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Exploring enablers and barriers to accessing health services after a fall among people with intellectual disability

Abstract:

Background: Adults with intellectual disability (ID) experience high rates of falls making falls prevention an important health need. The purpose of the study was to seek perspectives of older adults with ID and their caregivers to i) explore the experiences of older adults with ID when seeking healthcare services after a fall, and ii) identify enablers and barriers when taking up evidence-based falls recommendations.

Method: A qualitative exploratory study was undertaken as part of a prospective observational cohort study. Semi-structured interviews were conducted with a purposeful sample. Data were analysed thematically using Colaizzi's method.

Results: Seventeen interviews were conducted (n=21). Emergent themes demonstrated that participants had limited knowledge about falls prevention. Enablers included individualising falls prevention strategies. Barriers included not being offered access to established fall prevention pathways.

Conclusion: There is an urgent need to develop high quality falls prevention services for older adults with ID.

Key words: Intellectual disability, accidental falls, referral and consultation, barriers and enablers

Introduction:

A recent systematic review of nine studies reported that the prevalence of falls in adults with ID is approximately 40% (95%CI 0.25 – 0.53) (*blinded for review*). This prevalence is higher than in the general community where falls increase at an older age and where 25 - 35% of adults aged 65 years and older fall each year (Bloch et al., 2010; Milat et al., 2011). Identified risk factors for falls amongst people with ID include having a history of falls, seizures, challenging behaviours and higher levels of mobility (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010; Enkelaar, Smulders, van Schrojenstein Lantman-de Valk, Weerdesteyn, & Geurts, 2013; Hsieh, Rimmer, & Heller, 2012, *blinded for review*) which are different to the general community (Ambrose, Paul, & Hausforff, 2013).

Randomised controlled trials and multiple systematic reviews (Hopewell et al., 2018; Hu, et al., 2016; Sherrington, et al., 2019, Tricco et al., 2017) provide evidence for effective strategies that reduce the risks and rate of falls and injurious falls in community dwelling individuals aged 65 years and older. The evidence is strongest for exercise interventions, as well as vision assessment and treatment, environmental assessment and modification, and vitamin D and calcium supplementation (Tricco et al., 2017). Consequently, guidelines and falls models of care have been developed to increase awareness of these strategies in the wider community and their supporting health professionals (Australian Commission on Safety and Quality in Healthcare, 2009; Department of Health, Western Australia, 2014; Moncada & Mire, 2017).

While there has been limited research investigating the best available evidence for reducing falls among people with ID, evidence suggests that exercise-based interventions, environmental safety and caregiver education are important to reduce fall-related injuries

(Van Hanegem, Enkelaar, Smulders, & Weerdesteyn, 2014, Cahill, Stancliffe, Clemson, & Durvasula, 2013, Axmon, Ahlström, & Sandberg, 2019). Further large trials are required that evaluate the effects of falls prevention strategies to inform the falls management in people with ID (Finlayson, 2018).

Current falls guidelines and models of care are not specifically applicable to adults with ID because their risk factor profile differs from the general population (Enkelaar et al., 2013; Finlayson, 2018). However, researchers have observed that individualised approaches are beneficial when tailoring healthcare services to adults with ID (Bergstrom, Elinder, & Wihlman, 2014; Reppermund & Trollor, 2016; Smulders et al., 2013).

While more improvements are required to develop suitable evidence-based falls prevention recommendations and tailored services to adults with ID, accessing existing services are also a cause for concern. Older adults with ID face multiple barriers when seeking to access health care due to the lack of awareness and support of services (Ali et al., 2013). Currently, there are no studies which have specifically investigated the experiences of adults with ID seeking health services immediately after having a fall nor the barriers to taking up falls prevention services. The aim of the study was i) to explore the experiences of older adults with ID when seeking healthcare services after a fall and ii) identify enablers and barriers to taking up falls prevention recommendations that have been provided to them.

Methods

Design

This study was part of a larger convergent mixed methods study which sought to investigate the rate of falls in older adults with ID living in the community as well as explore

participant's experiences of seeking healthcare services after a fall. A fall is defined as 'an event which results in a person coming to rest inadvertently on the ground or floor or other lower level' (World Health Organisation, 2018). A fall will be classified as injurious if it results in bruising, laceration, dislocation, fracture or complaint of an onset of persistent pain as a result of the fall, which is concordant with previous research conducted in this area (Hill et al., 2011). The protocol for the larger study is reported elsewhere (*blinded for review*). A descriptive phenomenological approach was taken for this qualitative phase of the study as it allowed the researcher to report on the lived experience of the participants in relation to falls events (Liamputtong, 2013).

