Introduction

Measurement is fundamental to research. Research can be hampered by the lack of suitable assessment instruments, especially in relation to newer research topics such as people with intellectual disability (ID) and end-of-life (EOL) issues. This paper reports on three instruments used to assess adults with ID on issues related to EOL.

Concerns Related to Self-Report Assessments on End of Life for Adults with Intellectual Disability

Evaluation of any assessment must deal with reliability and validity, but for adults with ID and EOL~~,~~ there are additional concerns. These are (a) the cognitive and communication needs of this group, and (b) the sensitive nature of the topic. In part, both issues can be evaluated by monitoring missing data due to (a) inability to understand or answer assessment questions, or (b) because the person finds the topic too confronting, is unwilling to answer (some) questions, and may even withdraw from the assessment process. Researchers have an ethical responsibility to actively ensure that participants know they can withdraw at any time, and to monitor and report any adverse events.

Cognitive and communication needs. Assessing knowledge, understanding, or internal emotional states such as fear involves asking the individual to self-report. Instruments are designed to meet the cognitive and communication needs of people with ID, typically through simplified item wording and easier response options (Finlay & Lyons, 2001; Stancliffe, Wilson, Bigby, Balandin, & Craig, 2014).

Researchers have identified desirable linguistic and other features that make questions easier to understand and respond to by people with ID. These include avoiding negative wording and the passive tense; using simple sentences; keeping meaning and vocabulary simple and clear; avoiding uncommon or technical terms; using pictures of concrete concepts to increase understanding and responsiveness; using concrete examples when asking about abstract concepts; and employing simple response scales (Fang et al., 2011; Finlay & Lyons, 2001). One approach to quantifying comprehensibility is to use

readability statistics (Stancliffe et al., 2014). Velez and Ashworth (2007) proposed using readability formulas when designing and testing questionnaires. When interviewing people with ID about sensitive or taboo content, Finlay and Lyons (2001) recommended use of vignettes and/or asking what other people would do.

Using mainstream instruments without modification often presents difficulties for adults with ID with understanding questions and communicating answers (Finlay & Lyons, 2001; Stancliffe et al., 2014), and can result in much missing data, preventing people with ID the from expressing their views, and creating difficulties for researchers because of data loss (Stancliffe et al., 2014). Therefore, evaluation of self-report assessments for people with ID should include analysis of missing data, to help identify how appropriate the instrument is for this population (Stancliffe et al., 2014).

These issues have led to the creation of many ID-specific instruments (Finlay & Lyons, 2001). However, instrument development should not take place in a vacuum. Where possible, ID researchers should build on available mainstream knowledge and instruments. Thus, it is common practice to adapt existing mainstream assessments and to test the modified versions for usability, reliability and validity when assessing people with ID.

Sensitivity of the topic. EOL is a sensitive, even taboo topic often avoided by caregivers out of concern that the person with ID will become upset (Kirkendall et al., 2016; Todd, 2004, 2013; Wiese, Stancliffe, Read, Jeltes, & Clayton, 2015). Such concerns raise the question of whether people with ID would be willing to talk about these issues or instead find them too distressing.

The appropriateness of these concerns has not been evaluated directly by researchers, although indirect evidence suggests that such worries may be overstated. Becoming upset is a normal response to discussing dying and death. That said, Tuffrey-Wijne, Bernal, Butler, Hollins, and Curfs (2007) noted that adults with mild or moderate ID “relished the opportunity” (p. 85) to discuss EOL issues. McEvoy,

MacHale, and Tierney (2012) interviewed adults with ID about death and reported that "No person chose to end the interview…. subsequent follow-up with staff indicated no evidence of ill effects from the interview process" (p. 195). Until recently, dying and death were rarely considered by ID researchers (Todd, 2003), so some basic instruments for EOL research have yet to be developed.

Guscia et al. (2006) noted that "other factors also require consideration in establishing an instrument's suitability …; for example, completion time, assessor training requirements, ease of administration" (p. 154). There is also the issue of instrument content acceptability to participants. Withdrawal provides one indication that the content may be unacceptable. We will also briefly comment on these issues in our evaluation of EOL assessments.

The Current Study

This study examined three instruments, (a) the Concept of Death Questionnaire (CODQ) (McEvoy et al., 2012), (b) the End-of-Life Planning Scale (EOLPS) (Wiese, Stancliffe, Clayton, Read, & Jeltes, 2014), and (c) a revised version of the Collett-Lester Fear of Death Scale, version 3.0 (FODS3.0)(Lester, & Abdel-Khalek, 2003). Each was used with a sample of adults with ID and a sample of disability support staff. Assessment findings and group comparisons, involving the same participants as the current paper, are ~~paper~~ reported in a companion paper (Stancliffe, Wiese, Read, Jeltes, & Clayton, 2016). The current paper examines the development and psychometric characteristics of these instruments.

Because measurement approaches are still developing, we needed to adopt somewhat different instrument-development approaches to the three EOL areas.

Concept of death. Given the availability of the CODQ (McEvoy, et al., 2012), we undertook the first independent psychometric evaluation of this instrument.

End-of-life planning. There was no available EOL-planning assessment, so we developed a new ID-specific instrument, the EOLPS (Wiese et al., 2014). This paper reports on the development and psychometric evaluation of this instrument.

Fear of death. We adapted a mainstream assessment, the FODS3.0 (Lester & Abdel-Khalek, 2003) to measure fear of death by people with ID. Here, we report the process of adaptation and the results of psychometric evaluation.

Details of pilot testing procedures, instrument development and modification are set out in the Method section. The Results section contains the psychometric findings.

Method

Our study had two parts. Part 1 involved developing or modifying the instruments, pilot testing and refinement. In Part 2, the final versions were used with adults with ID and disability staff to evaluate each instrument's psychometric properties (reported in the current paper) and to evaluate participants' substantive responses (see Stancliffe et al., 2016). To help with continuity, we present the Part 1 method and results, followed by the Part 2 method and results.

