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Pattern of multimorbidity in middle-aged and older-aged people with mild intellectual disability in Australia

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Abstract

Background: Non-communicable diseases (NCDs), also known as chronic diseases, now constitute a major proportion of ill-health across most adult and older populations including in people with intellectual disability. The current paper is a comparative analysis of prevalence of NCDs across mid-aged and older-aged people with mild intellectual disability.

Method: Comparative data comes from two cross-sectional surveys using similar methodology and timeframes. The analysis sample comprises mid-aged group (30–50 years, $N = 291$) and older-aged group (≥60 years, $N = 391$).

Results: People with mild intellectual disability start developing NCDs in early to mid-adulthood and increases with age. The mean number of NCDs in mid-aged group was 0.86 (SD, 0.84) compared to 3.82 in older group (SD, 2.67).

Conclusion: There needs to be early identification and management of NCDs using relevant health promotion and preventative measures at optimal intervention points. The training of healthcare professionals needs improvement.

KEYWORDS
ageing, Australia, chronic diseases, intellectual disability, multimorbidity, non-communicable diseases

1 | INTRODUCTION

COVID-19 has been at the forefront of health challenges since early 2020, yet the burden of non-communicable diseases (NCDs), also commonly referred to as chronic diseases, continues to be of major concern (Azarpazhooh et al., 2020; Benziger et al., 2016). These findings are consistent with multiple rounds of the Global Burden of Disease study, co-hosted by the World Health Organisation [WHO] (Vos et al., 2020). The increasing prevalence of NCDs shows clustering in individuals, with studies referring to them as comorbidity or multimorbidity interchangeably. Comorbidity refers to the presence of an additional disease in the presence of one major index medical condition, whereas multimorbidity is defined as the presence of two or more coexisting health conditions (see Harrison et al., 2021; WHO, 2016). In Australia, the latest national report published by the Australian Institute of Health & Welfare [AIHW] shows that 47% of the Australian population has one or more NCDs, which contributed to 89% of all deaths (AIHW, 2022). Multimorbidity affects nearly 1 in 3 people aged 45–64 years, and 1 in 2 people over the age of 65, with commonly reported NCDs including arthritis, asthma, diabetes, osteoporosis, and mental and behavioural health conditions (AIHW, 2021).

For people with intellectual disability, although there has been ongoing increase in the life expectancy (Coppus, 2013), it still remains lower than the general population (O'Leary et al., 2018). The age limit for 'ageing' in people with intellectual disabilities varies across studies. Some have argued that as life expectancy continues to increase,

particularly for people with mild intellectual disability, a better comparative age group is the one closer to availability of aged-care services, which in many countries is 60 years (Janicki et al., 1999). Higher prevalence of NCDs in people with intellectual disability have been reported by several studies (Cooper et al., 2015; Emerson et al., 2016; Folch et al., 2019; García-Domínguez et al., 2020; McMahon & Hatton, 2020; Olsen et al., 2021). Key findings from the Intellectual Disability Supplement of the Irish Longitudinal Study on Disability and Ageing (IDS-TILDA) report a continuing rise in NCDs over the span of 10 years in a cohort of people over the age of 40 years (McCarron et al., 2013, 2017). Moreover, people with intellectual disability also have higher incidence and prevalence of mental health disorders (Cooper et al., 2007, 2015; Hussain et al., 2021). Higher levels of multimorbidity often lead to excess of medications to manage various conditions, with unintended iatrogenic effects (McCarron et al., 2017; Pazan & Wehling, 2021). This pattern of NCDs is also seen in people with Down syndrome, who are at increased risk of endocrine and auto-immune disorders (Real de Asua et al., 2015; Verstegen & Kusters, 2020) as well as early-onset dementia (McGlinchey et al., 2020).

