.3)	44 (64.7)	
Requiring some or total assistance	33 (14.5)	8 (5.6)	1 (6.7)	24 (35.3)	<0.001

Table 2. Medical History and Functional Status of Adult Clients (Age ≥ 40 Years) at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 227); Stratified by Type of Service Received (Con't)

Characteristics of Clients (n = 227)*	n (%)				P Value†
	Total*	Employment Development Centres	Training Development Centres	Residential Services	
Bathing					
Bathing independently	146 (64.3)	129 (90.8)	7 (46.7)	8 (11.8)	
Requiring some or total assistance	81 (35.7)	13 (9.1)	8 (53.3)	60 (88.2)	<0.001
Dressing					
Dressing independently	161 (70.9)	132 (93.0)	12 (80.0)	15 (22.1)	
Requiring some or total assistance	66 (29.1)	10 (7.0)	3 (20.0)	53 (77.9)	<0.001
Bladder					
Continent	172 (75.8)	125 (88.0)	14 (93.3)	31 (45.6)	
Requiring some or total assistance	55 (24.3)	17 (12.0)	1 (6.7)	37 (54.4)	<0.001
Bowel					
Continent	176 (77.5)	130 (91.5)	14 (93.3)	30 (44.1)	
Requiring some or total assistance	51 (22.5)	12 (8.5)	1 (6.7)	38 (55.9)	<0.001

As 2 adults MINDS clients (aged ≥ 40 years) were receiving more than one type of service from MINDS, they were excluded from the chi-square analysis in this table.

†P value calculated using chi-square test.

‡ 'Others' category includes other syndromes (e.g. Apert syndrome) as well as structural causes (e.g. hydrocephaly) and head trauma.

§Numbers add up to more than 227 because some clients had more than one medical comorbidity.

|| For exercise, those receiving residential services were excluded from this analysis as they already had fixed exercise periods during their stay in the residential home.

Table 3. Univariate Factors Associated with Caregiver Availability Amongst Adult Clients (Age ≥40 Years) at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 227)

Factors	Has Caregiver (n = 227)			
	No (n (%))	Yes (n (%))	Crude OR (95% CI)	P Value
Sociodemographic Characteristics				
Age (years)				
40 to 49	30 (20.5)	116 (79.5)	1.00	-
50 to 59	25 (35.2)	46 (64.8)	0.48 (0.25 – 0.89)	0.042
≥60	5 (50.0)	5 (50.0)	0.26 (0.07 – 0.95)	0.021
Gender				
Female	26 (23.6)	84 (76.4)	1.00	0.370
Male	34 (29.1)	83 (70.9)	0.76 (0.42 – 1.37)	
Ethnicity				
Non-Chinese	9 (24.3)	28 (75.7)	1.00	0.841
Chinese	51 (26.8)	139 (73.2)	0.88 (0.39 – 1.98)	
Services received				
Non-residential	32 (20.4)	125 (79.6)	1.00	0.002
Residential	28 (41.2)	40 (58.8)	0.37 (0.20 – 0.68)	
Medical History				
Principal diagnosis for intellectual disability				
Cause other than Down's syndrome (excluding unknown causes)	20 (24.1)	63 (75.9)	1.00	0.692
Down's syndrome	13 (20.6)	50 (79.4)	1.22 (0.55 – 2.69)	
Has a medical condition				
No	16 (18.8)	69 (81.2)	1.00	0.061
Yes	44 (31.0)	98 (69.0)	0.52 (0.27 – 0.99)	
Functional Status				
Mobility				
Dependent	18 (58.1)	13 (41.9)	1.00	<0.001
Independent	42 (21.4)	154 (78.6)	5.08 (2.30 – 11.20)	
Communication				
Partially/non-communicative	51 (28.5)	128 (71.5)	1.00	0.200
Fully communicative	9 (18.8)	39 (81.3)	1.73 (0.78 – 3.82)	
Feeding				
Requiring some or total assistance	17 (51.5)	16 (48.5)	1.00	0.001
Independent	43 (22.2)	151 (77.8)	3.73 (1.74 – 8.00)	
Bathing				
Requiring some or total assistance	32 (39.5)	49 (60.5)	1.00	0.002
Independent	28 (19.2)	118 (80.8)	2.75 (1.50 – 5.04)	
Dressing				
Requiring some or total assistance	27 (40.9)	39 (59.1)	1.00	0.003
Independent	33 (20.5)	128 (79.5)	2.69 (1.44 – 5.00)	
Bladder				
Requiring some or total assistance	21 (38.2)	34 (61.8)	1.00	0.034
Independent (continent)	39 (22.7)	133 (77.3)	2.11 (1.10 – 4.04)	
Bowel				
Requiring some or total assistance	20 (39.2)	31 (60.8)	1.00	0.029
Independent (continent)	40 (22.7)	136 (77.3)	2.19 (1.13 – 4.26)	