Ethical considerations

This study received ethics approval from (*blinded for review*) Human Research Ethics Committee (*number blinded for review*). All participants provided informed consent. Where participants with ID did not have the capacity to consent, written consent was provided by the next-of-kin or legal guardian. Details of gaining informed consent from the participants is presented elsewhere (*blinded for review*).

Sample selection

It has been suggested that people with ID experience aged related changes from the third decade in life (Connolly, 2006; Coppus, 2013) therefore, participants in the larger cohort study were adults with ID aged 35 and over and/or their caregiver. Those participants who fell in the first phase of the study were purposefully sampled and recruited for the follow up interviews. A purposive sampling technique was employed to gain multiple perspectives on the issues around the topic (Patton, 2014).

Participants were selected using maximum variation sampling strategy so that the sample included participants with variability in age, gender, mobility status, and care support needs. The type and level of caregiver support and the different experience when seeking health services after a fall was also considered. Caregivers who supported the participants after the fall were also invited to participate in the interviews, since it was known from the first phase of the study that over 90% of participants required caregivers' support to provide informed consent and support to communicate with the researcher (*blinded for review*). Data obtained from the interviews were continuously examined by the research team to explore the emerging themes and to examine whether the data adequately described the participants' experiences. Interviews ceased when researchers agreed that data saturation had been reached, with no new data being generated and data gathered fitting into previously described themes (Liamputtong, 2013). The aim of data saturation is to provide sufficient themes to be identified which illustrate and confirm the patterns and scope of the study topic (Polit & Beck, 2017).

Data collection and procedure

Individual face to face, semi-structured interviews were conducted with participants at their preferred location and were approximately 30 to 45 minutes in length. The interviews were organised as soon as possible after the fall was reported to ensure that recalling of events were as accurate as possible (Lamb, Jørstad-Stein, Hauer, & Becker, 2005). Semi-structured interviews permitted open-ended questions for informants to share their experience without restrictions. Interviews were audio-recorded and where participants consented, a video was recorded to capture any information that could have been conveyed through non-verbal means, such as facial expressions or gestures. The

researcher also kept a diary and make notes at each stage of the data collection and procedure and these were subsequently discussed with the two other researchers prior to and after each interview.

A number of steps which were taken throughout the data collection and analysis phases of the study followed the criteria for 'trustworthiness' as defined by Lincoln and Gruba (1985). To achieve credibility and dependability, the chosen methodology of a descriptive phenomenological approach, a well-established qualitative methodology, was used. Furthermore, the data collection and analysis steps were conducted and documented as previously described which would ensure the credibility of the findings.

The interview schedule (Appendix 1) was designed in accordance with evidence-based falls prevention recommendations (National Institute of Health and Care Excellence, 2013; Moncada & Mire 2017). The researcher (PH) tailored the interview according to the experiences shared and if the participant was an adult with ID, appropriate lay language was used. Preferred alternative forms of communication were used where required. The researcher also prepared adapted communication resources to facilitate the interview. These adapted communication resources were developed based on recommendations for respective engagement of adults with ID during research (Kidney & McDonald 2014).

Analytical approach

The trustworthiness criteria of confirmability and transferability (Lincoln & Gruba, 1985) were achieved during the data analysis phase. Specifically, following Colaizzi's descriptive method of interpretation (Sanders, 2003), the researcher (PH) familiarised herself further with each interview during the transcribing process. Interview videos were also reviewed and notes made regarding body language and gestures that participants with

ID used to contribute to the interview. Subsequently, the verbatim transcripts of the interviews and notes from video observations were analysed using the data management program NVivo 12 (QSR International Pty Ltd. Version 12, 2018) whereby the researcher searched for statements significant to the research aims. Meanings were formulated from the statements while observing the concept of 'bracketing', focusing on the recorded experiences rather than any preconceived ideas on falls recommendations. 'Bracketing' is noted as capturing the participant's experience whilst remaining outside the experience, in other words "looking beyond preconceptions became known by various interchangeable terms: phenomenological reduction, epoche or bracketing (Tufford & Newman, 2012). Themes and theme clusters were generated from the formulated meanings. The experiences of seeking and receiving health care after a fall and the perceived barriers were described using these themes.

Interviews and videos were reviewed by all team members independently. Team members also met at every stage of the analysis to ensure rigour and trustworthiness of the results. Formulated meanings and theme clusters were initially conceptualised by the first researcher (PH) and after independent review and subsequent discussion were agreed by two other team members (CB, AMH). Emergent themes were developed and agreed upon by all team members (PH, CB, AMH). As noted, the triangulation of the analysis was used to enhance trustworthiness of the findings.

