Developing and piloting the QOMID – quality outcome measure for individuals with intellectual disabilities and dementia

Karen Dodd, Alick Bush and Alexandra Livesey

Dr Karen Dodd is based at Surrey and Borders Partnership NHS Foundation Trust, Surrey, UK.
Dr Alick Bush is based at St Andrews Healthcare, Nottingham, UK.
Dr Alexandra Livesey is Clinical Psychologist at Surrey and Borders Partnership NHS Foundation Trust, Surrey, UK.

Abstract

Purpose – *Outcome measurement is a key priority for services. There are no papers on specific overall quality outcome measures for people with intellectual disabilities who have dementia. The purpose of this paper is to describe the development and piloting of a new measure.*
Design/methodology/approach – *A process was developed to measure quality outcomes across all stages of dementia. The reliability of the tool was measured using Cronbach's α coefficients, along with data about its clinical utility.*
Findings – *The QOMID has good reliability, face validity and internal reliability suggesting that all domains contribute equally towards the construct of quality outcome. An exploratory factor analysis revealed that there may be four or five sub-factors within the QOMID, The clinical utility of the assessment tool was explored and it can be concluded that the QOMID is simple, fairly quick and effective.*
Research limitations/implications – *The scale has good psychometric properties and the initial parameters for the QOMID were met. Further exploration of factors needs to be considered with a larger sample of participants.*
Practical implications – *The scale was liked by assessors and gives a practical tool that can both measure the quality outcome for people at each stage of their dementia, and help to develop more effective care plans.*
Originality/value – *This is the first measure to look at quality outcomes for people with intellectual disabilities and dementia and which takes a staged approach.*

Keywords *Outcomes, Psychometrics, Dementia, Staff, Intellectual disabilities, Improving care*

Paper type *Research paper*

1. Introduction

Person centred care is the focus of attention for both people in the general population and people with intellectual disabilities who develop dementia, with an increasing emphasis on what constitutes good person centred care. National guidance in the UK (SCIE, 2009) emphasised that "high quality support for people with dementia begins with the recognition that each person is an individual with their own needs, preferences and life story".

Within the field of intellectual disabilities there has been a longstanding focus on person centred care. O'Brien's "five accomplishments" (respect, choice, participation, relationships and ordinary places) were the foundation for person-centred planning in the USA (O'Brien, 1989). Person-centred planning was adopted as government policy in the UK through the "Valuing People" White Paper in 2001 (Department of Health, 2001).

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A series of scandals and reports of abusive practice in the UK concern the neglect, abuse and deaths of predominantly older people (e.g. The Francis report (Francis, 2013) CQC report on

wider hospital failure (Care Quality Commission, 2013)). Greig, Chief Executive at the National Development Team for inclusion in his blog (Greig, 2013), commenting on these reports, concluded that one issue that all hospital Trusts need to start thinking was to "Start measuring life related outcomes rather than processes – look at how treatment enables the person to get on with the rest of their life".

The focus of dementia care is on personalised care in which "we will get the best outcomes if we focus on individuals and their needs in the context of their families and communities, providing treatment or support for specific conditions including dementia, but never losing sight of the person" (Pickup, 2012).

Dementia strategies and care standards from many nations (e.g. National Dementia Strategy (Department of Health, 2009; Alzheimer's Australia, 2007)), and the Netherlands' "National Dementia Plan (Ministry of Health, 2004)" all focus on people being supported to "live well" with dementia, rather than suffer from it. However what constitutes "Living Well" with dementia varies as the dementia progresses. It is important to take the learning from holistic person centred care to look at the quality outcomes for people and apply it initially to people with intellectual disabilities who develop dementia, and then to the wider population with dementia.

This paper describes the development and piloting of a measure to look at quality outcomes for individuals with intellectual disabilities and dementia across the progression of the illness; how it can be used as a tool to improve the lives of people with intellectual disabilities who develop dementia, and its extension to other groups within the wider population with dementia.

2. Review of literature

2.1 Outcome measurement for people with dementia in the general population

There has been a greater focus on measuring either specific outcomes or quality of life measures within the mainstream dementia literature.