Table 4. Univariate Factors Associated with Caregiver Identity (Parent vs Sibling) Amongst Adult Clients (Age ≥40 Years) Who Had Either Parents or Siblings as Their Caregivers at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 148)

Factors	Caregiver Identity (Parent vs Sibling), Excluding 'Others' (n = 148, Excluding 19 Who Indicated 'Others' as their Caregivers)			
	Siblings n (%)	Parents n (%)	Crude OR (95% CI)	P Value
Caregiver Characteristics				
Age of caregiver				
40 to 59 years	50 (92.6)	4 (7.4)	1.00	<0.001
≥60 years	21 (22.3)	73 (77.7)	43.45 (14.06 – 134.27)	
Current marital status of caregiver				
Not married	30 (40.5)	44 (59.5)	1.00	0.100
Married	41 (55.4)	33 (44.6)	0.55 (0.29 – 1.05)	
Housing type				
HDB 1 to 3 room	24 (49.0)	25 (51.0)	1.00	1.00
HDB 4 to 5 room or private property	47 (47.5)	52 (52.5)	1.06 (0.54 – 2.11)	
Current employment status of caregiver				
Not employed	27 (31.4)	59 (68.6)	1.00	<0.001
Employed	44 (71.0)	18 (29.0)	0.19 (0.09 – 0.38)	
Monthly household income				
<\$899	19 (43.2)	25 (56.8)	1.00	0.476
>\$900	52 (50.0)	52 (50.0)	0.76 (0.37 – 1.55)	
Characteristics of Client				
Sociodemographic Characteristics				
Age (years)				
40 to 49	39 (38.2)	63 (61.8)	1.00	-
50 to 59	28 (68.3)	13 (31.7)	0.29 (0.13 – 0.62)	0.001
≥60	4 (80.0)	1 (20.0)	0.16 (0.02 – 1.44)	0.101
Gender				
Female	33 (44.6)	41 (55.4)	1.00	0.511
Male	38 (51.4)	36 (48.6)	0.76 (0.40 – 1.46)	
Ethnicity				
Non-Chinese	12 (50.0)	12 (50.0)	1.00	1.00
Chinese	59 (47.6)	65 (52.4)	1.10 (0.46 – 2.64)	
Services received				
Non-residential	41 (37.6)	68 (62.4)	1.00	<0.001
Residential	28 (75.7)	9 (24.3)	0.19 (0.08 – 0.45)	
Medical History				
Principal diagnosis for intellectual disability				
Cause other than Down's syndrome (excluding unknown causes)	21 (37.5)	35 (62.5)	1.00	0.118
Down's syndrome	25 (53.2)	22 (56.8)	0.53 (0.24 – 1.16)	
Has a medical condition				
No	26 (44.1)	33 (55.9)	1.00	0.503
Yes	45 (50.6)	44 (49.4)	0.77 (0.40 – 1.50)	
Functional Status				
Mobility				
Dependent	10 (83.3)	2 (16.7)	1.00	0.014
Independent	61 (44.9)	75 (55.1)	6.15 (1.30 – 29.20)	

Table 4. Univariate Factors Associated with Caregiver Identity (Parent vs Sibling) Amongst Adult Clients (Age ≥40 Years) Who Had Either Parents or Siblings as their Caregivers at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 148) (Con't)