The final step undertaken following Colaizzi's method is the returning of results to the participants. This step was not completed as the research team concurs with one of the criticisms of this final step in that the researchers and participants will inevitably have differing perspectives (Giorgi, 2006).

Finally, Lincoln & Gruba's 'authenticity' criteria was achieved in the final report of findings. Specifically, in the words of Polit and Beck (2017) that is, "The text has the authenticity in inviting readers to a vicarious experience of the lives being described and enables the readers to develop a heightened sensitivity to the issues being depicted". The rich descriptions of the participant stories for this study follows in the results section.

Results

Participant characteristics

There were 36 participants who sustained one or more falls in the first phase of the research (*blinded for review*). Of all these falls, 13 falls were followed up with an interview with the 13 participants and /or their caregivers. Twenty-one participants [five older adults with ID, one parent, one nurse, 14 Disability Support Workers (DSW)] engaged in 17 interviews. The characteristics of the sample are presented in Table 1. Four separate interviews were conducted with older adults with ID, who were capable of holding a conversation with the researcher and one interview was conducted with an older adult with ID alongside a DSW. Two individual interviews were conducted with a nurse and a parent respectively. One group of three DSWs and one group of two DSWs were interviewed together as they were all involved in the post-fall care of an older adult participant with ID. Eight interviews were conducted with individual DSWs. Seven of the 13 falls that were followed up resulted in an injury (including two fractures), and of those seven falls, three required a hospital admission.

Examples of how formulated meanings were derived from significant statements are presented in Table 2. From these meanings, seven theme clusters were identified: the account of the fall, consequences of the fall, immediate care after a fall, rehabilitation after

a fall related hospitalisation, knowledge of falls and how falls impact on the health of people with ID, intrinsic and extrinsic barriers to engaging in falls prevention, and enablers to receiving health services after a fall. Examples of how the emergent themes were derived from the theme clusters are presented in Table 3. Five emergent themes informed the phenomena and they are presented as follows.

Limited awareness about falls as a problem to be addressed and about falls prevention strategies

Limited awareness that falls were a problem and should be reported and investigated was repeatedly demonstrated in the participants' reflections about their post fall experiences. Participants' reflections also exposed their limited knowledge about suitable falls prevention strategies. This included participants with ID, DSWs, family members and health professionals. Not being aware that reporting falls as recommended in current guideline care (Moncada & Mire, 2017) formed a barrier to engaging in evidence-based strategies. A participant with ID reported "*I don't discuss my falls with them (family practitioner)*" (P20) and "*I don't really talk about my falls with people*" (P20). Another participant with ID (P10) appeared confused and shook his head when the researcher mentioned that he should have told this doctor about the fall and said "I am not ill" (P10). An experienced DSW reported that DSWs do not receive the training regarding falls prevention in people with ID.

The challenge is with staff training, um, behaviours attributed to self-harm to what a fall can happen because we are not actually assisting that person the correct way and their reaction to cause a fall, they do, they need training. It's very difficult for people, they go

in and do their induction, their (manual handling) those sorts of things. They don't focus on the triggers that cause falls or what things that can cause falls. (P 7)

This was confirmed with the interviews completed with four other DSWs, with experience ranging from two months to 12 years of experience, who reported that they have not had any falls specific training for people with ID. Only one participant, who was a parent reported doing research about falls because she also takes care of her elderly parents:

Bits and pieces from experience, probably also in the early days it was also information that was sent to parents, um, reading up on, problems for elderly online and looking at the, the risk factors for elderly people like steps and stuff like that.
(P21)

No comprehensive falls prevention pathway commenced after a fall even if injurious

National guidelines for managing falls risk for older adults recommend that local doctors ask older patients about their falls history annually (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). A multifactorial assessment is recommended after an older adult has a fall(s) to identify risk factors and develop a tailored intervention plan to reduce the risk of further falls (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). While there are no falls prevention guidelines designed specifically for older adults with ID, when falls were reported to a health professional, caregivers shared that there was no initiation of services through an existing older persons' falls prevention pathway of care (see Figure 1). One of the service providers was noted to have a falls policy whereby it was mandatory for a person with ID to visit a doctor after a fall. When the interviews were conducted with this

providers' DSW they concurred that the doctors were either in a rush, *"Dr (name) was really really rushed, he sort of just came straight through and had a quick look, so I dealt mostly with the nurse"* (P12) or treated each visit as an isolated incident without follow up care, *"the GP (general practitioner) just ask him if he had any pain? And then try to check his pulse, um blood pressure and then have a look over and it was all good,"* followed by *"just write, like, all good and he is under observation in case of any changes you should take him back."* (P9)