Studies have varied in their approach and focus. Some studies have addressed specific elements of a person's life or functioning, e.g., social engagement (e.g. Morgan-Brown *et al.*, 2012); agitation (e.g. Husebo *et al.*, 2011; Chenoweth *et al.*, 2009); interventions with caregivers or co-residents in the form of education, training, support groups (e.g. Acton and Kang, 2001), or pharmacological treatments, exercise and other psycho-social interventions with the person with dementia (e.g. Hogan *et al.*, 2008).

A review of available quality of life outcome assessments that could be used to assess outcomes of the use of assistive technology found a lack of appropriate evaluation tools (Peterson *et al.*, 2012). Phillips *et al.* (2012) in a review paper showed that case conferencing provided opportunities to improve care and palliative care outcomes for older people by engaging family and all relevant internal and external health providers in prospective care planning.

Other work has focused on developing, evaluating or reviewing quality of life or other specific outcome measures that can be used either with people with mild or moderate dementia or with carers.

In a review of outcome measures, Moniz-Cook *et al.* (2008) found measures that covered the domains of quality of life, mood, global function, behaviour and daily living skills. Family carer domains included mood and burden, which incorporated coping with behaviour and quality of life. The only specific staff domain identified was morale, but this included satisfaction and coping with behaviour. In their conclusion 22 measures across nine domains were recommended in order to improve the comparability of intervention studies in Europe. Overall she argued that a more cohesive approach to outcome measurement in dementia care research would lead to a more robust evidence base.

Brod *et al.* (1999) postulated that health care professionals might have a better ability to intervene to improve quality of life than to change other aspects of the disease, whilst Ready and Ott (2003) reviewed the available Quality of Life Measures at that time and concluded that one important

issue is whether Quality of Life measures are sensitive to change over time, which they thought was critical in evaluating response to treatment and to determine the effects of disease progression on quality of life.

Banerjee *et al.* (2009) reviewed the use of disease-specific measures of health-related quality of life in dementia and concluded that little is known about the natural history of health-related quality of life in dementia or what attributes or interventions promote or inhibit health-related quality of life for people with dementia, whilst in a further study Hurt *et al.* (2010) found that impaired insight is associated with better health-related quality of life in people with moderate dementia.

A systematic review of outcome measures (Jones *et al.*, 2012) found a total of 228 measures that looked at carers of people with dementia. In all, 44 measured burden, 43 were mastery measures, 61 mood measures, 32 Quality of Life measures, 27 social support and relationships measures and 21 looked at staff competency and morale measures. They concluded that the choice of instrument has implications for both the person and future funding of interventions. If an instrument is not sensitive enough to detect changes in certain populations, then the effect of an intervention may be underestimated and interventions which may appear to be beneficial to people are not deemed cost effective and are not funded.

One of the most vocal proponents of what is needed for good dementia care is David Sheard, the founder of Dementia Care Matters. His work (Sheard, 2011) has focused on achieving positive outcomes for people with dementia. He concluded that "Achieving real outcomes is all about not focusing on policies, procedures and systems but balancing and measuring quality of service and quality of life".

2.2 Outcome measurement for people with intellectual disabilities and dementia

Outcome measurement for people with intellectual disabilities and dementia is still in its infancy, and there is a paucity of literature. Strydom *et al.* (2009) on behalf of the IASSID Special Interest Research Group on Ageing and Intellectual Disabilities undertook a systematic literature search from 1997 to April 2008. This review did not identify any specific literature on measuring outcomes for people with intellectual disabilities and dementia.

There is a lack of published research on the efficacy of strategies to guide the provision of daily care (Jokinen, 2005). One study found that small group living may provide better opportunities to maintain or enhance quality of life for the person with intellectual disability and dementia as compared to large group settings, e.g., nursing homes (Chaput, 2003). Some studies indicated that specific approaches to measuring quality of life could be undertaken. McCallion and McCarron (2007) suggested that "Common concepts within a quality of life framework (Schalock *et al.*, 2002) may need to be adapted or modified in dementia care and offer potential for the establishment of a proactive approach".