Factors	Caregiver Identity (Parent vs Sibling), Excluding 'Others' (n = 148, Excluding 19 Who Indicated 'Others' as their Caregivers)			
	Siblings n (%)	Parents n (%)	Crude OR (95% CI)	P Value
Communication				
Partially/non-communicative	61 (54.0)	52 (46.0)	1.00	0.011
Fully communicative	10 (28.6)	25 (71.4)	2.93 (1.29 – 6.67)	
Feeding				
Requiring some or total assistance	11 (73.3)	4 (26.7)	1.00	0.055
Independent	60 (45.1)	73 (54.9)	3.35 (1.01 – 11.05)	
Bathing				
Requiring some or total assistance	31 (66.0)	16 (34.0)	1.00	0.004
Independent	40 (39.6)	61 (60.4)	2.96 (1.43 – 6.09)	
Dressing				
Requiring some or total assistance	26 (70.3)	11 (29.7)	1.00	0.002
Independent	45 (40.5)	66 (59.5)	3.47 (1.56 – 7.72)	
Bladder				
Requiring some or total assistance	21 (70.0)	9 (30.0)	1.00	0.008
Independent (continent)	50 (42.4)	68 (57.6)	3.17 (1.34 – 7.51)	
Bowel				
Requiring some or total assistance	20 (71.4)	8 (28.6)	1.00	0.007
Independent (continent)	51 (42.5)	69 (57.5)	3.38 (1.38 – 8.29)	

Table 5. Independent Factors Associated with Having a Caregiver and Caregiver Identity (Parent vs Sibling) Amongst Adult Clients (Age ≥40 Years) at the Movement for the Intellectually Disabled of Singapore (MINDS) (n = 227)

Factors	Adjusted OR (95% CI)*	P Value
Having a Caregiver		
Mobility (independent) vs mobility, dependent	4.23 (1.86 – 9.62)	0.001
Has medical history vs no medical history	0.55 (0.25 – 0.95)	0.048
Age of client 50 to 59 years vs those aged 40 to 49 years	0.33 (0.21 – 0.95)	0.045
Age of client ≥60 years vs those aged 40 to 49	0.22 (0.10 – 0.60)	0.030
Having Parent as Caregiver vs Having Sibling as Caregiver		
Age of caregiver >60 years vs age of caregiver <60 years	45.81 (13.87 – 151.35)	<0.001
Caregiver married vs not currently married	0.39 (0.14 – 0.98)	0.048
Recipient of residential services vs recipient of non-residential services	0.15 (0.05 – 0.46)	0.001

*Most parsimonious model presented. Odds ratio (ORs) reported are adjusted for all variables presented in model.

As expected, having a primary caregiver was associated independently with greater functional independence (mobility) of the client (adjusted odds ratio, aOR, = 4.23, 95%CI, 1.86 to 9.62, $P = 0.001$); whereas having a history of doctor-diagnosed medical problems (aOR = 0.55, 95% CI, 0.25 to 0.95, $P = 0.048$); and older client age (client aged ≥ 60 years vs client aged 40 to 49 years, aOR = 0.22, 95% CI, 0.10 to 0.60, $P = 0.030$) were associated independently with not having a primary caregiver. In terms of caregiver identity, amongst clients who had primary caregivers ($n = 167$), the majority either relied on parents or siblings as their caregivers (88.6%, 148/167, combined). The factors associated with having a parent as caregiver (as opposed to having a sibling as caregiver) in this population of older adults with ID are listed in Table 4 (univariate analysis) and Table 5 (multivariate analysis). Parent-caregivers were less likely to be currently married (aOR = 0.39, 95%CI, 0.14 to 0.98, $P = 0.048$) compared to sibling-caregivers, independent of greater age. Interestingly, being a recipient of residential services was associated with a lower likelihood of having a parent as the primary caregiver (aOR = 0.15, 95%CI, 0.05 to 0.46, $P = 0.001$).

