

‘I hate having nobody here. I’d like to know where they all are’: can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment?

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Objective: To ascertain if similarities or differences exist in perceptions of quality of life (QoL) amongst nursing home (NH) residents with different levels of cognitive impairment (CI).

Method: Face-to-face interviews using a simple 15-item semi-structured interview schedule with 61 older people with a CI (13 mild, 20 moderate and 28 severe) living in three Dublin area based NHs.

Results: Four key themes of QoL with accompanying sub-themes were identified: (1) social contact, (2) attachment, (3) pleasurable activities and (4) affect. Whilst some similarities existed between the three groups, results showed emerging differences, particularly between those with a mild and severe CI. In particular, the narratives of those with a severe CI reflected an absence of social contact, a quest for human contact and a lack of awareness of structured pleasurable activities. A large majority also reported feelings of loneliness, isolation and a search for home.

Conclusions: Findings support the increasing evidence that people with a CI and even those with a probable advanced dementia can often still communicate their views and preferences about what is important to them. Whilst apathy, depression and anxiety are common features of advanced dementia, the social inclusion of these people in the day-to-day ethos of NH life needs a lot more careful consideration. More research is also needed to better understand the chronic and unique needs of this very vulnerable group of people.

Keywords: cognitive impairment; quality of life; nursing home residents; qualitative research

Introduction

Quality of life (QoL) has become a major focus of dementia care research. A recent literature search, using the keywords ‘quality of life’ and ‘dementia’ on CINAHL, PsychInfo, PubMed and Medline, yielded a total of 387 citations for the period 1980–1999, but for the period 2000–2009, a total of 2240 citations were found, reflecting the huge growth of interest in this topic. These findings are not surprising given the current and predicted global rise in prevalence rates of Alzheimer’s disease and the related dementias (Ferri et al., 2005) and the absence of a cure for an illness that by its very nature is progressive and can straddle up to two decades (Lau & Brodney, 2008). Increasingly, researchers wish to find out more about what is it like for people living with this progressive illness in order to better understand the issues facing a growing and vulnerable group and in order to develop more responsive treatments and service interventions.

Much of the earlier work on QoL and dementia was based on community samples; however, a growing and burgeoning body of literature is now emerging, reporting on the QoL of nursing home (NH) residents with a cognitive impairment (CI). Whilst such studies have produced valuable findings, limited attention has been paid to attempting to extrapolate differences and

similarities in QoL findings amongst people with a wide range of CI including those with a severe CI. Whilst the reasons for this are obvious, it has meant that this group of people has, by and large, been excluded from most research studies on dementia and QoL. We attempted to, as best as we could, address this gap in the literature.

Literature review

Although dementia and QoL has received much research attention over recent years (Dröes et al., 2006; Ettema et al., 2005; Gerritsen et al., 2007; Selai & Trimble, 1999), there is still no universal definition of QoL; nor has a gold standard been developed for its measurement. One dilemma long debated is whose views should be sought; however, in recent years, growing international evidence has accumulated demonstrating that most people with dementia (PwD) can respond well to questions asked about their QoL (Brod, Stewart, Snads, & Walton, 1999; Cahill et al., 2004; Logsdon, Gibbson, MsCurry, & Teri, 2002; Mozley et al., 1999; Ready, Ott, Grace, & Fernandez, 2002; Trigg, Jones, & Skevington, 2007) and that proxy informants, i.e. family caregivers, formal caregivers and researcher observations may not accurately reflect

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75 the views of PwD (Dröes et al., 2006; Edelman, Fulton,
Kuhn, & Chang, 2005; Hoe, Hancock, Livingston, &
Orrell, 2006; Sloan et al., 2005). Invariably, studies
have shown how proxy informants associate QoL in
80 dementia, with the severity of the CI, with dependency
levels and functioning, perspectives which are not
always in accordance with PwD's own reports
(Edelman et al., 2005; Gonzalez Salvador et al., 2000;
Hoe et al., 2006; Missotten et al., 2007; Sloan et al.,
85 2005). Thus, it has been argued that the subjective
definition of QoL by PwD, represents the best way
of understanding their priorities and experiences
(Brod et al., 1999; Kane, 2003; Sloan et al., 2005).