A small number of studies looked at outcomes for specific interventions. Rosewarne (2001) used structured psychotherapeutic groups to promote individual quality of life and maintain the person's level of functioning, whilst Kalsy *et al.* (2007) showed that staff training that is focused on challenging behaviour can positively influence staff knowledge by changing attributions of the controllability of the behaviour associated with dementia, however the subsequent outcome for the individual with dementia was not clear. Nichols (2011) demonstrated that using personalised technology made a positive difference to their lives.

Approaches such as dementia care mapping (DCM) may be useful in planning care for people with intellectual disabilities and dementia. DCM is used to observe and evaluate the quality of life of people living with dementia, and to enhance person-centred care. In their small study (Finnamore and Lord, 2007) of eight adults with intellectual disabilities and dementia, DCM highlighted examples of good and bad practice. The process demonstrated positive outcomes after the intervention, however they concluded that the DCM training and time requirements to achieve this may be beyond the resources of some intellectual disability services.

A pilot study to evaluate the usefulness of an accepted health-related quality outcome measure – Dementia quality of life measure (DEMQOL and DEMQOL-Proxy) (Smith *et al.*, 2005) outcome measure for people with Down's syndrome and dementia was undertaken by

Dodd (2010). She concluded that in a trial with 30 people, DEMQOL was not an appropriate tool to use with people with intellectual disabilities and dementia because of the complexity of the language and concepts, and that DEMQOL-Proxy is not an appropriate tool to use with carers of people with intellectual disabilities and dementia because of the way staff think about people with intellectual disabilities and dementia.

Recommendations of international dementia organisations were reviewed by Janicki (2011), and a framework for dementia care quality measurement for people with intellectual disabilities was proposed. The review concluded that agencies should promote dementia capable practices that include: early and periodic assessments; physical modifications in living settings; specialised staff education for stage adapted care; and flexible long-term services that recognise and plan for progression of decline and changes in functioning.

However, a literature search found no papers on specific overall quality outcome measures for people with intellectual disabilities who have dementia.

3. Developing a measure of quality outcome for people with intellectual disabilities and dementia

There are a range of approaches in place within the general population that can be used to measure either a specific element of dementia care or a global measure of quality of life either by direct assessment of a person with mild or moderate dementia or by asking carers. However current measures view dementia as a "stable" disease rather than one which is progressive. Quality outcome measures need to be sensitive to the progression of the disease, and not just able to be used for people with early or mid-stage dementia (Ready and Ott, 2003).

A key component of excellence in dementia care is the ability of the system to continuously adapt their understanding, care and resources as the person's dementia progresses. Staff in services often receive training as people are identified as having dementia, but do not adapt what they do so that it is in line with the person's changing needs – this often leads to staff feeling that they cannot care for the person and that they are always "lagging behind".

The aim of this study was to develop a tool that would measure quality of care and therefore the quality outcome for the person in line with the standards of best practice (British Psychological Society and Royal College of Psychiatrists (BPS and RCPsych), 2009) which took account of "stage adapted care" (Janicki, 2011) for people with intellectual disabilities and dementia.

The specific goals were to develop a quality outcome measure that: could be used with anyone with dementia; was stage specific (early, mid- and late-stage dementia); reflected the guidance in the BPS/RCPsych (2009) document for assessment, diagnosis, treatment and support of people with intellectual disabilities and dementia; was fairly quick to administer; could be used in any service setting; and could be used to help both evaluate quality outcomes and plan to improve them.

The tool is based on the standards from the BPS and RCPsych (2009) guidance. It needed to be able to distinguish how quality outcome may change in a particular domain as the dementia progresses. Descriptors of a good quality outcome for the individual were developed for each of the three main stages of dementia – suspected/early, mid- and late-stage. See Table I for an example of one of the domains. In all, 15 domains were identified at the development stage of the work.

4. Steps in using the measure

The assessor is required to first decide which stage of dementia the person currently is in, based on their current assessment of functioning and professional opinion. This determines which set of descriptors should be applied for all of the domains at this point in the person's dementia. The achievement of the quality outcome for each domain is rated on a four-point scale where 1 is: this is rarely achieved for this person; 2 is: this is sometimes achieved for this person; 3 is: this is mostly achieved for this person; and 4 is: this is completely and consistently achieved for this person.