Discussion

Profile of Older Adults with ID in a Singaporean Population: Residential Versus Non-Residential Clients

In this population of clients ≥ 40 years old cared for by MINDS, the median age was a relatively young 46 years, and the prevalence of various chronic diseases (e.g. hypertension, diabetes and dyslipidaemia) was roughly comparable with the general Singaporean population. For instance, in this population, the self-reported prevalence of hypertension, diabetes and dyslipidaemia was 15.9%, 7.5% and 17.6%, respectively; compared against national figures for the 40 to 49 age bracket (16.7% had hypertension; 12.1% had diabetes, and 18.0% had dyslipidaemia).²³ While somewhat reassuring, however, this is unlikely to be so in the future. On the other hand, the overall prevalence of psychiatric illness (excluding mental retardation) was 16.3% which is higher than the local national average lifetime prevalence of affective, anxiety, or alcohol use disorders among adults aged >21 years which is 12%.²⁴ Our data show that there were 2 types of clients: the clients receiving non-residential services at the EDCs and TDCs, and then the clients in residential care, which generally tended to be older, female, and lack a primary caregiver, and have greater functional impairment. Currently, those receiving non-residential services formed the bulk of clients under MINDS' care. However, in the future, it is likely that this trend will reverse. Given the increased availability of prenatal screening that enables early detection of conditions like Down's syndrome (amounting for almost one third

of clients), and the gradual ageing of the pre-existing population of older adults with ID in Singapore, it is likely that the older, more functionally-dependent clients will form a larger proportion of the older adults with ID in Singapore. Accumulated disabilities and comorbidities resulting in increased caregiver burden would necessitate institutionalisation, or admission for respite care, and hence increase future demand for residential services. One way of reducing this burden could be to better manage the clients' medical conditions. For example, a much lower percentage (5.6%) of clients at the EDCs had epilepsy, compared to those in TDCs and residential services (about 20%); this is likely due to occupational hazards precluding those with poorly controlled epilepsy from vocational training. Similarly, those clients receiving residential services had a strikingly higher percentage (38.2%) of additional psychiatric diagnoses; quite likely due to the additional behavioural challenges in these clients that cause higher caregiver burden and greater stress.²⁵⁻²⁷ Perhaps better management of these comorbidities could reduce or delay the institutionalisation of older adults with ID, placing less strain on services.

Profile of Caregivers for Older Adults with ID in Singapore: Parent-Carers Versus Sibling-Carers

The majority of caregivers were either parents or siblings of the older adult client with ID; the percentages are roughly similar. Again, with ageing of the pre-existing population with ID, caregiver issues are likely to be more acute in the future. Increased age of client was in itself associated with decreased carer availability, independent of both medical comorbidities (having doctor-diagnosed chronic disease) as well as functional status (mobility). A possible explanation is that caregivers themselves have caregiving issues that become more acute with the progression of time, independent of the handicap-specific characteristics of clients with ID.²⁸ For example, parent-carers, with increased age, have poorer health precluding them from providing care for the older adult clients with ID.^{12,13} Sibling-carers, on the other hand, with increased age, need to care for either their own families or ageing parents,²⁹ making care for the older adult client more challenging. This underlines the need for greater caregiver support (e.g. increased availability of respite care, caregiver training), in order to delay relinquishing of the care of family members with ID into the care of out-of-home facilities.³⁰ The majority either relied on parents (46.1%) or siblings (42.5%) as their caregivers. Of note, parent-caregivers were less likely to be currently married (i.e. divorced, or widowed) compared with sibling-caregivers, and this result was independent of the caregiver's age. This suggests that in our local context, parent-caregivers may have less sources of psychological support (e.g. lack of spousal support) when caring for their

older adult child with ID, and this should be taken into account when providing support for caregivers.

Enhancing Assistance for Older Adults with ID in Singapore

There were 2 areas in which services for older adults with ID could be enhanced in our local population: increasing access to opportunities for regular exercise and speech therapy to enhance communication. The prevalence of regular exercise among MINDS clients staying at home was low (9.4%), comparing against the prevalence of regular exercise (16.7%) in the general population in the 40 to 49 age bracket.²³ Promoting physical activity amongst older adults with ID can increase cardiorespiratory fitness,³¹ and is beneficial when started from adolescence.³² However, opportunities for exercise at home might not always be available as supervision is needed for safe exercise in this group of clients with special needs. An alternative is to provide designated periods of exercise in the EDCs/TDCs, where supervision can be carried out more easily by trained therapists/aides. However, more therapists/aides need to be engaged to meet these needs. At MINDS, for instance, at the EDCs currently 4 full time occupational therapists (OTs) serve a client population of 990; on the other hand, for the TDCs and residential services, there are 2 full time OTs, 2 physiotherapists (PTs) and 2 therapy aides serving 180 clients in the TDCs and another 150 in the residential sector. Higher staff-to-client ratios could potentially provide more opportunities for regular exercise for these patients. Additionally, a majority of the population was fully independent in all activities of daily living, except for communication (in which only 21.1% were fully communicative). Speech therapy would thus be an important service in this regard. However, currently, in terms of service provision, at MINDS there is only 1 speech therapist working part-time to cover the whole adult sector (EDCs, TDCs and residential services). Currently, MINDS provides psychologist support for all its adult centres. However, the cost of employing psychologists is borne by MINDS and there is little government support to employ psychologists to meet the needs of older adults with ID. Considering that the prevalence of psychiatric conditions is already higher than the national prevalence after excluding pre-existing mental retardation, more resources are needed to ensure that there is adequate psychologist support for this vulnerable population. More support can be provided to improve the availability of health services for older adult clients with ID.