QoL is generally accepted as a multi-dimensional
concept (Bond, 1999; Ettema et al., 2005); however, to
90 date, there is little agreement about what domains best
represent QoL in PwD (Bond, 1999), and although
there is a growing number of disease-specific scales
available, the relevant domains included in the scales
vary considerably (Schölzel-Dorenbos, Van der Steen,
95 Engels, & Olde Rikkert, 2007). In almost all dementia-
specific QoL measurements, 'affect' has been found to
be an essential domain (Ettema et al., 2005; Schölzel-
Dorenbos et al., 2007). In addition, most scales contain
at least one of the following domains: (1) self-esteem,
100 (2) activities, (3) enjoyment and (4) social interaction
(Ettema et al., 2005). Banerjee et al. (2009), in a recent
review of the literature on predictive and explanatory
factors of QoL in dementia, suggested that other than
depression, no other factor (i.e. demographics,
105 cognition, activity limitation or behavioural disorders)
has been clearly associated with QoL.

Whilst research using these scales has yielded very
useful information, a growing body of literature
suggests that to rely solely upon quantitative methods
110 restricts access to other useful knowledge and that
qualitative approaches in dementia research can widen
and complement current knowledge and can help to
generate new ideas and concepts (Gibson, Timlin,
Curran, & Wattis, 2004). It is for this reason that
115 qualitative approaches are now being recommended.
In addition, qualitative research can help gain a better
understanding of what really matters to PwD and may
bring out the voice of people in more advanced stages
of dementia; voices which have been largely excluded
120 from research (Wilkinson, 2002). In keeping with these
recommendations, efforts are now increasingly being
made to elicit the PwD subjective views and to acquire
their individual accounts about their QoL (Dröes et al.,
2006; Jonas-Simpson & Mitchell, 2005; Moyle,
125 McCallister, Venturato, & Adams, 2007; Train,
Nurock, Manela, Kitchen, & Livingston, 2005).

QoL, dementia and long-term care

This emerging body of qualitative research has
revealed that PwD associate their QoL with: (1) a
130 general feeling of happiness and contentment, (2) their
relationships with others, particularly their family,

(3) attachment and feelings of belonging, (4) health,
(5) being given freedom and choice, (6) having access
to privacy, security and feeling treated with dignity and
respect, (7) self-esteem, feelings of worthiness, being
135 useful, meaningfulness, (8) enjoyment of activities and
having something to do and look forward to, (9) spir-
ituality, and (10) finances (Dröes et al., 2006; Jonas-
Simpson & Mitchell, 2005; Moyle et al., 2007; Train
et al., 2005). Conversely, losses and death have been
140 reported as having a negative effect on QoL (Dröes
et al., 2006; Jonas-Simpson & Mitchell, 2005). Most
findings elicited in those qualitative studies concur with
current theoretical models of QoL in dementia,
145 although as Dröes et al (2006) point out, not every
domain referred to by PwD is represented in every
measurement instrument. In addition, findings using
qualitative research have challenged the large cognitive
components included in most QoL frameworks.
150 As when PwD have been asked about their QoL,
disease-orientated issues have not always emerged
(Byrne-Davis, Bennett, & Wilcock, 2006).

Whether quantitative or qualitative, this broad and
emerging body of literature now shows that in the
context of NH residents with dementia, activities are
155 usually reported as being very beneficial and having a
positive effect on QoL (Harmer & Orrell, 2008; Train
et al., 2005). Whilst lack of meaningful activities has
been repeatedly identified as a feature of residential life
in dementia (Orrell et al., 2008; Van der Roest et al.,
160 2007), and whilst activities are desirable and beneficial
to most, it seems that enjoyment of activities may no
longer be relevant to those with a severe dementia
(Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992).
In long-term care, depressed residents (Gonzalez-
165 Salvador et al., 2000; Wetzels, Zuidema, de Jonghe,
Verhey, & Koopmans, 2010) and residents assessed as
having a poor QoL (Ballard et al., 2001; Lyketsos
et al., 2003) are noted to be less engaged in activities,
have fewer interactions with other people and are more
170 socially withdrawn.