Table I Example of a domain

Area	*Suspected/early stage dementia*	*Mid-stage dementia*	*Late stage dementia*
5. Interaction with others	The person experiences calm and constructive interaction with family, staff and friends, who adapt the amount of language used and use symbols and pictures as required to ensure the person experiences positive interactions 1 2 3 4	The person experiences calm and constructive interaction with family, staff and friends, with no confrontation; no time pressures; and validation of roll back memories. The person experiences positive interactions and is always approached from the front to prevent surprise and panic 1 2 3 4	The person experiences calm and constructive interaction with family, staff and friends, with protected 1:1 time each waking hour to ensure that the person experiences positive interactions 1 2 3 4

All domains in the measure must be completed. If the domain is rated less than 4, the person or support team completing the measure should specify what actions are required to improve the person's quality outcome in that area of their life.

The Quality Outcome Measure for Individuals with Dementia (QOMID) is completed by the assessor in discussion with the relevant carers of the person. Wherever possible, and depending on ability, the person with dementia should be asked how they would rate their experience in each domain. Additional information for the assessor to make an inclusive judgement may come from family, support staff, advocates, care managers or anyone else involved with the person and their support.

4.1 Expected scoring

The aim, in supporting the person with dementia, is for them to have high-quality outcomes throughout the progression of their dementia. As dementia is a progressive condition, it is vital to ensure that the person's changing needs are recognised and met. This means that at as the person moves into each stage of dementia, the quality outcome score for each domain may start at 2 or 3, but as people work together to improve the person's quality outcomes, the scores should reach the maximum of 4 in each domain. This may mean that scores may fluctuate during the course of the dementia as support "catches up" with the person's changing needs.

4.2 Forward planning

The QOMID is designed to help the support team and the professionals to work with the person and their carers to both prevent deterioration in quality outcome and to forward plan effective care. For each domain that is scored at less than 4, the person or support team is asked to specify what needs to be put in place to improve the person's quality outcome for that domain. These actions can then be included in the person's support plan. In addition, by looking at the descriptions for the next stage of dementia, the professional can begin to help the person and their supporters to think about what needs to be put in place to maintain the person's quality outcome.

5. Results of the face validity trial

In all, 21 QOMIDs were completed across the two services involved in the face validity trial. 18 people with intellectual disabilities were living in residential care homes for people with intellectual disabilities, with one person in each of supported living, with family and in a nursing home for older people. 19 people had Down's syndrome and two had non-specified intellectual disabilities.

The professionals had rated five people as at early stage dementia, nine people at mid-stage and seven people at late stage dementia. The QOMID was used in a variety of ways, primarily at assessment and reviews, but in one case each at a workshop to shape up the support plan and as an observation tool.

A number of questions were asked about using the QOMID. Everyone felt the instructions for completion were easy to understand and to follow. Time taken to complete the QOMID ranged from 20-60 minutes with a mean of 41.19 minutes.

Feedback from the assessors who completed the scale was positive and it was therefore concluded that the QOMID has good face validity as a measure of quality outcomes for people with intellectual disabilities and dementia. Based on the initial face validity trial, a small number of adaptations were made to the QOMID.

An additional two domains were added to reflect two areas that were identified as important – positive risk taking and respect for human rights, making a total of 17 domains (see the list below); the whole measure was checked for sentence length and amendments made; a section was added for each domain to give space to record the evidence for their decision for each domain. Final QOMID domains are:

1. Person centred approaches to support.
2. Positive risk taking.
3. Respect for human rights.
4. Consistency of approach.
5. Interaction with others.
6. Emotional reassurance to cope with changes.
7. Orientation.
8. Daily living.
9. Carrying out preferred activities.
10. Flexibility of support.
11. Environment.
12 Behaviour.
13. Health.
14 Support from well-co-ordinated agencies.
15. Nutrition.
16. Mobility.
17. Continence.