Where a fall resulted in hospitalisation, the event acted as an enabler to addressing some falls risk factors for the participant with ID. However, allied health services such as occupational therapy and physiotherapy services were mainly provided to support the participant to return home from hospital safely. One DSW shared that *"(the occupational therapist) came in and they fitted the bed rail on that same morning (of discharge)"* (P17) and *"in the first week physio was like (here) ... every day, they are here for a few hours..."* (P18). However there was no mention of a health professional incorporating falls risk assessment and implementing falls prevention care for the participant with ID who had sustained the injurious fall. The lack of resources mean that comprehensive and quality health care was not provided to ensure caregivers are empowered to support the participants they care for carry out falls prevention strategies. One DSW reported that exercises programs were prescribed to two persons with ID but the team of DSWs were not confident with the program.

Staff like to have pictorial and to be shown, actually being shown that it's the safe way to protect themselves and the individuals that they are working with, um, and I don't think any training has been carried out with it." (P8)

Risk factors for falls and fall injuries that were addressed incidentally when other medical health checks were completed

Although people with ID were not provided with specific falls prevention services after a fall, some fall risk factors found in to be associated with falls in older people were addressed incidentally when other aspects of health care were being managed. All participants with ID were under the care of a local doctor and for some of the participants, it was during these annual health visits that some of the risk factors for falls were addressed. These were reported as including medication review, vitamin D supplements for bone health, eye health examination and blood marker screening (Sousa et al., 2017). However, these healthcare behaviours, while in some cases incidentally addressing falls risk factors, did not include specific falls prevention screening. One nurse stated, *“two or three times a year, nevertheless, we would have (P10) to the doctor for blood test and for immunisation and for follow up” (P11)*

Falls prevention guidelines recommend the older people engage in specific strength and balance exercises, with this being established as an effective means of reducing falls (Australian Commission on Safety and Quality in Healthcare, 2009; Guirguis-Blake, Michael, Perdue, Coppola, & Beil, 2018). Nearly all caregivers were making efforts to assist the participant with ID to engage in some form of physical activity such as attending a pool, gym, park or social dancing, however these were carried out as recreational activities that did not include specific exercises recommended for reducing falls risk, namely sustained levels of balance challenge (Sherrington et al., 2019). One participant shared that, *“in the pool, the swimming instructor has got me doing ‘ballet leg’ exercises” (P1)* and demonstrated this point by raising her hands and flexing her knees (video observation). More than half of the

persons with ID discussed that they were not participating in any formal exercises or activities that incorporated elements known to be effective for falls prevention (Guirguis-Blake et al., 2018; Sherrington et al., 2019).

Foot care was reported as being comprehensively addressed for all participants with ID, which is known also to reduce falls risk (Corbacho et al. 2018; Spink et al. 2011). Participants visited the podiatrist regularly for reported conditions such as diabetes or foot deformity. One parent shared that *“(participant with ID) always has to have closed in footwear because of her slightly deformed foot, um, so she always has fairly steady, well made joggers”*. (P21)

Advocacy played an important role in receiving services after a fall

People with ID are more likely to receive health screening if they had someone to advocate for them (Lennox et al. 2016). The interviews consistently demonstrated that all participants with ID required a care provider to advocate for care needs. This advocacy ranged from reporting the fall to a health professional to implementing falls prevention strategies such as exercise programs. The strength of some advocacy efforts were conveyed in these words: *“It was when (participant) went into hospital is when I really hammered asking for help because we were then going into the new area of changing over of funding.....can you help us? Well they sent physios out to us”* (P7) and following this the DSW further advocated for more services and awareness from her employer stating that *“The funding was the hiccup for us and it did cause us some concern, but we got them (the employer) on board, I got to mention that falls are really important”* (P7).

Individualised strategies were effective in overcoming barriers to undertaking falls prevention strategies

Supporters recognised that it was challenging to engage adults with ID in specific strength and balance activities. Instead they focused on assisting the adult with ID to engage in any mode or intensity of physical activity and if successful this was perceived as a positive outcome. A common theme of using individualised strategies emerged as a means of encouraging the person with ID to engage in physical activity. One of these strategies was the use of incidental exercise, *“they always put the ramp down and I don’t always want them to because he is quite capable of getting on and off buses.”* (P15). The participant with ID (P14) who was with P15 during the interview concurred with this statement by nodding in agreement. He smiled and vocalised positively upon hearing about the bus ride. He also sat up tall and pointed up reinforcing the message that he likes climbing the steps (video observation).

