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Research Article

Expanding Assessment of Fear of Falling among Older Adults with an Intellectual Disability: A Pilot Study to Assess the Value of Proxy Responses

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Introduction. Fear of falling (FOF) has emerged as an important health concern in older adults, yet it has rarely been investigated in people with intellectual disabilities (ID). Valid and reliable measurement approaches are a particular challenge. Scales that have been developed to measure FOF have not been validated for use with older people with ID and are not routinely used with proxy respondents. **Method.** 63 people comprised purposeful samples of 3 groups, people with ID ($n = 21$), their nominated key workers ($n = 21$), and additional support workers ($n = 21$). Test-retest reliability and interrater reliability were assessed for using a dichotomous, single-item FOF screening measure. The degree of FOF and activity restriction due to FOF were also investigated. **Results.** Inter-rater reliability was found to be moderate to excellent with Kappa = 0.77 on ratings of the FOF item. Test-retest reliability for each group of reviewers for the FOF item were also found to be excellent (0.95). **Conclusion.** The global item is a suitable screening measure for FOF in older adults with ID and can assist in identification of individuals requiring further assessment. Proxies, if carefully selected, can provide consistent and reliable reports of the presence of FOF in people with ID.

1. Introduction

Fear of falling (FOF) has emerged as an important health concern in all older adults given its demonstrated association with restrictions in daily activity and in many cases activity avoidance [1]. The substantial body of literature that has emerged addresses prevalence, risk factors, and consequences [2–4]. Reported prevalence of FOF in the general elderly population is as high as 85% [3]; identified risk factors include having had a previous fall [5], increasing age [4], female gender [6], dizziness, depression and anxiety [7], and balance and gait disorders [8] and documented consequences of FOF include a decline in physical and mental performance, activity avoidance, and a loss of health-related quality of life [9, 10]. A consequence of FOF is an increased risk of falling [5, 11] and there is a likelihood of additional falls, given reported rates of 29% and 92% of FOF among recent fallers with previous falls [3, 12]. Studies suggest that FOF

is a psychological experience resulting in reduced physical activity leading to poor balance, mobility impairment, and social isolation [13]. Such consequences may lead to increased likelihood for falling in the future.

By comparison very little is known about FOF among older people with ID despite studies showing that older people with ID have higher rates of falls, multiple falls and falls-related injuries than the general population [14–16]. However, aging people with ID appear to present with some of the risk factors already associated with FOF in the general population such as increasing age and longevity [17], depression and other mental health disorders [18, 19], disorders of balance and gait [20–22], and visual impairment [23]. The presence of such risk factors suggests the potential for a significant likelihood of FOF in people with ID.

Tools and scales developed to measure FOF in older adults include the Survey of Activities and Fear of Falling in the Elderly (SAFFE) [24], the Activities-specific Balance

Confidence (ABC) Scale [25], the Falls Efficacy Scale (FES) [26], the Short FES [27], the Geriatric Fear of Falling Measure [28], and the Fear of Falling Avoidance Behaviour Questionnaire (FOFABQ) [29]. Utilizing such tools with older adults with ID is problematic as they have not been validated for use in the population and their self-report nature adds to challenges in accurately measuring FOF in many people with ID. Work is required on testing the suitability of instruments and finding ways to work with individuals with communication difficulties perhaps by investigating the use of proxy respondents.

One way to minimize challenges is to rely upon a dichotomous single-item screening measure—“are you afraid of falling? Yes or No.” In a comparison of 4 instruments measuring FOF the single-item approach was found to have acceptable criterion-related validity when compared to a performance-based measure of physical function (-0.47), a self-report measure of physical function (-0.61), and to the original Fall Efficacy Scale-International (FES-I) (0.70). Predictive validity compared to the same measures was also found to be acceptable (0.43 , -0.56 , and 0.71 , resp.) with $P < 0.001$ in all cases [30]. In addition, assessment of FOF using a global single-item has been demonstrated to have substantial test-retest reliability (0.66) [26] and good feasibility in other studies in the general population [5, 31]. Finally, in an additional study with 30 subjects a single-item measure was found to be more sensitive to fear of falling than the Modified Fall Efficacy Scale [8]. All of these findings encourage the use and testing of the value of a single-item FOF measure.