6. Evaluating the utility of the QOMID

The aim of the study was to assess the clinical utility of the QOMID based on the qualitative and quantitative results of the pilot:

- How easy is the QOMID for people to administer?
- How long does the QOMID take to complete?
- Is the QOMID appropriate for people with all stages of dementia?
- Is there a difference in how it is rated between professionals working within services for people with intellectual disabilities compared to services for older people?

7. Main results

7.1 Descriptive analysis

In all, 11 services across England participated in the study. A total of 72 evaluation forms, each representing one person with dementia were analysed – 16 from the original face validity trial and a further 56 from the main pilot phase (see Table II).

Table II Description of people with dementia

Diagnosis	Down's syndrome	Other intellectual disabilities	Older people from the general population
	67%	22%	11%
Living environment	Own home	Supported placement	Residential/nursing home
	12%	23%	65%
Age range	46-55	56-65	65+
	24%	52%	24%
Stage of dementia	Suspected/early	Mid-stage	Late stage
	26%	47%	29%

7.2 Clinical utility of the QOMID

A fundamental aspect of the pilot was to establish the clinical utility of the QOMID. This was established through asking participants to rate the QOMID on a number of criteria. As can be seen from Table III, the majority of assessors found the QOMID easy or fairly easy to use.

The time taken to complete the QOMID ranged from under 15 minutes to over 120 minutes. The mean was 31-45 minutes ($n = 66$). Most people completed the QOMID either face to face with person and family or staff carers or as part of a review of care.

In order to further explore the utility of the QOMID version 2 and to establish if there were any factors that contributed to variance between QOMID ratings, QOMID version 2 scores were artificially subdivided into categories. Results could only be determined for the scores in the main pilot ($n = 56$), and are shown in Table IV.

These categories were used to establish if there were differences between the groups on overall rating of the ease of use of the QOMID. No significant differences were found on the overall "Ease of use" category ($F(3, 52) = 1.977$, $p = \text{ns}$).

ANOVAs were computed to establish if there were any differences between the three dementia stage groups on rating of "Ease of use" and "Plan to alter care plan". There were no significant differences found between the groups and plans to alter care plan ($F(3, 50) = 0.520$, $p = \text{ns}$). However there was a small difference between ease of use and the dementia status groups

Table III Clinical utility of the QOMID

	Easy/fairly easy (%)	*Difficult/very difficult (%)*
Clarity of instructions	95.5	4.5
Ease of use	92.5	7.5
Ease of assigning dementia stage	79.1	20.9

Table IV Scores achieved on the QOMID

Category	*Total score*	*Average score per domain*	*Number of people in category*	*% of total sample*
Excellent	60-68	3.5 or more	25	44.6
Good	51-9	3 or more	22	39.3
Adequate	43-50	2.5 or more	8	14.3
Poor	34-41	2 or more	1	1.8
Unacceptable	33 or less	Less than 2	0	0
Total			56	100

$F(3, 66) = 3.157$, $p < 0.05$). *Post hoc* analysis identified that there was a significant difference between ratings of ease of use between participants in "Suspected" and "Early" stage dementia, with those in the Suspected group rated as significantly easier to rate using the QOMID ($t(12) = 3.432$, $p < 0.01$). No other differences were found between the dementia stage groups. This suggests that stage of dementia does not significantly affect the utility of the QOMID. This is an important finding as the QOMID was designed to be used across all stages of dementia. Therefore this result supports the face validity of the assessment already established and answers the research question about the use of the QOMID across stages of dementia.

ANOVAs were computed to establish if there were any differences between the three dementia stage groups on the rating of "Ease of Instructions". Overall there was a small difference in ease of understanding instructions between dementia groups ($F(3, 65) = 4.449$, $p < 0.01$). The differences are between suspected and late groups and suspected and early stage groups ($t(12) = 2.825$, $p < 0.05$) and ($t(12) = 3.439$, $p < 0.01$).

ANOVAs were computed to establish if there were any differences between the three dementia stage groups on the rating of "Ease of assigning dementia". Overall there was a small difference in ease of assigning dementia between dementia groups ($F(3, 66) = 5.880$, $p < 0.01$). The differences are between suspected and late groups and mid and late stage groups ($t(24) = 3.324$, $p < 0.05$) and ($t(51) = 3.784$, $p < 0.01$).