Advisory group. A project advisory group ~~The group~~ provided feedback and advice about the instruments used in the current study. ~~consisted of~~This group consisted of a disability service manager, a self-advocate with ID, a parent of an adult child with ID, a palliative pastoral-care coordinator, a clinical nurse consultant (advance care planning), a senior intensive-care specialist, a senior academic lawyer, and the four Sydney-based authors (RJS, MYW, GJ and JMC). All had expertise in aspects of EOL. ~~The group provided feedback and advice about the instruments used in the current study.~~

Ethics

We obtained University of Sydney (no. 2014/061) ethics approval. Written consent was given by all participants.

Part 1 Method: Instrument Development and Pilot Testing

Here we describe the development and pilot testing of the three instruments. Brief descriptions of the final versions of each are presented in the Part 2 section of the Method.

The authors had extensive EOL experience to inform instrument development, including ID-specific EOL research (RJS, MYW, SR), EOL service delivery to adults with ID (GJ), and palliative care research and clinical palliative experience with the general population (JMC). This combined experience helped us to develop relevant, easy-to-understand content and assessment procedures, appropriate to people with ID.

Part 1 Participants

Eleven people with ID (~~7~~ seven men, four~~4~~ women) and two disability staff (both women) from two disability services in Sydney, Australia participated. Inclusion criteria were: 21+ years, no known terminal diagnosis, and able to self-consent to participation. Disability staff were permanently employed. Pilot participants were not involved in Part 2.

Part 1 Procedure

Every participant did not necessarily complete all three instruments. Some chose to stop part way due to fatigue or comprehension difficulties (particularly with early versions of some instruments), personal choice, or time constraints. To minimise literacy and comprehension difficulties, each instrument was administered via a personal interview, with the interviewer reading the questions aloud and recording the answers. Authors RJS and MYW administered all assessments.

Part 1 Instrument Development and Pilot Testing

Concept of Death Questionnaire (CODQ).

The CODQ (McEvoy et al., 2012) was designed for people with ID, so we hoped to use it unchanged. Our pilot testing with five participants with ID and two staff revealed that the CODQ worked satisfactorily, so no changes were made.

End-of-Life Planning Scale (EOLPS)

We created the End-of-Life Planning Scale (EOLPS) (Wiese et al., 2014) specifically for people with ID. The initial draft EOLPS was revised twice following review and discussion among several authors. It was then reviewed twice by the advisory group and further extensive changes made. Following additional refinement by the authors, pilot testing began (described below).

EOLPS subscales. Seven subscales were developed, based on the seven EOL planning content areas identified by Wiese (2014). Within each subscale, our key interest was whether people with ID understood that they could make that type of EOL decision for themselves (e.g., bequeathing), and whether they could outline a simple plan to ensure their EOL wishes were known, so EOLPS questions address these issues. ~~Like the CODQ (McEvoy et al., 2012), question format was consistent from one EOLPS subscale to the next.~~

EOLPS vignettes. Each section of the CODQ (McEvoy et al., 2012) involved a short EOL vignette about a named fictional individual, followed by a consistent series of questions about the vignette. McEvoy et al.'s (2012) findings and our pilot testing showed that this approach worked well for people with ID, so we emulated this structure for the EOLPS. We added one or two photos to each vignette to depict key terms or situations (e.g., a photo of a ring in the bequeathing vignette about leaving the ring to a friend). Finlay and Lyons (2001) noted that pictures can increase understanding and responsiveness when interviewing people with ID. Pictures provide a concrete representation of aspects of the vignette and may reduce the memory load of verbally-presented vignettes. Pictures about EOL have been used successfully with adults with ID (Tuffrey-Wijne et al., 2007).

In wording each EOLPS vignette, we used simple words and short sentences to maximise understanding. In addition to expert review, we used readability statistics to assess ease of understanding and to check that wording modifications improved readability.

Scoring. We used a three-point scoring system simple enough for people with ID to communicate different responses (cf Stancliffe & Parmenter, 1999). Fang et al. (2011) found that adults with ID respond more consistently to a 3-point response scale than a 5-point scale. To accommodate the limited vocabulary of many people with ID, there was no scoring requirement for use of technical terms like "advance care planning" when answering EOLPS questions.

EOLPS pilot testing. The EOLPS was piloted with eight adults with ID over multiple separate sessions with refinements between sessions. Some sessions involved one researcher administering the EOLPS and another observing. Sometimes a disability staff member was also present and provided feedback. Pilot testing resulted in multiple revisions of vignette and question content and wording, changes of pictures, and refinement of item scoring.

Fear of Death Scale

Initial review of the FODS3.0 revealed multiple limitations for use with adults with ID, so we modified it to create the FODS3.0-ID. We retained the item content and factor structure of the FODS3.0, but changed the order of presentation of the factors, item wording, response scale, and mode of administration and responding. These changes arose initially from review and discussion among the researchers and by the advisory group, followed by pilot testing and further refinement.

Order of factors. The FODS3.0 presents the four 7-item factors in the order: own death, own dying, death of others, and dying of others. We changed the order to have dying precede death (as it does in real life), and others' dying and death administered before one's own, as it is easier to start with a situation for others and presumably is less confronting than contemplating one's own demise. The order of the items within each subscale was unchanged.

Item wording. The Flesch Reading-Ease Test (Flesch, 1948) readability score was 67.3 (U.S. 8th grade) for the FODS3.0 items, underlining likely comprehension difficulties. We simplified the wording for 26 of the 28 of items. Two items were unchanged and two others had very minor changes of one or two words. Major wording changes were made to simplify most other items. For example, the FODS3.0 item "Being reminded that you are going to go through the experience also one day" was changed to "Being reminded that one day you will die too". We made the questions shorter – FODS3.0 items had 35% more words than FODS3.0-ID items. We altered long, complex or unfamiliar words. For example, the FODS3.0 item "Watching the deterioration of the person's mental abilities" was changed to "Watching the person's mind get sicker".