2. Self-Report versus Proxy Reporting in Intellectual Disability Research

Even when people with ID are able to self-report concerns have been raised that response bias, acquiescence, and social desirability are potential barriers to reliable research findings [32–35]. On the one hand, the remarkable diversity of people with ID makes it very difficult for researchers to develop a general interview protocol that will enable self-report across the population [36]. Yet there are studies reported where people with ID have been demonstrated to be competent informants [37–39] and competent data collectors [40–43]. Despite research paradigms increasingly advocating the meaningful inclusion of people with ID in research process and design [44, 45], even with the best of intentions on the part of the researcher, the presence of severe communication difficulties, maladaptive behavioural issues, and a severe or profound intellectual disability may limit an individual's ability to participate unless there is a nominated proxy to report on their behalf [46, 47].

Proxy responding may help confirm objective data that the participant may report during an interview, offer support for a participant during the interview process, or offer answers on behalf of a participant. Concerns have been raised, however, as to whether the responses provided by proxies are reliable and consistent with those that might be given by a self-reporting person [40, 48, 49]. The usefulness

of proxy respondents in ID research has become a research topic in its own right with much of the research occurring in the domain of quality-of-life (QOL) studies [40, 50–54] with varied findings. Concordance between proxy and self-reporting persons has been noted in a number of studies, particularly when measuring with standardized, objective measurements of QOL [51, 52, 54]. On more subjective measures of QOL findings are of less agreement between proxy and self-reporting persons [52]. Andresen et al. [55] report that when measuring health-related quality of life (HRQOL) proxies tended to overestimate the self-reporting person's level of impairment and underestimate their experience of pain.

Studies in the generic literature on self-reporting persons and proxies highlight similar concerns and question the validity of proxy reports [56, 57]. However, as Stancliffe [49] and others highlight there are studies where good agreement between proxy respondents and self-reporting persons have been demonstrated [46, 58, 59]. Within the related methodological debate Magaziner et al. [60] have stressed that inclusion of data from proxy reports has the potential to increase sample size, improve generalizability, and reduce sample bias. The exclusion of the proxies of people with more severe cognitive and communication disabilities may also disenfranchise this group further, lose valuable data, and generate misleading results [61]. Further research on the parameters within which proxy reports increase the potential for inclusion appears warranted. One issue worthy of further consideration in work with people with ID is the closeness of the relationship between the individual and the designated proxy.

The type and nature of relationship, including the level of interaction and the frequency and proximity of the interaction between proxy and self-reporting person, have been found to be particularly important [47, 51] with Mcvilly et al. [51] stating in regards to validity of responses “If proxies are selected on the basis of close and regular contact, it does not seem to matter if they are male or female, co-habiting family members or non-cohabiting support workers.” The length of time an individual is known to the proxy has also been shown to be a critical consideration [62].

Concerns have also been raised about the type of issues proxies are asked to report on. Looking specifically at data on people with ID, there is QOL literature supporting concerns for the validity of proxy responses when questions require subjective appraisals [63]. For example, in comparing proxy and self-report responses on The Choice Questionnaire [64] and the Comprehensive Quality of Life Scale—Intellectual Cognitive Disability (5th ed.) [65], Perry et al. [52] concluded that staff may be adequate proxy respondents when gathering objective data but not when measuring the subjective opinions of the individuals being supported.

Less is known about the validity and reliability of proxy reporting in injury and disease prevention. Given the established relationship between fear of falling and actual falls, as well as the reported high prevalence of falls in people with an ID, establishing the utility of proxy reporting in measuring fear of falls appears warranted. The overall aim of this study, therefore, was the pilot assessment of the reliability of proxy

reporting on a global single-item measure of FOF for use with older people with ID.