Other research has shown that the QoL of PwD in
NHs is associated with good interpersonal relation-
ships and social contact (Moyle et al., 2007). Social
networks, support and participation, whether from
175 inside or outside the facility, have been associated with
happiness and well-being (Hanestad, 1997). Even in the
case of advanced dementia, it has been suggested that
interpersonal relational aspects of care are very rele-
vant to those who are in this final phase of dementia
180 (Koopmans, van der Molen, Raats, & Ettema, 2009) as
these people were very likely to have a very positive
response when approached.

In keeping with the literature recommendations,
this study uses a qualitative approach to elicit peoples'
185 own subjective views and individual accounts about
their QoL in general and in relation to their lives in
NHs. In particular, the study aims to examine if
differences or similarities exist in perceptions of QoL
amongst NH residents with different levels of CI.
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Methods

This study was exploratory/descriptive and used a qualitative design. Sixty one residents with different levels of CI and who were living in three Dublin area based NHs were interviewed. The study received ethical approval from Trinity College Dublin Ethics Committee.

The NHs

Three NHs were included in this study. These NHs were a sub-sample from an earlier and recently published study that focused on dementia and CI prevalence rates in Dublin-based NHs (Cahill, Diaz-Ponce, Coen, & Walsh, 2010). In this earlier work, four NHs were randomly selected¹ and 100 residents (25 from each facility) were randomly screened for CI. For the purpose of this article, one of these four NHs was excluded since it was exclusively religious (nuns and priests) and preliminary analysis of data showed the unprecedented way in which religion dominated perceptions of QoL for this group.

The three NHs sampled were relatively similar in size and staffing. NH 1 had a bed occupancy of 64; NH 2 had 45 and NH 3 had 50. Each was Private and located in the Dublin metropolitan area. Most of the residents, particularly those with a mild or moderate CI, had private single bedrooms. Most of those with a severe CI shared a bedroom with at least one other. Each NH employed an activity co-ordinator to deliver their activities. No NH offered any activities to their residents during weekends.

Participants

Of the three NHs ($N=75$), and for the purpose of this article, nine participants were excluded from the analysis since they remained cognitively intact. Five others had a severe dementia with significant communication difficulties resulting in blank interviews and consequently could not be included in the analysis. The final sample was composed of 61 men and women, of whom 13 were mildly cognitive impaired, 20 had a moderate impairment and 28 were severely impaired. This research study is based on these 61 men and women.

Data collection instruments

Face-to-face in-depth semi-structured interviews were used to collect the data. In addition, the Mini-Mental State Examination (MMSE; M.F. Folstein, S.E. Folstein, McHugh, & Fanjiang, 2001) was used to screen for CI.

Interview schedule

We designed a simple 15-item semi-structured interview schedule (Appendix 1). Questions posed were

primarily based on published qualitative research studies on QoL and dementia (Dröes et al, 2006; Train et al., 2005). The interview started by asking the participants to talk about their daily lives in long-term care and what was important to them now. It then progressed to asking specific questions about sources of happiness and sadness, privacy, homeliness, activities, interactions with fellow residents and staff, what residents favoured most about living in long-term care and what they liked least. Interviews were conducted in private locations in the NH and lasted about 20–30 min. All interview data were written down but not audio-taped because of resource constraints. Interview data were later typed up.

Mini-Mental State Examination

Folstein et al.'s (2001) recommendations for classifying CI severity were followed, i.e. normal cognitive function = 27–30, mild CI = 21–26, moderate CI = 11–20 and severe CI = 0–10.

Procedure

Potential participants and their relatives were informed about the study by NH staff members and provided with a written information sheet. In addition, prior to the researcher commencing the interview, the study's aims were further explained and participants were informed about the study protocol. In each of the NHs, written consent was sought from residents. In cases where participants had a severe CI or were deemed to have an advanced dementia and unable to give consent, their relatives' written consent was sought. Whenever possible, these residents were asked for verbal assent.