Response scale. The FODS3.0 has a 5-point Likert response scale. We changed the FODS3.0-ID to a 3-point scale (Fang et al., 2011).

Responding. Among the general community, FODS3.0 respondents circle a number between 1 and 5 to indicate "How disturbed or made anxious" they are about each item (Lester & Abdel-Khalek, 2003, p. 84). Based on Cuskelly, Moni, Lloyd, and Jobling (2013), we developed a 3-point visual response scale (a "concrete referent") for the FODS3.0-ID. This also enabled participants to respond by pointing if desired. This card depicted three vertical ~~adjoining~~ shaded small, medium and large bars, corresponding to the FODS3.0-ID responses *"Not frightened", "A bit frightened", and "Very frightened".* These words were printed below the relevant bar. Before asking the first question, the card was placed in front of the participant and explained.

FODS3.0-ID Pilot testing. Because of recruitment delays and logistical difficulties, we only piloted the FODS3.0 with one participant with ID and two staff. Methodologically, piloting was similar to the EOLPS, and led to successive additional changes, mostly refinement of question wording.

Part 1 Results: Pilot Testing

Characteristics of the Final Instruments

Based on readability scores using the Flesch Reading-Ease Test (Flesch, 1948), and item-difficulty characteristics noted by Finlay and Lyons (2001), we documented the difficulty of the CODQ, EOLPS and FODS3.0-ID in Table 1. Flesch scores of 90-100 are considered very easy to read (a U.S. 5th grade level). Scores of 80-90 equate to easy reading (6th grade) and of 70-80 indicate fairly easy reading (7th grade).

TABLE 1

Part 2 Method: Psychometric Evaluation

Part 2 Participants

Participants were 39 adults with ID and 40 disability staff. They came from five disability services providing sheltered employment and/or community living to adults with ID. Inclusion criteria for all participants were the same as Part 1.

Participants with ID. Participants with ID averaged 48.62 (*SD* = 11.55) years. There were 25 men and 14 women. Based on agency records or staff report, level of ID ranged from mild (*n*=26) to moderate (*n*=12) (1 missing). Many had additional disability diagnoses, the most common being psychiatric disability (*n*=16), and epilepsy (*n*=8).

Overall 17 people lived alone, 11 lived with others with disability, and 11 lived with others without disability (e.g., family). The 20 participants with ID with drop-in staffing ~~support~~ received weekly staff support on an average of 2.8 days for an average total of 9.7 hours. Only five people had paid support overnight (all had sleepover staffing). Some 28 people were employed, 23 in sheltered employment and 5 in mainstream jobs.

Only one person with ID had received professional bereavement support (counsellor), and none reported having EOL training. Almost all had experienced the death of others (e.g., family, friend), with only two people (5%) reporting no such experience.

Disability staff. Staff participants (31 direct-support workers, 9 managers; 13 men and 27 women) had worked in disability for an average of 7.6 years, and in their current position for 4.6 years. Mean age was 41.60 (*SD* = 12.40) years. Half (*n*=20) had completed a technical-college qualification, and a further 15 had a university degree. Most (*n*=32) had received no EOL training. Most with such training (*n*=7) had done a short course. All staff participants had experienced the death of others, and 27 had experienced the death of a person with ID.

Part 2 Procedure

All instruments were administered by one of the first two authors (RJS or MYW). All three EOL instruments were administered individually, with the interviewer reading aloud the vignettes (if applicable) and the questions. Repetition and paraphrasing questions to aid understanding were permitted. The interviewer scored the person's response to each question, using verbal probes as needed to clarify answers and maximise accurate scoring. For each EOLPS item, the interviewer placed a single sheet in front of the interviewee which showed the photo(s) for that item with the vignette printed below. During the FODS3.0-ID, the concrete referent was placed in front of each interviewee and explained, so interviewees could point to an answer if they wished. The CODQ was always asked first, followed by the EOLPS, then the FODS3.0-ID. The fixed presentation order for these three assessments was based on a two-part rationale. Firstly, we were concerned that asking about fear of death before anything else could risk inducing fear on subsequent instruments (hence FODS3.0-ID was assessed last). Secondly, it was a natural progression to ask about understanding death (CODQ) before questions about end-of-life planning (EOLPS).

Within each instrument, the items were presented in the same order, except for the CODQ, where we used a random vignette order as specified by McEvoy et al. (2012). All participants were periodically asked how they were coping and if they wanted to stop, especially if there were indications of discomfort.

Instruments

Concept of Death Questionnaire

The CODQ (McEvoy et al., 2012) assesses understanding of the five components of death (Causality, Finality, Non-functionality, Universality, and Inevitability). Most items relate to three vignettes. For example, one vignette states "Sheila's Mother is very ill in hospital. One day Sheila is told her mother is dead." The interviewer reads each vignette aloud then asks the same four questions. With 13 items, CODQ total scores can range from 0 to26. The CODQ has α=.75 for total CODQ scores and inter-rater agreement of r_s=.87, with an average 79.8% agreement (McEvoy et al., 2012).

End-of-Life Planning Scale

The EOLPS has seven subscales: (1) Bequeathing, (2) Preferred place of care, (3) Funeral wishes, (4) Preferred carers, (5) Advance care planning, (6) Things to take with me, and (7) Organ donation. Each subscale starts with a vignette read aloud by the interviewer. For example, the *Bequeathing* vignette says "Nina has a pretty ring. Her best friend Jill loves it. Nina thinks it would be nice if Jill could have the ring after Nina dies" and has a colour photo of a ring and a separate photo of a woman (Nina) looking pensive.