2.1. Methods. The study aim was addressed by examining the test-retest reliability among respondents on a global single-item measuring fear of falling (FOF) for use with older people with intellectual disabilities (ID) and to investigate the interrater reliability of FOF responses among self-reporting persons with ID (SRP), their key workers (KW), and additional support workers (ASW) who have supported the individual.

2.2. Participants. A purposive sample was selected of 21 people with ID who had previously participated in Wave 1 of Intellectual Disability Supplement—the Irish Longitudinal Study on Ageing (IDS-TILDA) [66]. IDS-TILDA is a longitudinal study of 753 over-age-40 randomly selected people with ID in the Republic of Ireland. Participants in this pilot study were living or working in a formal care setting, for example, residential campus, community group home, and were supported by keyworkers and support staff. Each of the individuals with ID selected nominated a key worker ($n = 21$) and an additional support staff ($n = 21$) to take part in the study. The following definitions guided selection of participants.

Self-reporting person (SRP): as well as being a member of the IDS-TILDA cohort, a self-reporting person had a mild or moderate ID, had demonstrated in prior interviews good communication skills, and consented to both participate in this additional and to have staff members independently respond on their behalf to the same questions.

Key worker (KW): a key worker (KW) assigned as part of general staffing and consistent with the provider's philosophy of care was either an intellectual disability nurse or a care worker who provided day-to-day support and interacted regularly with the SRP on at least two days per week for at least the previous six months. Most importantly they were identified by the SRP as their KW and the SRP feels comfortable with the designated KW answering questions on their behalf.

Additional support worker (ASW): an additional support worker (ASW) was identified by the SRP as someone who works in the residential/day service of the SRP and has provided some level of support to the SRP and the SRP feels comfortable with the ASW answering questions on their behalf.

2.3. Interview Process

2.3.1. Self-Report Interviews. Face-to-face independent interviews with SRPs, KWs, and ASWs using questions addressing history of falling and fear of falling occurred twice, with an intervening three-day period. "Three days" was chosen to reflect concerns that there was a sufficient period that the assessments were independent but that the period was not so long that there might be a change in the experience of falls that would influence an individual's FOF.

2.4. Measures

2.4.1. Sociodemographic Factors. Age and gender were gathered from all respondents. For SRPs information was also gathered on level of ID and living circumstances and for KWs and ASWs additional data collection addressed length of time working with SRP and their qualifications and job role.

2.4.2. History of Falling. History of falling was included as the presence of FOF tends to be more frequent among fallers [3, 12]. As per the Prevention of Falls Network Europe (PROFANE) guideline [67] fall history was assessed by asking of each SRP, KW, and ASWs if the person with ID had experienced a fall, slip, or trip in which s/he lost his/her balance and landed on the floor or ground or lower level in the past month. Those with a recent fall could suggest the presence of FOF in the individual.

2.5. Fear of Falling. FOF was measured using a global single-item asking the participant if he/she is afraid of falling—yes or no.

SRPs, KWs, and ASWs were then asked

- (1) to rate the degree of FOF the person with ID experiences as either "somewhat afraid" or "very much afraid" of falling
- (2) if they restrict their activities because of their FOF.

All respondents were also given the opportunity to express any comments about the individual's FOF.

2.6. Analyses. Data analysis was conducted using SPSS version 20.0. Descriptive statistics were used to report the demographic data of the 3 different groups. Degree of concordance between T1 and T2 among SRP, KW and ASW responses was examined and a phi coefficient calculated. Cohen's Kappa was used to measure the degree of inter-rater agreement across the 3 groups, that is, between SRP and KW, SRP, and ASW, and between KW and ASW. The classification by Landis and Koch [68] of the Kappa coefficient was used where 0.41 ± 0.60 as "moderate" agreement, 0.61 ± 0.80 as "substantial" agreement, and 0.81 ± 0.99 as "almost perfect" agreement.

3. Results

3.1. Demographics. As can be seen in Table 1, 66.7% of SRPs were female and 33.3% were male with a mean age of 53.5 years (SD 6.34). In terms of ID, 42.9% were in the mild range, 52.4% were in the moderate range, and 4.8% were unable to verify level of ID. With regard to living circumstances, 38.1% of SRPs lived independently/semi-independently, a further 38.1% were living in a community group home, 14.3% lived at home with relatives, and 9.5% were living in residential care.