One parent advised that *“you have to keep making it fun for her”* (P21) and recognised that it was important to create a safe and familiar space for the person with ID:

So when she is on one of the bikes, she can actually watch the boys on the skateboard ramp and she loves that. And she can actually sit there and ride her bike (in the gym) and watch the boys doing their thing and she can have a laugh and have a giggle at them. (P21)

Another DSW identified individual interests of the person with ID as motivators to increase physical activity:

I’ve introduced pet therapy into the house which we are getting permission forAnd she is very very good around the dog. So I am prepared to.. um, how that would increase her mobility, her stamina, her strength and she is motivated

which makes sense where she is motivated to do things something that really interest her. (P7)

Another means of encouraging positive behaviour to reduce falls risk was to ensure the person with ID was engaged in the decision making so that they enjoyed what they did: *“I think in a behavioural way definitely because my, my job with (participant) is to do the stuff that he wants to do that he enjoys” (P15).*

Overall this prospective exploratory study found that the lived experience of older adults with ID after a fall was that a service pathway to provide guideline standards of falls prevention management was not commenced after a fall was reported. This is presented as a framework (Figure 1) illustrating how health care offered to the person with ID differed from the recommended guidelines for providing post-fall risk assessment and treatment. (Department of Health, Western Australia, 2014; Moncada & Mire 2017). Health professionals did not refer participants to falls management services and annual falls risk screening was not initiated. Hospitalisation prompted provision of health services that could be considered relevant for falls prevention but this did not prompt the primary healthcare provider such as the local doctor to continue with follow up screening of falls risk and subsequent targeted interventions.

Discussion

This study explored the experiences of the person with ID and their caregivers when seeking health care after a fall. Participants' experiences did not reflect current guidelines of care for falls prevention for older adults (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). Even reporting an injurious fall to a health professional did not trigger screening of fall-risk, falls management and referral to relevant

falls prevention services. Other studies that investigated strategies to reduce falls in people with ID also found barriers to providing evidence-based care, including lack of consistent support for the person with ID, issues with caregiver attitudes and limited financial resources, both for access to and implementation of services (Pal et al. 2013; Smulders et al. 2013). This is the first prospective study to directly interview older adults with ID and their caregivers immediately after a fall and systematically compare subsequent actions against national falls management guidelines. Substantial gaps were found between guideline recommendations (Moncada & Mire 2017) and participants' experiences regarding the healthcare services they received, including risk screening, immediate follow up care after a fall and ongoing preventive management. Gaps in service delivery and barriers to providing screening, preventative care and adequate interventions for people with ID have also been found in other health areas including oral health (Petrovic et al., 2016), vision (Uzdrowska & Woodhouse, 2016) and mental health care (Whittle, Fisher, Reppermund, Lenroot, & Trollor, 2018). Lack of specialised services, inadequate caregiver support and limited awareness of the health condition were some of the barriers identified (Ali et al., 2013; Whittle et al., 2018).

Low levels of awareness about falls prevention were observed at multiple levels, from the older adult with ID and their caregivers through to healthcare providers they encountered as part of their post-fall experiences. A significant number of falls were not reported to a health professional indicating low levels of awareness about the importance of reporting falls. National falls guidelines state that older people should be asked once yearly if they have fallen because it has been established that one of the most significant predictors of falls is having a history of previous falls (Australian Commission on Safety and Quality in Healthcare, 2009). Conversely findings also demonstrated that care providers

were well-placed to identify the health needs of the older adults with ID and subsequently were able to advocate for services on their behalf. Therefore, care providers' lack of awareness about falls prevention formed a barrier to advocating for fall-risk screening and intervention for older adults with ID. Participant's inability to comprehend the need for, or the importance, of engaging in falls prevention strategies has also been described as a barrier to reducing falls risk for adults with ID (Pal, Hale, & Mirfin-Veitch, 2013). Previous research has identified increasing the level of awareness about falls encourages the engagement in falls prevention interventions (Hale, Vollenhoven, Caiman, Dryselius, & BATTERY, 2019).

Although falls were sporadically reported to a doctor, especially if injury occurred, further screening to identify modifiable of falls risk factors and subsequently refer to existing falls prevention services did not follow. This concurs with research findings in the broader area of fall prevention for community dwelling older adults, where it has been identified that there is limited engagement from local doctors regarding falls prevention. Research findings strongly suggest that a majority of doctors are unfamiliar with falls guidelines of care and only a small percentage of doctors screen older adults for fall risk (Mackenzie & McIntyre, 2019). No participants were referred to available comprehensive falls services or clinics, therefore it was not possible to comment on the suitability of these services for older adults with ID.