There were no significant differences on the scores based on living arrangements, and no significant differences between groups based on dementia status in domain scores.

Comparing scores from people within intellectual disabilities services to those in the older peoples mental health services indicated that there was no significant differences between people with intellectual disabilities and people with dementia in the general population ease of use; on ease of understanding instructions or ease of assigning dementia categories.

7.3 Reliability

In order to begin to establish the psychometric property of the QOMID as a standardised clinical measure, the reliability of the tool was assessed. In this pilot study the main reliability analyses were intra-class correlations and Cronbach's α for reliability and principle component analysis for the exploration of the factor structure.

Cronbach's α value of 0.70 or higher is acceptable regarding a measure's reliability (BPS, 1992). The internal reliability of the QOMID was considered with all 17 items. The mean total QOMID score was 23.61 (SD = 5.06). The measure was found to be highly internally consistent ($\alpha = 0.848$), see Table V.

Analyses of the corrected item-total correlations for the QOMID revealed that all but two of the correlations were at or above the 0.3 cut-off suggested by Field (2005) (see Table V). The remaining two were at 0.28 and deleting them did not improve Cronbach's α levels overall. Furthermore, since the Cronbach's α level was already above the agreed threshold of 0.8 (Field, 2005), deletion of any of the scale items is not indicated (Devellis, 1991).

7.4 Examination of factor structure

Principal component analysis (PCA). PCA was conducted to examine the factor structure of the QOMID. The current study used 72 participants within this analysis, and therefore had a ratio of 5:1 participants to scale items. This is usually considered to be adequate for exploratory factor studies (Costello and Osborne, 2005; Floyd and Widaman, 1995). However some authors argue that a more conservative participant to item ratio of 10:1 should be achieved (Tabachnick and Fidell, 2006). Initial examination of the QOMID showed that the majority of item correlation coefficients were above 0.3. The Kaiser-Meyer-Oklin values for the scales were 0.726 which exceeds the recommended value of 0.6 (Kaiser, 1974). The Bartlett's Test of Sphericity (Bartlett, 1954) was highly significant ($p < 0.001$). These results suggest that the QOMID is factorisable.

Table V Means and standard deviations for QOMID items, item-total correlations and Cronbach's α if item deleted

Item	*Mean*	*SD*	*Item-total r*	*α if item deleted*
1. Support	3.13	0.616	0.506	0.838
2. Positive risk taking	3.30	0.768	0.283	0.849
3. Human rights	3.57	0.602	0.524	0.837
4. Consistency of approach	3.56	0.664	0.411	0.842
5. Interaction with others	3.33	0.614	0.624	0.833
6. Emotional reassurance	3.37	0.760	0.314	0.847
7. Orientation	3.33	0.752	0.484	0.838
8. Daily living	3.50	0.694	0.598	0.833
9. Preferred activities	3.11	0.691	0.393	0.843
10. Flexibility of support	3.17	0.966	0.421	0.844
11. Environment	3.17	0.841	0.494	0.838
12. Behaviour	3.41	0.740	0.564	0.834
13. Health	3.37	0.708	0.285	0.848
14. Agencies	3.44	0.634	0.378	0.843
15. Nutrition	3.65	0.555	0.483	0.839
16. Mobility	3.50	0.720	0.640	0.830
17. Continence	3.54	0.719	0.487	0.838

Step two of the PCA using Kaiser's criterion revealed the presence of five possible QOMID factors with eigenvalues exceeding 1. These factors explained between 30 and 7 per cent of the variance in the QOMID. Examination of the scree plot highlighted a substantial break after the fifth factor. According to Catell's scree test, it was decided to retain five factors. This suggests that the QOMID has five possible sub-domains within the full scale. 13 of the 17 domains loaded most strongly onto factor 1, two domains loaded most strongly onto factor 2 and 1 factor loaded most strongly onto each of factors 3 and 4, although factor 5 was extracted, no domains were strongly positively loaded. See Table VI below for more detail. Caution needs to be taken here as this is only an exploratory factor structure analysis using a relatively small sample size. Further analysis will be needed to confirm or reject these initial findings.