In relation to KWs and ASWs, 88.1% were female and 11.9% were male. Overall 95.2% of KWs had worked with the SRP for more than 12 months and the remaining 4.8% having worked with them for 6 and 12 months. In the ASW group 90.5% had been working with the SR for more

TABLE 1: Demographic profile of respondents.

	Self-reporting person $n = 21$		Key worker $n = 21$		Additional support worker $n = 21$	
	n	%	n	%	n	%
Gender						
Male	7	33.3	3	14.3	2	9.5
Female	14	66.7	18	85.7	19	90.5
Age	Mean age	St Dev	Mean age	St Dev	Mean age	St Dev
	53.57	± 6.33	34.81	± 8.67	41.33	± 10.77
Length of time working with SR			n	%	n	%
<6 months			0	0	1	4.8
6 and 12 months			1	4.8	1	4.8
>12 months			20	95.2	19	90.5
Job role			n	%	n	%
Staff nurse			6	28.6	0	0
Health care assistant			5	23.8	9	42.9
Trainer/instructor			5	23.8	5	23.8
Manager			3	14.3	6	28.6
Social care worker			1	4.8	0	0
Houseparent			1	4.8	1	4.8

than 12 months, 4.8% had worked between 6 and 12 months, and a further 4.8% worked for less than 6 months.

In relation to roles within the organization 28.6% of KWs worked as staff nurses whereas none of the ASWs were nurses. An additional 23.8% of KWs worked as health care assistants whereas 42.9% of ASWs worked in this role. Managers represented 14.3% of KWs and 28.6% of ASWs; 4.8% of KWs were social care workers while no ASW had this job role. The remaining 4.8% of KWs and 14.8% of ASWs worked as houseparents.

3.2. History of Falling and Fear of Falling. Three SRPs (14.3%) reported a fall in the previous month. In comparison four (19%) of KWs reported that the SRP fell in the previous month and only one ASWs reported the SRP falling in the previous month. On the single FOF item six SRPs (28.6%) experienced FOF, a finding which was identical in the KW group and the ASW group.

Of those reporting an FOF in the SRP group two (40%) were “somewhat afraid” and three (60%) were “very afraid” of falling. One SRP was unable to understand the difference between “somewhat afraid” and “very afraid”. This differed slightly in the KW and ASW findings. Where six KWs (28.6%) said that the SRP was afraid of falling, three (50.0%) were “somewhat afraid” and three (50.0%) were “very afraid”, whereas four ASWs (67%) of ASWs believed the SRP to be “somewhat afraid” of falling and two (33%) said the SRP was “very afraid” of falling.

On the Activity Restriction item three SRPs (60%) confirmed that they limit their activity due to an FOF while two KWs (33.3%) felt the SRP restricted activity due to an FOF and three ASWs group reported that the SRP restricted activities due to an FOF.

3.3. Test Retest Reliability. Using the phi coefficient, it can be seen in Table 2 that test-retest reliability yielded identical concordance (1.00) between T1 and T2 in the SRP group on all of the FOF items and 0.84 on the history of falling item. Within the KW group there were also high levels of test retest concordance on the history of falling (0.86), FOF (0.89), degree of FOF (0.70), and activity restriction item (1.00). For the ASW group test-retest reliability was high for the history of falling and FOF item (1.00) and strong on the degree of FOF (0.64) and the activity restriction item (0.73).

3.4. Interrater Agreement. Inter-rater agreement between the SRP and KW (Table 3) was almost perfect on the history of falling item ($\kappa = 0.829$) and represented substantial agreement on the FOF global item ($\kappa = 0.767$). The Kappa statistic could not be calculated on the Degree of FOF item as the sample size for this item proved too small; however there was 50% agreement between the pairs and there was perfect agreement between SRPs and KWs on the Activity Restriction item ($\kappa = 1.00$).