Adults with ID experience high rates of falls at an early age (Cox *et al.* 2010; Hsieh *et al.* 2012, *blinded for review*) and the most common cause for injuries in people with ID is falls (Finlayson *et al.* 2010). Health professionals should therefore commence screening for older adults with ID for falls risk at a younger age compared to the general population. It was found that participants with ID were not routinely screened for falls and reporting a fall

to a health professional only occurred if the fall resulted in an injury which needed medical attention or according to one service provider, the organisational falls policy. National guidelines strongly recommend yearly screening for all older adults to ask if they have sustained any falls, since the strongest predictors of falls is a history of a prior fall (Australian Commission on Safety and Quality in Healthcare, 2009; Moncada & Mire, 2017). Falls-risk screening followed by tailored recommendations to manage fall identified risk factors were not demonstrated in the present study. Therefore identifying barriers to engaging in recommended falls prevention strategies was challenging.

The interviews identified that some of the participants received an annual health check at the local doctor and that some risk factors were screened and managed, such as medication, eye health and the need for calcium and vitamin D supplements from blood test. However bone density scans and vision assessment by an optometrist were not undertaken and these are also important to reduce fracture and falls risk. Research findings demonstrate that people with ID have poor levels of bone health (Burke et al., 2019) and have an increased prevalence of osteoporosis and osteopenia (Srikanth, Cassidy, Joiner, & Teeluckdharry, 2011) than aged-matched populations. People with ID also have a higher prevalence of visual defects (Uzdrowska & Woodhouse, 2016), which can be addressed with suitable optical means (Eisenbarth, 2018). These gaps in health screening are a significant barrier to reducing fall and resulting injury among older adults with ID.

Low levels of reporting, screening and management of risk factors for falls is not dissimilar to previous findings from other studies in adults with ID. Injury risk assessments and the management of risk have been shown to be limited and variable in people with ID (Finlayson, Jackson, Mantry, Morrison, & Cooper, 2015). Conversely, health checks have

been identified to have positive effects on the enhancement of health care in individuals with ID (Robertson, Hatton, Emerson, & Baines, 2014).

When a fall resulted in hospitalisation, rehabilitation services were provided to enable safe discharge home, however there was neither multifactorial assessment nor periodic follow up as recommended in falls prevention guidelines (Moncada et al., 2017). This is problematic as it has been found that when a fall results in a hospital admission, adults with ID are more likely to be readmitted within 30 days compared to the general population (Axmon et al., 2019) making post-discharge planning and follow up management critical in this population.

Exercise, including balance components, has been shown to be effective in reducing falls in adults with ID (Crockett, Finlayson, Skelton, & Miller, 2015; Hale, Mirfin-Veitch, & Treharne, 2016; Van Hanegem, Enkelaar, Smulders, & Weerdesteyn, 2014). Since adults with ID fall at rates which are higher than aged matched populations (Enkelaar et al., 2013; *blinded for review*) it is important that they engage in specific exercises for falls prevention. However participants reported very limited engagement in exercises of suitable intensity and mode. Participants were not provided with suitable recommendations and where exercise was prescribed, some caregivers reported needing more support to assist the older adult with ID to effectively engage in the exercises. Despite this, care providers shared individualised strategies that they used to motivate and encourage participants to engage in physical activity. These individualised strategies could also be used to facilitate falls prevention exercise programs, concurring with other research findings regarding exercise based interventions for falls prevention in adults with ID (Crockett et al., 2015; Pal et al., 2013).

Care providers' knowledge about disability was a strong enabler for them advocating for participants to receive health services. Conversely, lack of awareness that falls were a problem resulted in many falls not being reported to a health professional. When care providers were aware of participants' disability, experiences and falls risk factors they were able to advocate on their behalf for fall prevention services.

Strengths and Limitations

Multiple steps were taken to ensure trustworthiness of the data (Lincoln & Guba, 1985). Data were collected and analysed based on a methodology which included strategies to ensure rigour and trustworthiness (Sanders, 2003). This included method triangulation of data analysis by three researchers. All the participants underwent a thorough consent process to ensure they were making an informed decision to participate in the study (Ho et al., 20187). They were further sampled with maximum variation purposive sampling to ensure that the sample included participants with different characteristics and care situations in order to capture a wide array of experiences. Where possible interviews were conducted with the participants and their care providers separately which ensured that their experiences shared were authentic and not influenced by other parties. Interviewing caregivers augmented the narratives from the older adult with ID, providing a more holistic story of the fall trajectory, as caregivers were intrinsically part of the post-fall experience. All data were analysed and reported based on participants' first-hand accounts of their post-fall experiences.

Multiple perspectives were purposefully sought for one fall event to assist in understanding the post fall experience. A large proportion of adults with ID depend on multiple care providers and it was challenging to interview every individual involved.