Each subscale has three questions. Each is scored 0-2, so subscale totals range from 0-6. With 21 items, EOLPS total scores range from 0-42. Question wording varies from one subscale to the next to match the vignette content, but the meaning of each question is consistent across each subscale.

Question 1 asks "Who decides if …". For the *Bequeathing* subscale this question continues "who will get Nina's ring after Nina dies?" *Question 2* asks if the person *could* decide. *Question 3* asks what the person can do *now* (i.e., while alive and well) to ensure their wish is known. There is no requirement to use technical words such as "will", so long as the person can explain in basic terms what is planned.

Zero is scored for any EOLPS question with no response, an unintelligible or irrelevant answer. The reason for this approach is that if the person cannot answer clearly ~~response~~ they are probably not able to exercise their right to decide or to generate and convey their EOL plan.

Fear of Death Scale3.0-ID

The FODS3.0-ID (Wiese et al., 2014) contains 28 items in four 7-item factors: (a) others' dying, (b) others' death, (c) your own dying, and (d) your own death. Questions ask "How frightened are you of …". The 3-point response scale, 1 (not frightened), 2 (a bit frightened), and 3 (very frightened), is supported by a 3-point pictorial concrete-referent scale. Pointing is an acceptable response. Each 7-item factor has a total score ranging from 7-21. FODS3.0-ID total scores range from 28-84.

Scoring of nonresponses. Nonresponses (or irrelevant, unintelligible or "don't know" responses) provide no basis to determine the degree of fear, so we treated FODS3.0-ID nonresponses as missing data~~-~~.

~~Results~~

~~Part 1 Pilot Testing~~

~~Characteristics of the Final Instruments~~

~~Based on readability scores using the Flesch Reading-Ease Test (Flesch, 1948), and item-difficulty characteristics noted by Finlay and Lyons (2001), we documented the difficulty of the CODQ, EOLPS and FODS3.0-ID in Table 1. Flesch scores of 90-100 are considered very easy to read (a U.S. 5th grade level). Scores of 80-90 equate to easy reading (6th grade) and of 70-80 indicate fairly easy reading (7th grade).~~

~~TABLE 1~~

~~Administration time~~

~~We did not record administration time for each instrument, but the time to complete all three instruments with participants with ID was 20-30 minutes. This suggests typical administration time for each instrument is 7-10 minutes.~~

Part 2 Results: Psychometric Evaluation

Administration ~~t~~Time

We did not record administration time for each instrument, but the time to complete all three instruments with participants with ID was 20-30 minutes. This suggests typical administration time for each instrument is 7-10 minutes.

Missing Data

To evaluate missing data, we needed to (a) identify who withdrew and at what point, and (b) distinguish between questions not asked (because the person had withdrawn) and questions that were asked but no scoreable response was given.

Withdrawal

The number of participants with ID who withdrew before or during each of the three assessments is shown in Figure 1. One staff member withdrew, at the start of the FOD3.0-ID. As noted, assessments were presented in a fixed order – CODQ, EOLPS then FODS3.0-ID – so withdrawal usually also meant subsequent instruments were not administered. Significantly more participants with ID (*n*=9, 23.1%) withdrew from one or more EOL assessments than staff (*n*=1, 2.5%), $\chi^2 = 9.54$, $N = 79$, $df = 1$, $p < .01$.

FIGURE 1

With only one staff member withdrawing from a single instrument (FODS3.0-ID), it seems that all three assessments were acceptable to this group and did not result in significant discomfort. For participants with ID, only one person (2.6%) withdrew from CODQ assessment, suggesting good acceptability. Excluding those who were not assessed due to withdrawal from an instrument administered earlier, four (10.3%) participants with ID withdrew from the EOLPS and five (12.8%) withdrew from the FODS3.0-ID.

Reasons for withdrawal. Participants with ID's stated reasons for withdrawal were mostly about perceived discomfort with instrument content. Some simply agreed with the interviewer's invitation to stop, but gave no reason for withdrawal. We immediately supported their request, but did not probe further for the exact reasons for withdrawing. Others offered unclear reasons - one participant said "Want to stop". This could be seen as wishing not to discuss death, or that participation was too tiring. Others explained their reasons. One person with ID said "If it's death, I don't want to think about it" and commented that she did not like the EOLPS photos.

Responses to interviewer's offer to stop. We did not record interviewer prompts about stopping, but are confident that *every* participant was offered the opportunity at least once (usually several times). Only ~~9~~ nine participants with ID (23%) withdrew, and only ~~1~~ one (2.6%) declined to respond to any EOL assessment items. Only ~~1~~ one staff participant (2.5%) withdrew. Most participants in both groups declined the offer to stop and chose to continue. In a few cases, after choosing to continue, a

person with ID persisted with several items before then stopping. We propose that the procedures were effective in empowering participants in both groups to stop the assessment if they wished. The absence of adverse events provides further evidence that participants made appropriate judgements about withdrawal.

Psychometric Findings

Concept of Death Questionnaire

CODQ internal consistency. Our findings for Chronbach's alpha are shown in Table 2.

CODQ ~~construct validity~~reliability: Table 2 reports correlations between the five CODQ component scores and CODQ total scores. Because most scores had non-normal distributions, we used Spearman correlation. Lack of variance in staff scores meant that correlations could not be calculated.

TABLE 2

CODQ inter-rater reliability. Inter-rater reliability was evaluated for ~~8~~ eight participants (~~5~~ five with ID, ~~3~~three staff) by having a second rater sit in during each person's interview and independently score responses. There was 100% agreement on scoring for every CODQ item and for CODQ total scores. The correlation between raters on CODQ total scores for all ~~8~~ eight participants and for participants with ID was r_s=1.00. Correlations for staff could not be calculated because of non-existent variance (all ~~3~~ three scored at the scale maximum).