Inter-rater agreement between the groups of SRPs and ASWs was not as strong. There was moderate agreement between SRPs and ASWs on the history of falling item ($\kappa = 0.462$) and fair agreement emerged on the global FOF item ($\kappa = 0.300$) (Table 4). Inter-rater agreement on the Degree of FOF and the Activity Restriction items could not be calculated due to the small sample size in these items. However, the percentage results showed there was no agreement between the pairs on the Degree of FOF item and 50% agreement on the Activity Restriction item.

Agreement between the groups of workers also varied. Agreement between KWs and ASWs was fair on the history of falling item ($\kappa = 0.351$, $P = 0.035$) (Table 5) and was

TABLE 2: SRP, KW, and ASW concordance between T1 and T2.

	Self-reporting person	Key worker	Additional support worker	Total sample
Did you fall in the last month?				
φ	0.842	0.868	1.000	0.878
n	21	21	21	63
Are you afraid of falling?				
φ	1.000	0.894	1.000	0.963
n	21	21	21	63
Do you feel somewhat or very afraid of falling?				
φ	1.000	0.707	0.645	0.791
n	5	6	7	18
Do you ever limit your activities because of your fear of falling				
φ	1.000	1.000	0.730	0.892
n	5	6	7	18

TABLE 3: Inter-rater agreement between SRP and KW.

	SRP	KW	n	% Agree	Kappa	P value	CI
Did you fall in the last month?							
Yes	3	4	21	95.23	0.829	<0.001	(0.508, 1.15)
No	18	17					
Are you afraid of falling?							
Yes	6	6	21	90.48	0.767	<0.001	(0.46, 1.07)
No	15	15					
Do you feel somewhat or very afraid of falling?							
Somewhat	2	3	4	50.00	*	*	*
Very afraid	3	3					
Do you ever limit your activities because of your fear of falling?							
Yes	3	2	4	100.00	1.00	0.046	(1.00, 1.00)
No	2	4					

n = valid observations for Kappa.

*Kappa could not be calculated accurately due to small sample size.

not significant. The FOF item found moderate agreement between the two groups ($\kappa = 0.533, P = 0.015$) and was not significant. There was disagreement on the Degree of FOF item between the groups ($\kappa = -0.500$). Again, the Kappa coefficient analysis could not be performed on the Activity Restriction item due to the small sample size; however there was 50% agreement between the two groups on this item.

4. Discussion

In this study we set out to examine the test-retest reliability of a single-item global screening measure for use with people with ID. We also explored inter-rater agreement between self-reporting people with ID, their nominated proxies, and additional support workers.

The sample size within each group was small and certainly presents a challenge if we seek to generalize from these findings. There is scope to repeat this study with a larger sample and to investigate individual proxy factors that may

influence responses. Notwithstanding the limitation of small sample size we have evidence that a global screening item measuring FOF has excellent test-retest reliability for self-reporting people with ID, their key workers, and additional support workers. This is consistent with previous studies of the global screening FOF item in the general population [26, 30]. As well as the global screening item, we found that people with ID who self-reported were consistent in their responses to the degree of FOF they experienced and their activity restriction due to FOF. This is also supported, by previous research that people with ID can be reliable sources of information in research studies [37–39]. Use of a global item as a general screening measure with people with ID is therefore supported, but where FOF appears present in individuals with ID further assessment is recommended. Completing assessments is challenging as measurement tools for FOF have only been validated in the general population [24, 26, 27, 69]; further work is necessary to examine the validity and reliability of these tools for use in this population including further attention to the value of proxy responses.

TABLE 4: Interrater agreement between SRP and ASW.

	SRP	ASW	<i>n</i>	% Agree	Kappa	<i>P</i> value	CI
Did you fall in the last month?							
Yes	3	1	21	90.48	0.462	0.012	(-0.137, 1.06)
No	18	20					
Are you afraid of falling?							
Yes	6	6	21	71.43	0.300	0.169	(-0.14, 0.74)
No	15	15					
Do you feel somewhat or very afraid of falling?							
Somewhat	2	4	2	0.00	*	*	*
Very afraid	3	2					
Do you ever limit your activities because of your fear of falling?							
Yes	3	3	2	50.00	*	*	*
No	2	3					

*Kappa could not be calculated accurately due to small sample size.