In Australia, to the best of our knowledge, there are no cohort-specific longitudinal studies examining prevalence of multimorbidity in people with intellectual disability. The Australian Bureau of Statistics (ABS) conducts a triennial panel survey titled Survey of Disability, Ageing and Carers (SDAC), with the latest survey results available for the 2018 round (Australian Bureau of Statistics, 2018a). Drawing specific inferences from SDAC survey for people with intellectual disability is problematic as disability is defined more broadly as 'any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months'. Other smaller-scale previous Australian studies show that people with intellectual disability experience considerable multimorbidity (Bowers et al., 2014; Hussain et al., 2020; Reppermund et al., 2020). However, there are no comparative studies that look at differences in multimorbidity at earlier stages of adulthood compared to older ages, other than a study examining the health profile across the lifespan for people with Down syndrome (Bittles et al., 2007). Therefore, the aim of the current study is to undertake a comparative analysis of prevalence of NCDs in mid-aged and older-aged group of people with intellectual disability in Australia using similar methodology and timeframes. This in turn can provide insights for early detection and treatment of NCDs.

2 | METHODS

2.1 | Design and setting

This study used data from two different cross-sectional surveys of people with intellectual disability. For convenience and clarity, the two surveys are referred to throughout this paper by corresponding age groups: mid-aged group (30–50 years) and older-aged group (≥60 years). Both sample surveys were conducted across urban and rural regions of two states on Eastern seaboard of Australia namely, New South Wales (NSW) and Queensland. Together these states had approximately 49% of Australia's total population. Estimated sample size for each survey was around 350–400 participants. Full ethics approval was granted independently for both surveys by relevant HREC institutions (approval number: 5201500840 and HE14/019 for mid-aged and older-group respectively). Ethics approval for the study on comparative analyses was granted separately (approval number: 2022/014).

2.2 | Recruitment and data collection process

Similar initial recruitment methods were used for both surveys. All disability agencies listed in the Australian Disability Enterprise (ADE) directory operating in NSW and Queensland were contacted. They were provided detailed information on survey modality, ethics approval, copy of the plain-language participant information sheet, and survey form. Several ADEs who agreed to participate also had links to other disability agencies, which were used to access these organisations. Moreover, recruitment was not restricted to ADE and associated agencies, but expanded to include several other disability agencies through our professional disability networks. A similar approach was used: provision of detailed information, discussions about scope of involvement followed by agreement. Both surveys were also advertised in local media. As informed consent was a prerequisite for both surveys, the target sample was people with intellectual disability who could understand the plain-language information sheet. This precluded inclusion of people with moderate and profound intellectual disability, which is discussed in a later section of the paper. Post-approval, agencies requested their staff to independently discuss the survey contents with prospective participants and their carers/advocates (where available).

The differences in data collection for each sample survey are outlined below. For the older group, agencies were sent survey packs for distribution to prospective participants. Many disability agencies indicated willingness to make support staff available to provide respondents with a familiar face and help provide some information if required. However, their preference was for research team to organise interviewers as there was concern that some older respondents could find survey completion onerous. These agencies did not want completion to become responsibility of support staff. Hence, a small number of interviewers with prior experience in disability work were recruited and trained to assist with survey completion. In other situations, some respondent availed the option of a family member or friend to be present. At the time of the interview, the prospective respondents were provided with a duplicate plain-language information sheet. Where requested, the interviewer read out the questions and noted responses on the printed forms.

For the mid-aged group, prospective participants were provided a plain-language information sheet and survey form. They were given the option of having a support person (e.g., peer, family member or where appropriate a disability support worker) to be present and/or

assist them with survey completion. For this survey, no specific requests were made for interviewers, perhaps as the anticipated risk of agency staff being asked to help with survey completion was perceived to be lower.

2.3 | Measures

Both surveys included information on demographic characteristics such as age, sex, location, financial support in the form of disability pension and other sources of income, employment and living arrangements. For health measures, both surveys asked respondents to indicate whether they had medically diagnosed NCD/s. This list was drawn from the literature on major NCDs experienced by people with intellectual disability (Lennox et al., 2001; McCarron et al., 2017). An open-ended response option was also provided for other NCD/s not included in the list. The investigators did not have access to medical/clinical records of respondents due to strict privacy rules. Other measures included questions on social support and quality of life (QoL), which are not the focus of the current paper.

2.4 | Analysis plan

The data from both surveys was uploaded from paper forms onto a statistical database for analysis (SPSS, version 26.0). The aggregate sample for the mid-aged survey group was 362 respondents. However, after editing for age criterion, 59 cases were removed, with another 12 cases removed for several sections being incomplete for key variables, the analysis sample included 291 respondents. For the older-aged group from a total sample of 408 respondents, the analysis sample included 391 responses. Due to somewhat differing data collection process, extensive preliminary analyses were undertaken to detect response bias errors, which were found to be minimal by mode of survey.