Limitations

Our study has its limitations. This was a cross-sectional observational study and hence causality between associated

factors cannot be established. Furthermore, although the population in our study was drawn from a mix of both residential and non-residential older adults with ID and study participants came from multiple sites, they were all receiving community support (in the form of services from the voluntary welfare organisation, MINDS) at the time of the study. Even though MINDS is by far the largest provider of such services in Singapore which provides services to a nationwide catchment at multiple sites, the results of this study may not be fully generalisable to the entire population of Singaporean adults aged ≥ 40 years with ID. In terms of medical profile, only history of doctor-diagnosed disease was used; hence estimates may not be an accurate reflection of the true burden of disease in this population but may also be influenced by the degree of access to screening and medical care (for early detection of disease).

Conclusion

In conclusion, in our study population of Singaporean adults aged ≥ 40 years with ID, there were significant differences in sociodemographic characteristics, such as client age, client gender, availability of caregivers, and associated comorbidities between recipients of the 3 types of services available (EDCs, TDCs, and residential services). Clients in residential care tended to be older, female, and lack a primary caregiver, and have greater functional impairment compared to clients receiving non-residential services. Although the majority of clients were currently receiving non-residential services, this trend is likely to reverse in the future with the ageing of the pre-existing older adult ID population. Similarly, the majority of clients had a primary caregiver; almost equal numbers relied on either their parents or siblings as caregivers, but sibling-carers are likely to become more predominant in the future. Increased age of client was in itself associated with decreased carer availability, independent of both medical comorbidities and functional status. This suggests that caregivers themselves have caregiving issues that become more acute with the progression of time, and need additional support to fulfil their caregiving role. In our local context, we feel that further resources such as better facilities and greater staffing should be made available to provide regular exercise and speech therapy for older adults with ID, and greater financial and social support should be provided to their caregivers to empower them to continue fulfilling their noble and selfless caregiving role.