End-of-Life Planning Scale

EOLPS internal consistency. Table ~~3~~ 2 shows the findings on internal consistency.

~~TABLE 3~~

EOLPS ~~construct validity~~reliability: Table ~~3~~ 2 presents Spearman correlations between the seven EOLPS subscale scores and EOLPS total scores. Because of lack of variance in staff scores, several correlations could not be calculated.

EOLPS inter-rater reliability. Inter-rater reliability was evaluated in the same manner as the *CODQ*. Table ~~4~~ 3 shows EOLPS inter-rater agreement findings.

TABLE ~~4~~3

Fear of Death Scale 3.0-ID

Missing data imputation. As noted, no response to an FODS3.0-ID item was scored as missing. Where up to ~~2~~ two of the ~~7~~ seven items were missing in a factor, we imputed the missing value to equal the mean of non-missing scores for that factor. More than two missing items was considered too much for a factor score to be calculated. FODS3.0-ID total scores were the sum of the four imputed factor scores.

Internal consistency of FODS3.0-ID. The internal consistency results are presented in Table ~~5~~2.

~~TABLE 5~~

FODS3.0-ID ~~construct validity~~reliability: Table ~~5~~ 2 shows the Spearman correlations between the four FODS3.0-ID factor scores and FODS3.0-ID total scores.

FODS3.0-ID inter-rater reliability. FODS3.0-ID inter-rater reliability was evaluated identically to preceding instruments and is shown in Table ~~6~~3.

~~TABLE 6~~3

Nonresponses to FODS3.0-ID items. When CODQ and EOLPS questions are asked, nonresponses (no response, don't know, irrelevant or unintelligible responses) were assigned a substantive score, a score of zero indicating lack of knowledge. FODS3.0-ID nonresponses were scored as missing and so could affect factor scores and total scores. It is therefore important to examine the missing FODS3.0-ID data to see how many participants had missing FODS3.0-ID factor scores and total scores due to nonresponding and, if relevant, identify problematic items.

There were no disability-staff nonresponses to FODS3.0-ID items. For participants with ID, there were 17 instances of nonresponding, or 1.9% of all FODS3.0-ID questions asked, suggesting this was a

minor issue. Moreover, 11 of these nonresponses came from a single respondent, so that participant had only 2 of the 4 FODS3.0-ID factor scores available, with the total FODS3.0-ID also missing. This participant was the only person with FODS3.0-ID factor scores or total score unavailable due to nonresponding. Of the other ~~5~~ five participants with ID with nonresponses, ~~4~~ four had only one nonresponse and ~~1~~ one had two nonresponses. Based on FODS3.0-ID scoring rules, these missing items were imputed, so all five participants had all their FODS3.0-ID factor scores and total score available for analysis.

At the item level, 14 (50%) of FODS3.0-ID items had between ~~1~~ one and ~~3~~ three participants provide nonresponses, but for 10 items this involved a single nonresponse. Items 11, 13 and 14 had ~~2~~ two nonresponses and item 26 had ~~3~~ three (9.7% of participants with ID who were asked this question). These findings suggest no notable comprehension problems with individual items.

Discussion

This study shows that people with ID can complete assessments about EOL issues. The three assessments have acceptable to excellent reliability, with evidence of several forms of validity. There were no adverse events. Compared to disability staff, more people with ID withdrew, suggesting that more people with ID experienced fatigue and/or discomfort. Any discomfort was managed effectively through offering participants the opportunity to withdraw from assessment, together with routine emotional support.

We discuss each instrument separately, followed by examination of general issues, limitations and conclusions. Because the main focus was on use of these instruments with people with ID, we devote little attention to disability staff findings.

Concept of Death Questionnaire

Comprehensibility. Using a Flesch Reading-Ease Test score of 80 or above as an indicator of easy comprehensibility, the CODQ vignettes were easy to understand (Table 1). Although the CODQ questions had somewhat lower readability scores, they were sufficiently comprehensible for people with ID to be able to answer. That said, both assessors reported a need to paraphrase CODQ question 2 from "What can Sheila's mother do now that she is not living anymore?" to "What can Sheila's mother do now that she is dead?"

Reliability. Streiner and Norman (1995) proposed that Cronbach's alpha of 0.5 -0.7 shows acceptable internal consistency, 0.7-0.9 good, and above 0.9 excellent. For total CODQ scores for individuals with ID, McEvoy et al. (2012) reported α=.75, and we found α=.80, showing that the CODQ has good internal consistency. CODQ component scores also had good internal consistency except for Cessation. CODQ inter-rater agreement was excellent. Other evidence of reliability came from ~~Evidence of construct validity came from~~ correlations between CODQ component scores and total scores that ranged from .21-.82 and averaged .51 for participants with ID.

Validity. ~~Evidence of construct validity came from correlations between CODQ component scores and total scores that ranged from .21-.82 and averaged .51 for participants with ID.~~ Stancliffe et al. (2016) and McEvoy et al. (2012) found that participants with mild ID scored higher on the CODQ than those with moderate ID, indicating better understanding. Further, Stancliffe et al. (2016) found that disability staff had higher CODQ scores than participants with ID. These findings provide evidence of criterion-related validity, because these groups are expected to differ on an assessment of understanding.

Staff data. Almost all staff scored at the CODQ scale maximum (Stancliffe et al., 2016), so it was ~~mostly~~ not possible to calculate alpha or ~~component~~subscale:total correlations for staff, except ~~for~~ alpha for the finality component and ~~for~~ CODQ total scores.

With cautions about the reliability ~~and construct validity~~ of some CODQ component scores, available data show that this instrument is a valid and reliable instrument for assessing understanding of death by adults with ID. The independent psychometric data from the current study, complementing McEvoy et al.'s (2012) findings, strengthen this conclusion.