For the current paper, univariate and bivariate analyses were undertaken for demographic factors and health conditions. For each of the health condition, we also analysed the data by age and sex separately. No significant statistical differences were found at the bivariate or multivariate level by demographic variables. Therefore, we have outlined descriptive comparative analysis of prevalence of NCDs across the two age groups.

3 | RESULTS

3.1 | Demographic characteristics

The key demographic characteristics of participants in both age groups are provided in Table 1. For the mid-aged group, age was reported in 5-year age categories comprising 30–35 (30.2%), 36–40 (18.2%), 41–45 (22.3%), and 46–50 years old (27.8%). The older-aged group was asked to provide age at last birthday, as well as date of birth as we were not sure all the respondents could correctly report age categories, especially when there were at the cusp of age across two adjoining categories. The age range for older-group was from 60 to 87 years, with a mean age of 65.2 years (SD: 4.44 years) and a median of 64 years. The distribution by 5-year age groups showed: 60–65 years (~60%), 66–70 years (28.2%), 71–75 years (10%), 76 years, and older (1.8%).

There was a higher proportion of male respondents in both groups: 55.0% in the mid-aged group and 62.7% in the older-aged group. This pattern is in line with Australian disability agency data, where more males are listed with disability agencies. Geographic location was comparable across both groups, with 62.9% of the mid-aged group and 60.4% of the older-aged group located in metropolitan areas, and the remainder living in regional areas (see Table 1). Living arrangement showed fewer respondents in the mid-aged group living alone (18.2%) compared to older-aged group (29.7%). This is attributable both to shifts in intergenerational living arrangements and some of the older-aged respondents not having partners, and some whose family members had died, whereas some of the mid-aged group was still living with family. Almost all participants in both groups received disability pension—over 93% of the mid-aged group and 98.2% of the older-aged group. Some additional income sources were reported by both groups. Income from family sources was lower in the mid-aged group (5.5%) compared to 16.6% in the older-aged group, a difference mainly attributed to the latter being beneficiaries of some family inheritance income (see Table 1). Other income sources were from part-time or full-time employment. Nearly a third of both groups (30.6% of mid-aged group versus 39.6% of older-aged group) participated in part-time work. Although there was a small proportion who worked full-time, this was more of being included in 'supported employment'.

3.2 | Health conditions

The prevalence of NCDs reported by each age group is shown in Table 2. Most health conditions were more prevalent in the older cohort. For example, 5.5% of the mid-aged group had asthma compared to 16.1% in older-aged group. Similarly, only 0.7% of the mid-aged cohort had high levels of cholesterol compared to 2.3% in the older group. However, the difference in prevalence of hypertension was smaller—7.9% in mid-aged group versus 8.7% in older-aged group. Nearly 11% of the mid-aged cohort had cardiovascular disease compared to 14.8% of older-aged group. The prevalence of diabetes (type 2) was 8.9% and 25.6% in mid-aged and older-aged groups respectively. Since type 2 diabetes is both a NCD in its own right as well as a risk factor for other NCDs, we assessed age differences within and across both mid-aged and older-aged groups. There was a linear trend by age of increasing prevalence with 6% in 30–40 year olds, and 12% of 40–50 year old. In the older-group, there was further increase to around quarter of the sample 25.6% in 60–65 and 25.4% in ≥66 year age groups (see Figure 1).

For other health conditions, we observed a varied pattern by age group. For example, there was small difference for hypothyroidism (4.1% versus 6.6% in mid-aged and older-aged groups, respectively).

TABLE 1 Demographic characteristics of respondents in mid-aged and older-aged groups.