TABLE 5: Inter rater agreement between KW and ASW.

	KW	ASW	<i>n</i>	% Agree	Kappa	<i>P</i> value	CI
Did you fall in the last month?							
Yes	4	1	21	85.71	0.351	0.035	(-0.166, 0.868)
No	17	20					
Are you afraid of falling?							
Yes	6	6	21	80.95	0.533	0.015	(0.13, 0.93)
No	15	15					
Do you feel somewhat or very afraid of falling?							
Somewhat	3	4	4	25.00	0.500	0.248	(-1.24, 0.24)
Very afraid	3	2					
Do you ever limit your activities because of your fear of falling?							
Yes	2	3	4	50.00	*	*	*
No	4	3					

*Kappa could not be calculated accurately due to small sample size.

Good concordance was found in this study on SRP and KW responses on FOF. It can be argued that FOF items have observable characteristics and therefore the concept may lend itself more favorably to objective measurement. This supports previous findings on concordance between SRPs and proxies on objectively measured quality-of-life measures [51, 52, 54]. However, agreement between SRPs and proxy was weaker on the degree of FOF. This is most likely because degree of FOF is a more subjective experience. This finding supports previous reports of less agreement between proxy and SRP on subjective measures of QOL [52, 55].

Findings from this study also support the importance of choosing the “right” proxy for research studies [47, 62] and provide some guidance to improve the reliability of data collected by proxy suggesting that the person with the most frequent day-to-day contact and intimate relationship with the person with ID is the one who participates. The strong agreement between SRPs and KWs suggests that the service provider approach of assigning a KW for each individual with ID is one that both supports a person-centered approach and leads to good awareness and understanding of each individual. In addition KWs hold the promise of meeting criteria for

improving reliability in proxy responses previously identified by [47, 51, 62]. Clearly the study had a small sample size and further investigation is warranted with larger samples. Despite this limitation, the success in recruiting suitable samples is noteworthy and demonstrates that while it may be difficult to identify KWs with whom people with ID are in contact with on a daily basis it is possible and the less strong concordance found with responses from ASWs emphasizes the criticalness of such success.

4.1. Limitations. The findings are based on a small number of individuals reporting FOF. Caution is recommended in generalizing these results both to the wider population of people with ID and to use of proxy respondents in general. However, larger-scale studies informed by this data will help provide more conclusive data. There are also challenges still to be addressed in understanding the quality of measures of fear of falling particularly for those with severe and profound ID. These issues must also be addressed in future studies.

Although this study was rigorous in identifying the most reliable proxy, it did not measure the influence of the frequency of contact, the level of interaction, or the proximity

between each proxy and the SRP on proxy responses. Such data would clearly add to our knowledge about suitable proxies in research studies. The authors recommend the inclusion of these elements in any future study of proxy responses. Nevertheless, this study has identified that a thorough approach in choosing the right proxy can help yield reliable data.

FOF in people with ID has not received the scrutiny it merits. Limitations notwithstanding, this study may also be a starting point for service providers and health care professionals to begin to think about FOF as an important factor influencing the quality of life of people with ID.

In conclusion, the findings from this study suggest that a global single-item measure of FOF is suitable for use with people with ID and that proxies if carefully selected can provide consistent and reliable reports of the presence of FOF in people with ID. This is important given the high prevalence of falls in people with ID and the established association between fear of falling and actual incidence of falls reported in the generic population. In addition, this study lends support to previous findings that proxies may not be suitable to report more subjective aspects of FOF.

Given that screening for FOF proved possible, further work is now warranted to validate FOF scales for use with people with ID.

Ethical Approval

IDS-TILDA and its related studies were reviewed and approved by the Faculty of Health Sciences Ethic Committee at Trinity College Dublin.

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