End-of-Life Planning Scale

To our knowledge the EOLPS is the first instrument for adults with ID to assess understanding and self-determination about EOL planning.

Comprehensibility. Readability scores for EOLPS vignettes and questions suggested they were easy to understand (Table 1). All participants looked at the photos for each item, and many individuals with ID pointed at or commented on the photos. We took no data on the role of photos in aiding comprehension, but anecdotally they appeared helpful, although one person commented that she did not like looking at these photos.

Reliability. For adults with ID, internal consistency was excellent for the EOLPS total scores (α=.91) and acceptable for five of the seven EOLPS subscales (.56-.67, Table ~~3~~2). However, two subscales (Bequeathing, Carers) had unsatisfactory internal consistency (.32 and .48 respectively), so it seems prudent to treat these scores with caution. ~~Construct validity~~Reliability was clearly demonstrated with high correlations between all EOLPS subscales scores and total scores for the full sample (.87-.94, mean=.90) and the ID sample (.77-.89, mean=.82). Inter-rater agreement was excellent for six subscales, and acceptable for Bequeathing.

Validity. ~~Construct validity was clearly demonstrated with high correlations between all EOLPS subscales scores and total scores for the full sample (.87-.94, mean=.90) and the ID sample (.77-.89, mean=.82).~~ Evidence for face and content validity came from several sources. Firstly, the seven EOLPS domains were based on multiple interviews and focus groups with community living staff who supported adults with ID, many of whom had experienced the death of a client with ID (Wiese, 2014).

Secondly, the EOLPS was reviewed in detail by the expert advisory group and subject to careful pilot testing. Evidence for criterion validity arises from Stancliffe et al.'s (2016) findings that (a) participants with mild ID had significantly higher EOLPS scores than those with moderate ID, and (b) disability staff had much high EOLPS scores than adults with ID. These group differences are each in the expected direction.

Staff data. Because of a ceiling effect for many staff (Stancliffe et al., 2016), alpha and subscale:total correlations for staff were often unable to be calculated.

In conclusion, the EOLPS has acceptable to excellent reliability, with evidence of several forms of validity.

Fear of Death Scale 3.0-ID

Comprehensibility. The readability score indicated that FODS3.0-ID questions were easy to understand. This conclusion was supported by very low levels of nonresponding to FODS3.0-ID items.

Reliability. Internal consistency of the original FOD3.0 instrument is well established with the general population (Lester & Abdel-Khalek, 2003). For adults with ID and for disability staff, FODS3.0-ID internal consistency was excellent for total scores and good for each of the four factors. For participants with ID, correlations between FODS3.0-ID factor scores and the total score ranged from .79-.90 (mean=.86), providing ~~clear~~ further evidence of ~~construct validity~~reliability. FODS3.0-ID inter-rater agreement was excellent.

Validity. Basing the FODS3.0-ID closely on an existing, well-researched fear-of-death instrument provides evidence of content validity. ~~For participants with ID, correlations between FODS3.0-ID factor scores and the total score ranged from .79-.90 (mean=.86), providing clear evidence of construct validity.~~ Compared to disability staff, Stancliffe et al. (2016) reported that adults with ID had significantly higher FODS3.0-ID scores, indicating more fear. This result provides evidence of criterion-

related validity, because research on fears generally (not fear of death) shows individuals with ID are more fearful than people without ID (Duff et al., 1981; Gullone, Cummins, & King, 1996).

Staff data. Psychometric findings for staff data were similar to those for participants with ID.

Overall, the evidence was strong for the reliability of the FODS3.0-ID. There was evidence of content validity~~, construct validity,~~ and criterion-related validity.

Overarching Issues

Emotional discomfort, withdrawal and instrument acceptability. Kirkendall et al. (2016) noted widespread acceptance of the notion that "people with intellectual disabilities are unable to make decisions related to end of life and need to be protected." (p. 4), suggesting possible risks when asking adults with ID about EOL. Therefore, it is important to consider how these participants reacted during assessment, and how any discomfort was managed.

We encountered no adverse events. Some people with ID experienced transient emotional upset (as did a few disability staff members), but this resolved rapidly with routine emotional support. Although some content was challenging for some participants (e.g., the EOLPS photo of a coffin in an open grave), none seemed too confronting. During assessment, all participants were asked how they were coping (usually repeatedly) and offered the opportunity to stop. Overwhelmingly, they chose to continue and completed all assessments without significant discomfort. Some did withdraw, usually when prompted by the interviewer. When offered the opportunity to withdraw, people made an informed, self-determined decision, usually to continue. We suggest that such practices be adopted during routine use of these instruments, so that people with ID have the opportunity to talk about EOL, but are offered the chance to stop, especially if it is discomforting. Our findings indicate that with administration safeguards, these instruments can be used with minimal risk of serious discomfort or adverse outcomes. Mild discomfort when discussing EOL is not unusual and, in itself, should not automatically exclude people with or without ID. We propose that it is better to support people to

make their own judgements about their participation than to paternalistically protect them from a normal emotional response.

Significantly more participants with ID (*n*=9, 23.1%) than staff (*n*=1, 2.5%) withdrew from assessment at some point. Participants with ID may have found the assessments somewhat more discomforting, but people with ID found the questions harder to answer (see Stancliffe et al., 2016). That is, cognitive load and related assessment fatigue were no doubt greater for people with ID and may have contributed to the higher rate of withdrawal.

With low or non-existent staff withdrawal rates, all three instruments seemed acceptable to staff. Among participants with ID, the highest rate of withdrawal (12.8%) was from the FODS3.0-ID and the lowest (2.6%) from the CODQ. These results indicate moderate to good acceptability, but also point to the need to monitor participants with ID when administering these instruments.