Characteristic	Mid-aged group (*N* = 291)*	%	Older-aged group (*N* = 391)	%
Age*				
30–35	88	30.2		
36–40	53	18.2		
41–45	65	22.3		
46–50	81	27.8		
60–65			233	59.7
66–70			110	28.2
71–75			40	10.2
76 and older			7	1.8
Sex				
Female	129	44.3	146	37.3
Male	160	55.0	245	62.7
Location				
Metropolitan	171	58.7	236	60.4
Rural	101	34.7	155	39.6
Living arrangement				
Alone	53	18.2	116	29.7
With others	223	80.1	275	70.3
Source of income§				
Pension	271	93.1	384	98.2
Family	16	5.5	65	16.6
Other	123	42.2	26	6.6
Employment status				
Part-time	88	30.6	155	39.6
Full-time	34	11.7	55	14.1
None	165	56.7	181	46.3

*Numbers and % may vary due to missing information on some respondents.
§Exceeds 100% due to some respondents receiving income from more than one source.

TABLE 2 Health conditions reported respondents in mid-aged and older-aged groups.

	Mid-aged group (*N* = 291)	%	Older aged group (*N* = 391)	%
Condition				
Asthma	16	5.5	63	16.1
Hypercholesterolemia	2	0.7	9	2.3
Hypertension	23	7.9	34	8.7
Cardiovascular disease	31	10.7	58	14.8
Diabetes	26	8.9	100	25.6
Thyroid disorders	12	4.1	26	6.6
Musculoskeletal	16	5.5	41	10.5
Epilepsy	54	18.6	21	5.4
Cancers	1	0.3	41	10.5
Mental health disorders				
Anxiety	45	15.5	86	22.0
Depression	22	7.6	86	22.0
Other mental health conditions	25	8.6	13	3.3
Chronic pain	3	1.0	105	26.9
Dementia (early stage)	1	0.3	9	2.3
Incontinence	2	0.7	87	22.3
Parkinson disease	2	0.7	1	0.3
Sleep problems	-		87	22.3
Ageing-related conditions				
Sore gums (due to teeth loss)	-		35	9.0
Poor vision (e.g., cataract, other age-related issues)	-		114	29.2
Hearing impairment	-		98	25.1

By contrast, the difference in musculoskeletal conditions (composite of arthritis, back pain, and residual pain from falls/fractures) was two-folds: 5.5% in mid-aged and 10.5% in older-aged group. This difference was mostly attributable to much higher levels of arthritis reported by older respondents. Although the list of health conditions included three neurological conditions—epilepsy, Parkinson's disease, and dementia, the number of respondents was very small except for epilepsy. In the mid-aged group, 18.6% reported having epilepsy compared to 5.4% in the older-aged group (Table 2). There was a low prevalence of cancer (all types) in the mid-aged group (0.3%) versus 10.5% in the older-aged group. From the open-ended responses, most of the cancers in the older-aged group were skin cancer for both sexes, and breast cancer for female respondents.

Mental health disorders were prevalent among both groups. In the mid-aged group, 15.5% had anxiety (34.3%) compared to 22.0% in the older-aged group. However, for depression there was a marked difference—7.6% in mid-aged versus 22.0% in the older group (Table 2). Respondents in both survey groups were asked to report on other mental health conditions such as bipolar disorders, schizophrenia, or other disorders. These disorders were grouped together as the list of categories was becoming long with very small numbers within each category. Collectively, there were more mid-aged respondents with diagnosed other mental health conditions (8.6%) compared to older-aged group (3.3%).

The final part of our analyses focused on assessing multimorbidity as a combined measure of all NCDs. The mean number of health conditions experienced by the mid-aged group was 0.86 (SD ± 0.84) with a median of 1.0 condition and range of 0–6 conditions. For the older-age group, the corresponding values were much higher: mean 3.82 [SD ± 2.67], median 3.00, and range of 0–14 conditions. The differences in multimorbidity across the two age groups is outlined in Figure 2. It shows a clear increase in accumulation of NCDs as