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REFERENCES

1. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev* 2006;12:70-82.
2. Ward RL, Nichols AD, Freedman RI. Uncovering health care inequalities among adults with intellectual and developmental disabilities. *Health Soc Work* 2010;35:280-90.
3. Patja K, Mölsä P, Iivanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *J Intellect Disabil Res* 2001;45:30-40.
4. Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *J Intellect Disabil Res* 2009;53:898-904.
5. Hand JE, Reid PM. Older adults with lifelong intellectual handicap in New Zealand: prevalence, disabilities and implications for regional health authorities. *N Z Med J* 1996;109:118-21.
6. Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: a population study. *Am J Ment Retard* 1995;99:595-604.
7. McCarthy J, O'Hara J. Ill-health and intellectual disabilities. *Curr Opin Psychiatry* 2011;24:382-6.
8. Hand JE, Reid PM. Older adults with lifelong intellectual handicap in New Zealand: prevalence, disabilities and implications for regional health authorities. *N Z Med J* 1996;109:118-21.
9. Kim NH, Hoyek GE, Chau D. Long-term care of the aging population with intellectual and developmental disabilities. *Clin Geriatr Med* 2011;27:291-300.
10. Lin LP, Lin JD. Perspectives on intellectual disability in Taiwan: epidemiology, policy and services for children and adults. *Curr Opin Psychiatry* 2011;24:413-8.
11. Lin JD, Wu CL, Lin PY, Lin LP, Chu CM. Early onset ageing and service preparation in people with intellectual disabilities: institutional managers' perspective. *Res Dev Disabil* 2011;32:188-93.
12. Llewellyn G, McConnell D, Gething L, Cant R, Kendig H. Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. *Res Dev Disabil* 2010;31:1176-86.
13. Yamaki K, Hsieh K, Heller T. Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. *Intellect Dev Disabil* 2009;47:425-35.
14. Chou YC, Lee YC, Lin LC, Kröger T, Chang AN. Older and younger family caregivers of adults with intellectual disability: factors associated with future plans. *Intellect Dev Disabil* 2009;47:282-94.
15. Rowbotham M, Cuskelly M, Carroll A. Sustainable caregiving? Demands upon and resources of female carers of adults with intellectual disability. *J Women Aging* 2011;23:129-48.
16. Chou YC, Tzou PY, Pu CY, Kröger T, Lee WP. Respite care as a community care service: factors associated with the effects on family carers of adults with intellectual disability in Taiwan. *J Intellect Dev Disabil* 2008;33:12-21.
17. Jeevanandam L. Perspectives of intellectual disability in Asia: epidemiology, policy, and services for children and adults. *Curr Opin Psychiatry* 2009;22:462-8.
18. Westerinen H, Kaski M, Virta L, Almqvist F, Iivanainen M. Prevalence of intellectual disability: a comprehensive study based on national registers. *J Intellect Disabil Res* 2007;51:715-25.
19. Movement for the Intellectually Disabled of Singapore, 2011. Movement for the Intellectually Disabled of Singapore. Available at: <http://www.minds.org.sg/AdultSvcs.html>. Accessed 29 May 2013.
20. Janicki MP, Davidson PW, Henderson CM, McCallion P, Taets JD, Force LT, et al. Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *J Intellect Disabil Res* 2002;46:287-98.
21. Chou YC, Fu LY, Lin LC, Lee YC. Predictors of subjective and objective caregiving burden in older female caregivers of adults with intellectual disabilities. *Int Psychogeriatr* 2011;23:562-72.
22. Chou YC, Pu CY, Kröger T, Fu LY. Caring, employment, and quality of life: comparison of employed and nonemployed mothers of adults with intellectual disability. *Am J Intellect Dev Disabil* 2010;115:406-20.
23. Ministry of Health, Singapore. National Health Survey 2010. Singapore: Ministry of Health; 2011. Available at: http://www.moh.gov.sg/content/dam/moh_web/Publications/Reports/2011/NHS2010%20-%20low%20res.pdf. Accessed 29 May 2013.
24. Chong SA, Abdin E, Vaingankar JA, Heng D, Sherbourne C, Yap M, et al. A population-based survey of mental disorders in Singapore. *Ann Acad Med Singapore*. 2012;41:49-66.
25. Irazábal M, Marsà F, García M, Gutiérrez-Recacha P, Martorell A, Salvador-Carulla L, et al. Family burden related to clinical and functional variables of people with intellectual disability with and without a mental disorder. *Res Dev Disabil* 2012;33:796-803.
26. Martorell A, Gutiérrez-Recacha P, Irazábal M, Marsà F, García M. Family impact in intellectual disability, severe mental health disorders and mental health disorders in ID. A comparison. *Res Dev Disabil* 2011;32:2847-52.
27. Wei KC, Lee C, Mahendran R, Lim CG. Improving mental health care for people with an intellectual disability in Singapore: bridging the health-social care divide. *Singapore Med J* 2012;53:428-32.
28. Marcus YL, Rommel CH. Decision-making of Chinese caregivers for adult out-of-home placement. *J Intellect Disabil Res* 2006;50:678-89.
29. Perkins EA, Haley WE. Compound caregiving: when lifelong caregivers undertake additional caregiving roles. *Rehabil Psychol* 2010;55:409-17.
30. Nankervis K, Rosewarne A, Vassos M. Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *J Intellect Disabil Res* 2011;55:422-33.
31. Moss SJ. Changes in coronary heart disease risk profile of adults with intellectual disabilities following a physical activity intervention. *J Intellect Disabil Res* 2009;53:735-44.
32. Lin JD, Lin PY, Lin LP, Chang YY, Wu SR, Wu JL. Physical activity and its determinants among adolescents with intellectual disabilities. *Res Dev Disabil* 2010;31:263-9.