With only one ID participant withdrawal, the CODQ was evidently acceptable to participants with ID, mirroring McEvoy et al.'s (2012) findings. The higher rate of withdrawal by participants with ID from the EOLPS and FODS3.0-ID may have been partly due to the fixed assessment order. Instruments asked later were presumably more affected by the cumulative effects of discomfort and/or assessment fatigue. Fewer people may have withdrawn from the EOLPS and the FODS3.0-ID had these instruments been asked alone or first. Our initial concern that asking about fear of death might sensitise participants to react fearfully did not seem to be a problem in practice. There was no evident difference in participants' emotional response to the FODS3.0-ID from their response to the CODQ or EOLPS. Therefore, our decision to present the FODS3.0-ID last did not seem warranted, but we did not directly test this notion by presenting the FODS3.0-ID earlier in the sequence of assessments.

Withdrawal by 23% of participants with ID might suggest a problem with topic sensitivity or could be typical regardless of topic. When Stancliffe et al. (2014) assessed adults with ID using a loneliness assessment designed for the general community, nonresponsiveness was 75%. With an easier ID-specific

loneliness instrument, only 18% of participants with ID were nonresponsive, a result comparable with withdrawal by 23% in the current study. The large difference in responsiveness between the two loneliness instruments used by Stancliffe et al. (2014) suggests that item difficulty is more important than the sensitivity of the content.

Use of fictional CODQ and EOLPS vignettes may have helped to minimise discomfort because participants responded to an EOL situation involving someone else, not themselves (Finlay & Lyons, 2001). This notion is intuitively appealing, but we know of no research involving people with ID on sensitive content that compares questions about one's own views or experiences with vignette-based assessment.

Missing data. For participants who withdrew, subsequent questions were *not asked*, resulting in missing data for those items and/or instruments. When a question is asked, but elicits no response (or an irrelevant, unintelligible or don't-know response), there is a fundamental difference in scoring such nonresponses when assessing (a) knowledge and understanding (e.g., CODQ, EOLPS), and (b) subjective factors such as emotions (e.g., fear). With the former instruments, a nonresponse can be interpreted as indicating lack of knowledge or understanding, and scored accordingly. However, a nonresponse when asked about fear cannot reasonably be interpreted as an indicator of fear, and should be treated as missing data.

There was very little missing data due to nonresponses. As noted, in the CODQ and the EOLPS, nonresponses are assigned a score of zero and considered to indicate lack of understanding. For the FODS3.0-ID, nonresponses constituted missing data. There was a low level of missing FODS3.0-ID data for participants with ID (1.9%), and this only affected scores for one participant. That is, missing data due to nonresponding was not a problem for any instrument.

Use of photos and vignettes. Many aspects of death are abstract (Wiese et al., 2015) and questions about abstract concepts are harder for people with ID to understand and answer. Finlay and

Lyons (2001) recommended the use of concrete events when asking people with ID about abstract concepts. ~~Arguably, the~~The use of vignettes (CODQ, EOLPS) and photos (EOLPS) was intended to operationalise~~d~~ this recommendation.

Instrument administration. At 7-10 minutes per instrument, administration time is reasonable. With familiarisation and some practice, we consider that anyone with experience of interviewing people with ID could use these instruments without special training, so long as they responded appropriately to signs of discomfort.

Limitations and Future Research

One limitation ~~arises~~ arose from the fixed presentation order of the three assessments. It was not possible to tell whether withdrawal was due to the specific instrument content or the cumulative fatigue/stress of the preceding instruments. We focussed on ensuring participants knew about their right to withdraw and on promptly respecting their wishes. Future researchers should explicitly ask participants about their reasons for withdrawing, and systematically record and analyse these data.

One unanswered question was whether individuals with greater fear of death were more likely to withdraw. We were unable to evaluate this notion because we assessed fear of death last, so almost all individuals who withdrew from a preceding instrument did not complete the FODS3.0-ID. Future evaluations of acceptability and withdrawal should present the instruments on separate occasions and/or counterbalance the order of assessment. Logistically, it was not feasible for us to reduce assessment fatigue by presenting the three instruments on three separate occasions. Our failure to counterbalance was an oversight, which had the consequences just described. Counterbalancing assessment order would distribute withdrawal-related missing data more equally across the three scales, as each would be presented last only one-third of the time. Nevertheless, the problem described about determining the relationship between assessed fear of death and withdrawal from assessment

would be reduced but not eliminated. Using a counterbalancing condition, the FODS3.0-ID would only be presented first for one-third of participants.

The small amount of pilot testing of the FOD3.0-ID was not ideal. Nevertheless, the Part-2 FOD3.0-ID results were satisfactory and did not reveal unexpected administration problems that should have been remedied during piloting.

We assessed adults with mild or moderate ID who could self-consent. Therefore, the appropriateness of these instruments is unknown for individuals with ID with different characteristics.

In proposing suggestions for future research, we echo the sentiments of Todd et al. (2013) that research on EOL and ID should be included into other research topics. For example, the EOLPS could be used to assess one component of overall self-determination. Likewise, one validity issue for the EOLPS is the relationship between self-determination about EOL planning and self-determination in other areas of life.

Another key issue is the association between assessment results and real-life behaviour. For example, does assessed fear of death relate to engagement in learning about EOL or the outcomes of such intervention; do people with higher EOLPS scores actually do more EOL planning? At present, the answers to these questions are unknown.

Additional psychometric research is needed, including independent studies of reliability and validity for the EOLPS and FODS3.0-ID. Evaluation of test-retest reliability is necessary for all three instruments, to determine whether scores are stable over time, so they can be used with confidence in pre- and post-intervention research evaluating intervention effectiveness.