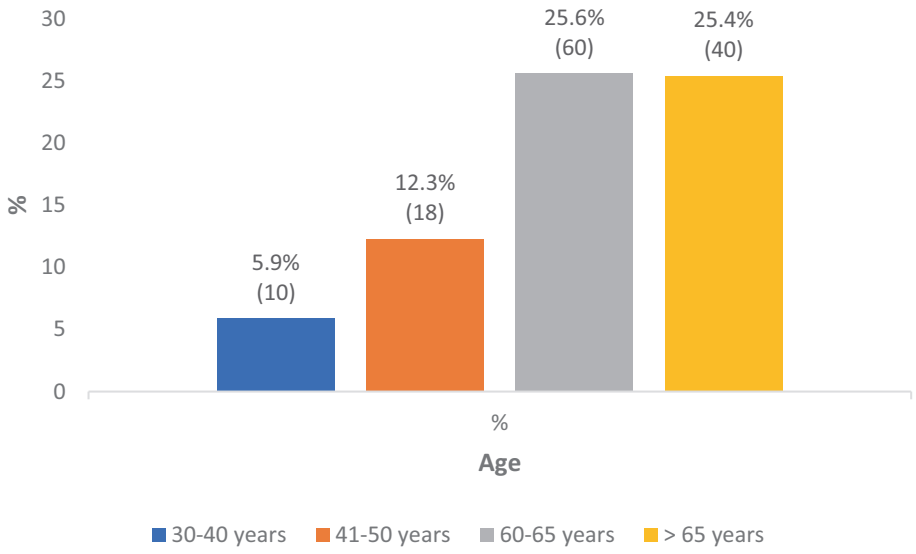

FIGURE 1 Prevalence of Diabetes in mid-aged and older-aged groups.

respondents' age. Briefly, over a third of the mid-aged group (38.5%) reported no NCD, 41.9% had one, 14.4% had two, and only 5.2% had three or more NCDs (of which 0.7% had four and 0.3% had five NCDs). In the older-group, only 8.4% had no NCD, 12.3% had one, and 15.1% had two comorbid conditions. The remaining two-thirds had considerable multimorbidity: 16.4% had three, 12.4% had four, 9.7% had five, and 25.8% had six and more NCDs (see Figure 2).

We assessed differences in multimorbidity using bivariate analysis for age, sex, and location for both groups. Though none of variables had statistically significant association with multimorbidity, the pattern was clearer by age than for sex or location. Due to small numbers, we aggregated health information by 10-year age-groups. As evident from Figure 3, younger adults (30–40 year group) were healthier with only 10.6% experiencing comorbidity and 2.8% having multimorbidity. The corresponding values for the 41–50 years were 17.8% and 6.8%. In contrast, the older group (60–65 years and >65 years) had much higher comorbidity and multimorbidity (see Figure 3). As a final step, we undertook multivariable linear regression analyses for age, sex, and location as predictors of multimorbidity. The model statistics indicated poor model fit (mid-aged group: R^2Adj = 0.014, $p = .052$; and older-aged group: R^2Adj = 0.047, $p = .061$) with none of the predictor variables showing statistically significant association.

4 | DISCUSSION

The comparative analysis presented in this paper shows that older people with mild intellectual disability have a higher prevalence of NCDs than their mid-aged peers, which is consistent with existing international literature. In this section, we will only focus on some of the major NCDs. The prevalence of asthma in adults with intellectual disability varies across studies. A British study by Emerson et al. (2016), reported a prevalence of 9%, and a Finnish cross-sectional multi-centre study by Olsen et al. (2021) of around 11% in people with mild intellectual disability (a group that corresponds closest to the current study population). The overall prevalence of asthma in Australia is 11%, with increase in prevalence beyond childhood into middle-age attributed to several environmental factors (Australian Institute of Health and Welfare, 2023). In the present study, the comparative prevalence of asthma of 6% in mid-aged group was lower than general population, and a higher prevalence of 16% in older-age group could include comorbidity with cardiovascular conditions and chronic obstructive pulmonary disease (Cazzola et al., 2012).

People with intellectual disability have also been known to be at earlier and higher risk of cardiovascular disease (CVD). A recent large-scale register-based Danish study showed cumulative incidence of 17% by age 39 years with greater incidence correlated with severity of intellectual disability (Wang et al., 2023). In our study, the prevalence of CVD was approximately 11% (mid-aged) and 15% in older-aged group. This figure could have been higher if the survey included people with moderate to severe intellectual disability, who have more complex health issues. The prevalence of diabetes in the mid-aged group was higher, but similar for the older-age group to the findings of a Dutch study by Cuypers et al. (2021) based on primary care data-linkage registry records. These findings along with many other studies (see Vancampfort et al., 2022) suggest a potential gap in preventative health including risk factor identification and management of diabetes in people with intellectual disability. As diabetes is also a risk factor for CVD (Dal Canto et al., 2019) and can cause other complications (Tomic et al., 2022), people with intellectual disability experiencing proportionately higher prevalence levels of diabetes as they age has implications for development of a range of NCDs.