Table VI Principle components analysis loadings for five extracted factors:

	Component				
Domain	*1*	*2*	*3*	*4*	*5*
1. Support	0.570	0.484	0.245	–0.318	0.311
2. Positive risk taking	0.324	0.564	–0.002	0.447	0.090
3. Human rights	0.589	0.212	0.342	–0.230	0.259
4. Consistency of approach	0.463	0.614	–0.152	0.094	0.405
5. Interaction with others	0.696	0.020	0.208	0.211	–0.182
6. Emotional reassurance	0.403	–0.335	0.058	0.603	0.310
7. Orientation	0.570	–0.048	–0.432	–0.035	–0.271
8. Daily living	0.678	–0.042	–0.345	0.061	–0.298
9. Preferred activities	0.452	0.295	0.141	0.229	–0.591
10. Flexibility of support	0.497	0.409	0.310	–0.308	–0.416
11. Environment	0.631	–0.562	–0.045	–0.323	0.088
12. Behaviour	0.655	0.044	–0.162	0.314	0.117
13. Health	0.362	–0.279	0.680	0.100	–0.034
14. Agencies	0.448	0.368	–0.321	–0.292	0.101
15. Nutrition	0.574	–0.498	0.237	–0.127	0.118
16. Mobility	0.727	–0.435	–0.002	0.030	–0.004
17. Continence	0.608	–0.267	–0.456	–0.147	0.090

7.5 Qualitative comments

Specific feedback about how the QOMID was used by professionals had not been requested. However a number of professionals had added comments to their response when sending the completed evaluation forms. These included:

- A very useful way of structuring reviews, and very keen to use it at the next review as an evidence-based way of monitoring change.
- Very helpful in focusing the group on how to improve support – staff in the support services found the process very interesting and helpful as well and thanked us for the opportunity for discussion.
- We have found the questions extremely helpful and a good way to review our care as well as that of the residential homes.
- Very useful and easy to use measure. It was pleasing to see the positive scores for some of the service users we support and at the same time useful to highlight the areas that are not so positive and in need of attention. This was a very helpful and engaging exercise for staff at the Care Home.

There were no negative comments.

7.6 Results summary

Overall, the results of the analysis suggest that the QOMID has good reliability and face validity. The QOMID has good internal reliability suggesting that all domains contribute equally towards the construct of quality outcome. An exploratory factor analysis revealed that there may be four or five sub-factors within the QOMID, however this will need to be considered further and with a larger sample of participants. The clinical utility of the assessment tool as a way of measuring quality outcome in people with dementia has been explored and it can be concluded that the QOMID is simple, fast and effective. There are some differences in how people rate the utility of the QOMID based on the stage of dementia the participant falls within, however these differences are minimal and the overall ease of use of the QOMID was rated as good. In addition, the unsolicited comments from professionals using the QOMID demonstrate that they liked the measure and found it a useful way of structuring care reviews, and to demonstrate both where people are doing well, and areas that require further support/change to the person with dementia's care plan.

8. Discussion

The aim of this work was to develop a measure for professionals to use to look at quality outcome for people with intellectual disabilities and dementia over the progression of their disease. Much of the focus within clinical services and research has in the past focused on the epidemiology and prevalence of dementia, the assessment and diagnosis process and more latterly the management and interventions for the person with dementia. Within services for people with intellectual disabilities, person centred care has been an underpinning concept for many years both in the UK and internationally.

The development of the QOMID built on the self-assessment framework that measured outcomes for services across 15 standards (BPS, 2009), and the longstanding clinical experience of the authors in working with people with Down's syndrome and dementia.