We did not evaluate sensitivity to change. Given the evident ceiling effects for staff on the CODQ and EOLPS reported by Stancliffe et al. (2016), these instruments would be insensitive to change among staff because almost all scored at the scale maximum. Evaluating interventions with individuals with ID

presupposes that the three instruments can detect clinically meaningful change. This issue too should be addressed in future research.

Conclusions

These three instruments for people with ID are potentially important for EOL research given that (a) "individuals with intellectual disabilities are often excluded from being direct participants and often research focuses on the perspectives of informal or formal caregivers" (Kirkendall et al., 2016, p. 10), (b) people with ID are routinely omitted from planning and decision making about their own EOL (Kirkendall et al., 2016), and (c) a key outcome of proposed interventions for people with ID is to educate and empower them about EOL planning and decision making (Wiese~~, Stancliffe, Read, Jeltes, & Clayton~~et al., 2015). These instruments can be used to identify individuals with knowledge gaps, low self-determination or high levels of fear, and to evaluate intervention effectiveness.

We acknowledge that there may be other important aspects of dying and death for which no assessments are available for use with adults with ID. Nevertheless, we believe that these three instruments represent important aspects of EOL, and that the availability of robust instruments represents a step forward for research and practice.

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Table 1: *Instrument characteristics associated with item difficulty*

Characteristic	Scale		
	CODQ	*EOLPS*	*FODS3.0-ID*
Vignettes			
Number of vignettes	3	7	na
Negatively worded sentences ("no", ~~or~~ "not" or "never" part of wording)	10%	10%	na
Passive sentences	42%	9%	na
Average words per sentence	6.8	11.1	na
Readability (Flesch Reading Ease[a])	81.7	84.5	na
Questions			
Number of questions	13	21	28
Negative questions ("no", "not" or "never" part of wording)	23%	14%	14%
Passive sentences	0%	33%	3%
Average words per sentence	7.5	15.0	6.0
Readability (Flesch Reading Ease[a])	74.3[b]	80.3	85.9[c]
Number of pictures	0	10 photos	0
Responses			
Response scale	3-point	3-point	3-point, concrete-referent scale

[a] The higher the Flesch Reading-Ease Test score, the easier the document is to understand.
[b] Readability of CODQ questions was assessed without including the probes "Why do you think that?"
[c] Readability of all FODS3.0-ID questions was assessed without the stem "How frightened are you of …"
na Not applicable.

Table 2: *Cronbach's alpha and subscale: total score Spearman correlation by group for each scale.*

Scale Subscale	No. of items	Participant Group: ID α	ID r_s	Staff α	Staff r_s	Full sample α	Full sample r_s
CODQ		(*n*=38)		(*n*=40)		(*N*=78)	
Causality	1	-	.41**	-	na	-	.45**
Finality	3	1.00[a]	.21	1.00	na	.84	.33**
Cessation	3	.02	.47**	na	na	.09	.55***
Universality	3	.95	.65***	na	na	.95	.59***
Inevitability	3	.91	.82***	na	na	.92	.79***
Total score	13	.80[a]	-	1.00[b]	-	.81	-
EOLPS		(*n*=33-37)		(*n*=40)		(*N*=73-77)	
Bequeathing	3	.32	.77***	na	na	.63	.90***
Place of care	3	.58	.83***	.73	1.00***	.77	.91***
Funeral wishes	3	.58	.89***	na	.47**	.69	.94***
Carers	3	.48	.79***	na	na	.68	.90***
Advance care	3	.65	.78***	1.00	.47**	.81	.87***
Take with	3	.56	.81***	na	na	.72	.89***
Organ donation	3	.67	.89***	na	na	.75	.92***
Total score	21	.91	-	.92[c]	-	.96	-
FODS3.0-ID		(*n*=24-32)		(*n*=38-39)		(*N*=62-70)	
Dying of others	7	.75	.79***	.77	.65***	.84	.81***
Death of others	7	.74	.86***	.76	.81***	.83	.85***
Own dying	7	.77	.87***	.86	.81***	.83	.76***
Own death	7	.80	.90***	.78	.78***	.85	.89***
Total score	28	.93	-	.90	-	.94	-

** p<.01, *** p<.001

na Not analysed because items/scores with zero variance have been removed.

[a] 1 item removed from analysis because of zero variance.

[b] 10 items removed from analysis because of zero variance.

[c] 15 items removed from analysis because of zero variance.

Note. Cronbach's alpha for Causality was not evaluated because that CODQ subscale contains only one item.

Table 3: *EOLPS percentage agreement by item and Spearman correlation between raters for each subscale total score by group for each scale.*

Scale	No. of	Participant Group					
		ID		Staff		Full sample	
Subscale	items	%	r_s	%	r_s	%	r_s
EOLPS		(*n*=5)		(*n*=3)		(*N*=8)	
Bequeathing	3	73%	0.62	100%	na	83%	0.78
Place of care	3	100%	1.00	100%	na	100%	1.00
Funeral wishes	3	100%	1.00	100%	na	100%	1.00
Carers	3	100%	1.00	100%	na	100%	1.00
Advance care	3	100%	1.00	100%	na	100%	1.00
Take with	3	100%	1.00	100%	na	100%	1.00
Organ donation	3	93%	1.00	100%	na	96%	1.00
Total Score	21	95%	0.98	100%	na	97%	0.99
FODS3.0-ID		(*n*=4-5)		(*n*=3)		(*N*=7-8)	
Dying of others	7	100%	1.00	100%	1.00	100%	1.00
Death of others	7	100%	1.00	100%	1.00	100%	1.00
Own dying	7	93%	1.00	100%	1.00	96%	1.00
Own death	7	100%	1.00	100%	1.00	100%	1.00
Total	28	98%	1.00	100%	1.00	99%	1.00

na Not able to be analysed because of zero variance.

Note: 1 participant with ID withdrew after item 8. Remaining FODS3.0-ID items had 4 participants with ID.