Mental health disorders in people with intellectual disability have been shown to occur at a higher rate than the general population (Cooper et al., 2007; Hussain et al., 2021). Respondents in both age-groups reported higher level of anxiety than the general Australian population, and prevalence of depression was higher than the general population in the older-aged group (Australian Bureau of

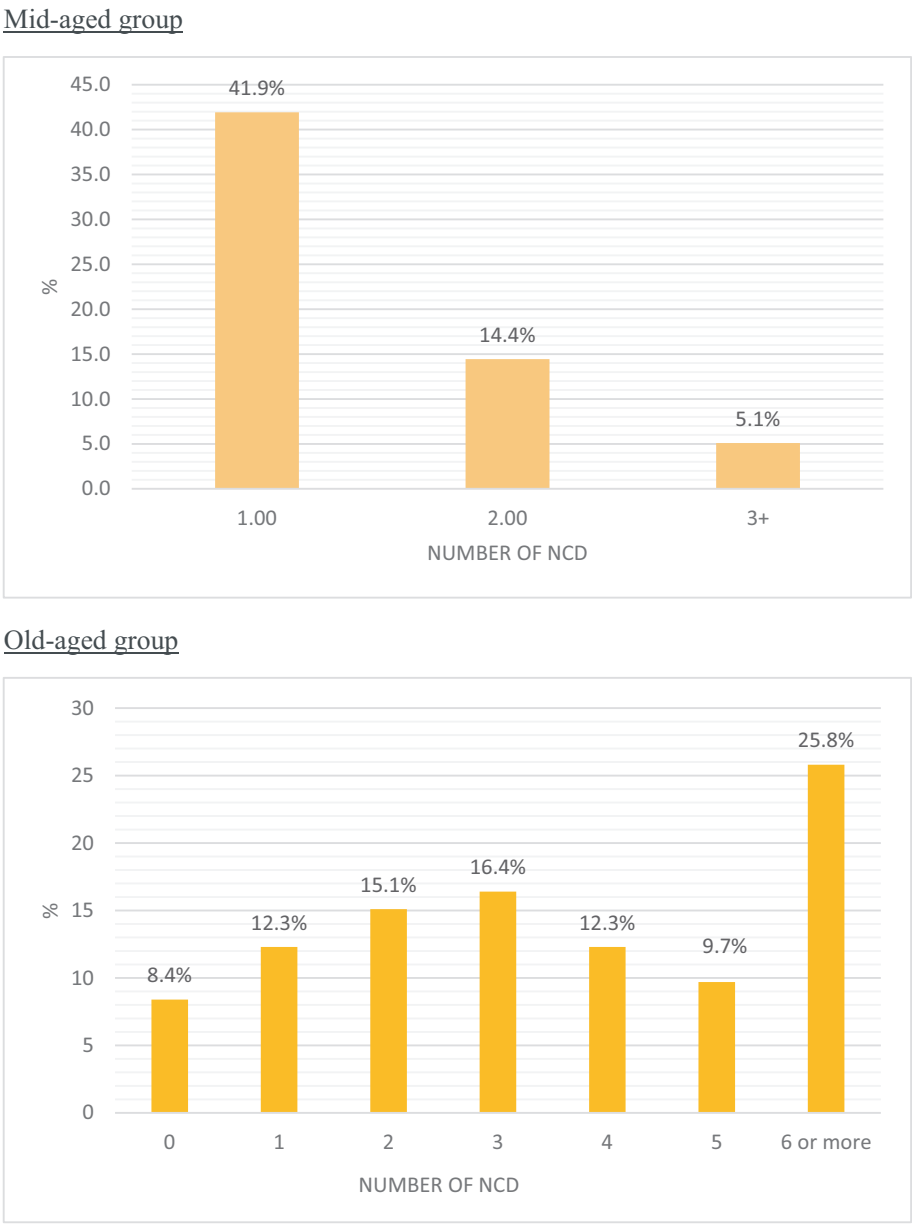

FIGURE 2 Number of non-communicable diseases in mid-aged group and older-aged groups.