The development of the measure was in two parts. Initial face validity work within our own services demonstrated that the QOMID had good face validity with professionals. The results of the main pilot demonstrate that the main hypotheses and evaluation questions have been achieved. The QOMID, on the basis of this pilot is shown to have good clinical utility. The results demonstrate that for the vast majority of people completing it, it was both easy to use, and the instructions for its use were simple to understand. Initially there was concern over how easy people would find it assigning the stage of dementia, but 79.1 per cent of professionals found it easy or fairly easy to assign the stage. Difficulties were primarily if the person seemed to be on the

border between two stages of dementia, when the professional needed to use their clinical judgement to assign the status. There were small but significant difference between some subgroups, and a larger study needs to be undertaken to look at these results as the groups are very small.

With regard to the length of time to complete the QOMID, the mean was between 30 and 45 minutes with a wide range of 15-120 minutes. Anecdotal feedback from some people using it said that the QOMID had been really useful in structuring an in depth discussion about the person with dementia, and that the time investment had been really worthwhile in terms of the outputs from the session. The QOMID was usually either completed with the person and their family and other key professionals in a clinic setting, or as part of a multidisciplinary and multiagency review. This approach concords with both the National Dementia Strategy (Department of Health, 2009) in terms of helping people to "Live Well with dementia" and also with the work of Pickup (2012) and her conclusion that the best outcomes arise when "the focus is on individuals and their needs in the context of their families and communities […] but never losing sight of the person".

With regard to clinical utility, the results demonstrate that it is appropriate for people with all stages of dementia and for people both within services for people with intellectual disabilities and dementia and those people who have dementia in older peoples mental health services.

The results of the analysis to look at the internal reliability of the tool were shown to be very positive, with a Cronbach's α of 0.846 which means that it has high internal consistency. Similarly the analyses of the corrected item-total correlations revealed that all but two of the correlations were at or above the 0.3 cut-off suggested by Field (2005) with the remaining two being only slightly lower, and deleting them did not improve Cronbach's α levels overall. Furthermore, since the Cronbach's α level was already above the agreed threshold of 0.8 (Field, 2005), deletion of any of the scale items is not indicated (Devellis, 1991). As a result of this, the wording for the two domains was looked at, and it may have been that this was not worded clearly enough to be thought about in the same way as other domains, and some small adjustments have been made in the final version. Further analysis to see if this had rectified the situation can be undertaken as more data are collected on the use of the QOMID. These results confirm that the QOMID is a reliable assessment as measured by the internal consistency of the tool.

Initial results on the factor structure indicate that the QOMID can be factorisable, and the results from this pilot indicate possible five factors. It was felt that at this stage the sample was too small to make any significant claims about factors. However, on inspection, it can be suggested that health (domain 13) and emotional reassurance (domain 6) are both separate factors, and that two domains, positive risk taking (domain 2) and consistency of approach (domain 4), are together a further single factor.

As clinicians it was imperative to us that the measure was seen by professionals working with people with dementia as a measure that would both enhance their practice and be clinically useful in ensuring that their services are able to deliver quality outcomes for the person with a dementia across the stages of dementia. The unsolicited comments indicated that the measure introduced a new and very useful way of structuring reviews of the person and would assure professionals across a number of issues. These include: that all areas of a person's life and outcome would be considered; ability to highlight what is positive for the person, but also areas that need attention; made sense to both professionals and to staff and families in what they were trying to achieve for the person and engaging people within the system around the person, and gave them an evidence-based way of monitoring change by using it repeatedly with the same person.

It can therefore be concluded that not only were the initial parameters for the QOMID met, i.e., that it could be used with anyone with dementia; was stage specific (early, mid- and late-stage dementia); reflected the guidance in the BPS/RCPsych document; was fairly quick to administer; could be used in any setting and could be used to help both evaluate quality outcomes and plan to improve them, but that it was a reliable and useful clinical measure. It also meets requirement of measuring life-related care rather than processes (Greig, 2013) and helping people to live well with dementia (Department of Health, 2009).

9. Plans for the future

The measure is available free to anyone who is interested in using it with people with dementia, and is available from the BPS web site (Dodd and Bush, 2013). The authors are aiming to collect further data about its use to undertake further statistical analysis and have set up online survey link to allow people to post their anonymised data.

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Corresponding author

Dr Karen Dodd can be contacted at: DrKaren.Dodd@sabp.nhs.uk