Therefore, accounts of the post-fall experience was in some cases based on the knowledge of one informant. A limitation of the study was that not all participants with ID were able to provide a perspective about their fall, but primary caregivers who had observed and experienced care processes and pathways were able to provided voice for those who experienced greater impairments. Over half of the participants enrolled in the earlier quantitative phase of this study had severe difficulties in communicating and hence were not able to share “first hand” experiences. However out of the 13 falls sampled, five post-fall experiences were directly described by the participant with ID.

Perspectives from other individuals who participated in the participants’ post-fall experience, such as the local doctor and allied health practitioners would also be valuable to amplify the post-fall experiences of older adults with ID. Health practitioners’ perspectives regarding treating this population are an important avenue for further investigation. These perspectives would aid in development of tailored and responsive fall prevention services for older adults with ID.

Conclusion

People with ID receive health care for injuries sustained after a fall but do not receive fall risk screening and preventive services which would assist to prevent future falls and injuries. Establishing comprehensive falls prevention services specifically tailored for people with ID is urgently required. These services may enable people with ID and their caregivers to seek targeted information and engage in falls prevention strategies. Education and resources are also recommended to empower carer providers with the necessary awareness, knowledge and skills to reduce falls risk and maintain healthy ageing. Further research to address the barriers people with ID face to engagement in suitable exercise

programs is also urgently required.

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Table 1 Characteristics of participants and their post-fall experiences

Participant	Characteristics	Supported environment	Fall event	Post-fall experience
1	65 year old female with ID	Lived in group home		
2*	DSW, female 3 years of experience (Worked for 8 months with participant 3)	DSW team leader in group home	Non injurious fall when transferring from wheelchair	Health professionals informed with limited implementation of strategies
3*	DSW, female 9 years of experience (Worked for 1.5 years with participant 3)	Group home		
4	DSW, female 1 year of experience (Worked for 2 months with participant with ID who fell)	Independent unit	Non injurious fall by 71 year old male, while walking up drive way	Health professionals informed with limited implementation of strategies
5	DSW, female 1 year of experience (Worked for 3 months with participant with ID who fell)	Independent unit		
6	DSW, female 2 years of experience (Worked for 8 months with participant with ID who fell)	Independent unit	Non-injurious fall from falling out of wheelchair, by 49 year old male, while	Health professional was informed with implementation of strategies to reduce risk

			trying to retrieve item that was out of reach	
7	DSW, female 12 years of experience (Worked for 14 months with participant with ID who fell)	DSW team leader in group home	Multiple falls in a single day around the home by a 59 year old, female participant, no detectable injuries	Was hospitalised and short term rehabilitation services provided for safe discharge, medication review completed
8	DSW, female 12 years of experience (Worked for 6 months with participant with ID who fell)	DSW team leader in group home	Non injurious fall by 61 year old male participant, fell while dressing in morning	Health professionals informed with limited implementation of strategies
9	DSW, female 6 months of experience (Worked for 6 months with participant with ID who fell)	Group home	Non injurious fall by 71 year old male participant, after tripping over feet while walking	Health professionals informed with limited implementation of strategies
10	67 year old male with ID	Lived in independent unit with daily support		First aid was provided and visited the doctor without further referral or recommendations
11	Community Nurse, female 25 years of experience (Worked for 5 years with participant 2)	Independent unit	Minor injuries from a fall walking through a park	
12	DSW, female 10 years of experience (Worked for 8 months with participant with ID who fell)	Independent unit	Injurious fall (cut and bruise) by 49 year old male participant with ID while walking	Sought medical attention with doctor, no referral or comprehensive pathway recommended
13	DSW, male	Activity centre		

	5 years of experience (Worked for 6 months with participant with ID who fell)			
14*	31 year old male with ID	Lived in a group home		
15*	DSW, female 1 year of experience (Worked for 1 year with participant 5)	Community access	Minor injuries (bruises) from a fall in the community. Lost balance while trying to push someone else in a wheelchair	Did not seek medical attention
16*	DSW, female 7 years of experience (Worked for 2 years with participant with ID who fell)	Group home		
17*	DSW, female 4 years of experience (Worked for 4 years with participant with ID who fell)	Group home	Injurious fall (fracture to lower limb) by 60 year old male participant, while transferring from bed	Hospitalised followed by short term rehabilitation services for safe discharge, no referral to falls clinic
18*	DSW, male 5 years of experience (Worked for 3.5 years with participant with ID who fell)	DSW team leader in group home.		
19	35 year old male with ID	Lived in independent unit with intermittent support	Injurious fall (fracture to lower limb) after slipping in the shower	Hospitalised followed by short term rehabilitation services for safe discharge, no referral to falls clinic

20	41 year old male with ID	Lived at home with parent	Minor injuries (bruises) from multiple falls when transferring from wheelchair	Did not seek medical attention
21	Parent	Home	Bruised and abrasion suffered after a fall by 42 year old female participant while walking in the community	Visited the doctor for injuries and wound care

Abbreviations: ID, Intellectual Disability; DSW, Disability support worker
 *Participant 2 and 3, 12 and 14 and 15, 17 and 18 were interviewed together.