Statistics, 2018b). Previous studies have found that up to a third of people with intellectual disability have a co-existing psychiatric illness (Mazza et al., 2020; Morgan et al., 2008), and are higher users of mental health services (Srasuebkul et al., 2021). Conditions that have previously been shown to be associated with intellectual disability at higher rates than the general population include schizophrenia and unspecified psychiatric disorders (Mazza et al., 2020). The much lower prevalence of other psychiatric disorders in our study apart from depression and anxiety could be due to selection bias, which is further discussed in section 4.1.

In addition to a discussion of prevalence of major NCDs, it is also important to outline issues in their prevention and management by healthcare professionals both internationally and in Australian context. An integrated systematic review of barriers and facilitators of primary care service utilisation by people with intellectual disability reported six key issues—training, knowledge and awareness, communication, fear and embarrassment, involvement in healthcare decision-making and time (see Doherty et al., 2020). From policy and service provision perspective, some of the barriers remain entrenched. For example, despite consensus guidelines in Canada outlining the need for regular health assessments for people with intellectual disability (Sullivan et al., 2018), a recent study by Maltais et al. (2020) reported that one-third of people with intellectual disability had not received a medical examination in the preceding year. A trial of incentivisation of annual health screening in primary care in United Kingdom provides some useful pointers that other health systems can adapt and adopt (Buszewicz et al., 2014). Similarly, audits of annual health checks of people with intellectual disability in the United Kingdom show that regular screening for health issues is quite feasible in primary care settings (Durbin et al., 2019). Admittedly, such changes have considerable resource implications, which are not feasible in the current already over-stretched health, disability, and ageing sectors without additional funding. Among interventions with relatively limited resource requirements that have potential for considerable dividends

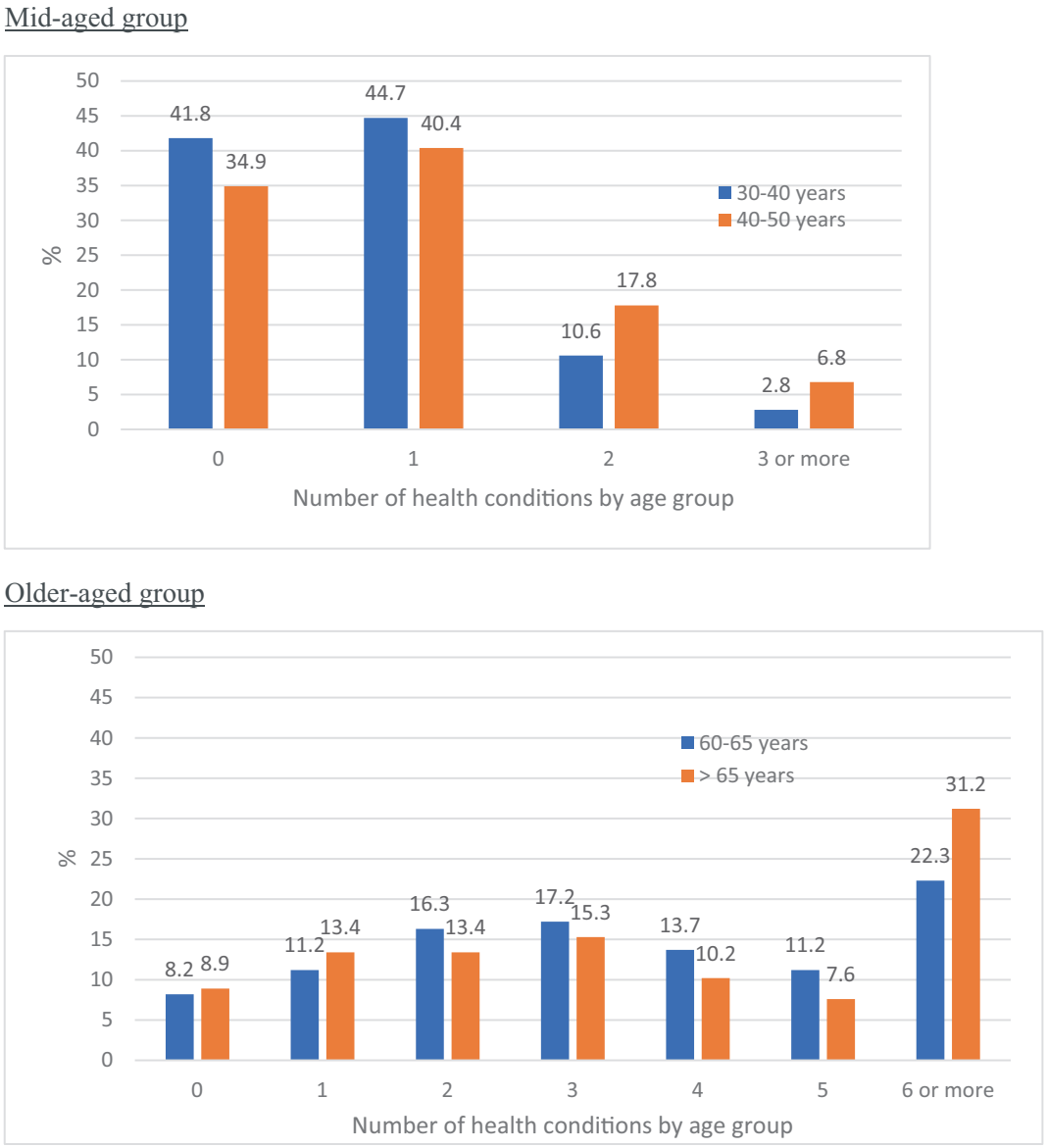

FIGURE 3 Multimorbidity in mid-aged group and older-aged group.

for reduction of NCDs is better integration of health promotion activities and risk-factor management (Kuijken et al., 2019; Roll, 2018).

In Australia, the government-funded National Disability Insurance Scheme (NDIS) pays for costs associated with disability to help individuals gain support and access to support services. Under the NDIS model, people with disabilities have more choice and control over how support is provided, more individualised service delivery, and funding portability throughout the nation (Buckmaster, 2017). However, recent studies have identified concerns pertaining to disability-related health support including for people with intellectual disability (Bigby, 2020; Perry et al., 2019). Beyond issues with NDIS service and support model, lack of targeted identification and management of NCDs that disproportionately affect people with intellectual disability indicates the need for upgrading training. Knowledge improvements without major resource impact are feasible during pre-service by enhancing current training of medical and allied health students, and in-service by allocating a fractional component in continued in-service education (Hussain et al., 2019).

4.1 | Limitations

The lack of access to clinical records due to privacy regulations requires caution in interpretation of results. It is likely that for some conditions, the true prevalence could be under-reported as respondents tend to remember conditions which require medication and/or affect QoL. Some degree of selection bias is also present, as people who were unwell (major mental and possibility physical ill-health) were excluded as prospective participants by disability agencies, including those with cancers and early-onset dementia. Such a selection bias can also under-estimate of multimorbidity. Also, some NCDs such as dysphagia, coeliac disease, constipation, breathing disorders

(other than asthma) were not included as the list was already long; and pilot-results indicated that some conditions got mentioned in the open-ended response category, which did not happen consistently in the main surveys. Such lack of information can also influence multimorbidity estimates. This is particularly the case for individuals with Down syndrome with differential survival rates across cohorts, which could lead to over-estimation in the younger cohort and under-estimates in older cohort. The results for comorbidity therefore need to be considered with these limitations.

5 | CONCLUSIONS

The present study addresses a gap in empirical evidence in Australia on NCDs experienced by people with mild intellectual disability across adulthood and older ages. The trends of increase in NCDs with age is consistent with many international studies. However, lack of access to clinical records requires some caution in inferring study findings as reflection of true prevalence of major NCDs. Also, other studies have shown a greater burden of NCDs and/or multimorbidity in people with moderate and severe intellectual disabilities. Nonetheless, for people with mild intellectual disability, the available information shows considerable ill-health in older age, which reinforces the importance of enhanced focus on health promotion to improve and sustain physical and mental health and reduce multimorbidity.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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