Table 2 Example of analysis – how formulated meanings were derived from participants’ significant statements

Significant statements of barriers	Formulated meanings
<p><i>“they checked her, checked her blood pressure, check her nose, checked her breathing, thought that there might have been a bit of a blockage but they checked and everything seemed to be fine” (P14)</i></p>	<p>The doctor was focused on assessing for injuries after a fall but no falls risk assessment or recommendations to engage in falls prevention strategies were provided</p>
<p><i>“The one for his shoulder, we just kept an eye on it, we checked movement here and you were fine weren’t you. So we just did an incident report and kept an eye on it, after the next day it was forgotten.” (P9)</i></p>	<p>DSW did not report fall to a health professional, not aware of the importance of reporting falls</p>
<p><i>“I don’t really talk about my falls with people”(P1)</i></p>	<p>Participant with ID was not aware that communicating about falls is important, making it challenging for others to support with falls prevention management</p>
<p><i>“vision, we had her vision tested as well because we were worried about depth perception, because she brought everything close to her. The doctors actually couldn’t say whether she had vision problems or not” (P9)</i></p>	<p>The inability to carry out a comprehensive assessment with the participant with an ID is a barrier to understanding the cause of falls</p>
<p>Significant statement of enablers:</p>	
<p><i>It was when (participant) went into hospital is when I really hammered asking for help because we were then going into the new area of changing over of funding.....can you help us? Well they sent physios out to us. (P10)</i></p>	<p>Hospitalisation provided an avenue for DSW to advocate for the participant with ID who fell</p>

Abbreviations: P – Participant; DSW – Disability support worker; ID – intellectual disability

Table 3. Identified theme clusters and resultant emergent themes

Formulated Meanings	Theme Clusters	Emergent Theme
<p>Participant with ID seemed unaware of his limitations and the insight to the precautions required to prevent a fall</p> <p>Participant with ID was seen by their local doctor but falls risk was not assessed and DSW did not advocate for further review</p> <p>Participant with ID fell because there was uneven ground and it was dark. No changes were made to environment and a health professional was not informed.</p>	<p>Intrinsic and extrinsic barriers to engaging in falls prevention</p> <p>Account of the fall</p>	<p><i>Limited awareness about falls as a problem to be addressed and about falls prevention strategies</i></p>
<p>DSW did not report fall to a health professional which indicates that the DSW was not aware of the importance of reporting falls.</p> <p>The doctor treated the fall as an isolated event.</p> <p>Participant with ID was not aware that communicating about falls is important, making it challenging for others to support him to engage in falls prevention strategies.</p> <p>Inability of health professionals to carry out a comprehensive assessment with the participant with an ID is a barrier to understanding the cause of falls</p>	<p>Immediate care after a fall</p> <p>Intrinsic and extrinsic barriers to engaging in falls prevention</p>	<p><i>No comprehensive falls prevention pathway commenced after a fall, even if injurious</i></p>
<p>Participant with ID visits specialist for review of medical condition (Epilepsy)</p> <p>Participant with ID has annual health checks at the local doctor</p>	<p>Knowledge about how falls impact on the health of people with ID</p>	<p><i>Risk factors for falls that were addressed incidentally when other medical health checks were completed</i></p>

Visible needs (spectacles and foot deformity) prompts health reviews (vision and podiatry)

Hospitalisation provided an avenue for DSW to advocate for the participant with ID who fell.

DSW requested further investigation when participant when to the local doctor after a fall.

DSW provided feedback to the organisation that more training around falls prevention is required.

DSW expressed need for more support and training to undertake falls prevention management for clients.

Falls prevention strategy was implemented to prevent similar a fall that resulted after hospital admission.

After hospital discharge, rehabilitation services were provided to increase mobility post-fracture

Caregiver found a method to motivate the participant with ID to participate in physical activity

Caregiver finds a creative and attractive method to incorporate incidental exercise for the participant with ID

Facilitators to receiving health services after a fall

Consequences of the fall

Knowledge of falls and demands of disability

Advocacy played an important role in receiving services after a fall

Abbreviations: ID, Intellectual Disability; DSW, Disability support worker