Data analysis

A thematic approach was used to analyse the data (Creswell, 2003). Thematic analysis involves searching in the interviews transcripts for common themes and sub-themes that are relevant to the topic under investigation (Daly, Kellehear, & Gliksmann, 1997). Typically, themes are derived from the data (induction) and can also be induced from the researcher's prior theoretical understanding (deduction) (Ryan & Bernard, 2003).

Initial coding of the data

Data were analysed manually. The two researchers took verbatim notes (Pope, Ziebalnd, & Mays, 2000) of each interview and all verbatim responses were written up in a word document. Both researchers read and re-read all interview data several times. All cases were classified into three groups according to CI severity (13 mild, 20 moderate and 28 severe). Fifteen interview scripts (five cases were randomly selected from each group) were then carefully re-read by both researchers

independently, and each researcher assigned preliminary codes to these 15 interviews. Subsequently, during a series of meetings, a set of 28 codes was agreed. Examples of these codes assigned include, hobbies, fun, environment, privacy, visitors and dependence. Most codes concurred with the previous work in the area and emerged from the specific open-ended questions used in the interview protocol (Coffey & Atkinson, 1996).

Consensus between coders

Since some difference of opinion on code categories emerged for those with a mild CI ($N=13$), both researchers read and coded all mild CI data independently, and then met to discuss and resolve through consensus any differences. For the remaining interviews ($N=38$), the coding was performed only by one of the researchers.

Emergence of themes

In each interview, the cutting and sorting technique as described by Ryan and Bernard (2003) was used. This involved researchers cutting out quotes reflective of the codes and pasting material onto a new word document (Ryan & Bernard, 2003). Each quote contained reference to who said what (participant number, gender and MMSE score) and where the quote appeared in the text (Ryan & Bernard, 2003). Any data which could not be placed into one of the existing codes was registered separately. After coding all the interviews, only three new codes emerged (insight, unfulfilled desires and self-identity).

The codes were then clustered into groups reflecting emerging themes and sub-themes. Four core themes, namely (1) social contact, (2) attachment, (3) activities and (4) affect were identified across all participants. For the purpose of the analysis, researchers focused attention on the similarities and differences found in each theme across the three subgroups of residents (mild, moderate and severe).

Results

Participants

Of the 61 participants, 13 were males and 48 were females. A total of 16 were single, 6 married, 2 separated and 37 were widowed. The mean length of time living in NHs was 2 years and 9 months (range 1 month to 13 years). Participants' ages ranged between 62 and 100 (mean = 85.3). The mean MMSE of residents interviewed was 12.6 (range 26 to 1). Sociodemographic characteristic profiles of the three participant groups can be seen in Table A1 (Appendix 2). A difference noted was that within the severe group, a greater number had been admitted to long-term care because of dementia. In contrast for those with a mild CI, larger numbers were admitted to long-term care as they could no longer live alone.

Curiously, the group of moderate residents had spent slightly less time in the NH than the other two groups.

Theme analysis

The four main themes identified were: 350

- (1) social contact (including sub-themes of family, residents and staff);
- (2) attachment (including sub-themes of feeling at home/missing home and connectedness);
- (3) pleasurable activities (including sub-themes of structured vs. unstructured activities, outings and momentary pleasures); 355
- (4) and affect (including the sub-themes of happiness, sadness/depression and loneliness).

Social contact

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Extensive comments about social contact (family, staff and fellow residents) were made by all three groups (Table 1). However, a striking sub-theme was the salience that 'the family' continued to have in the lives of most residents. This was especially evident for those with a mild to moderate CI who appeared to cherish family visits and who when asked 'what is important to your life now', often volunteered to talk about their family members. In contrast, for those with a severe CI, several claimed that they missed their families and several complained (rightly or wrongly) that family members now no longer visited – 'I have a family they don't bother visiting' (female, aged 87, MMSE = 1). 365

Staff also appeared to play a significant role in residents' lives across each of the three groups and were generally referred to in extremely positive terms, – 'very nice', 'good', 'friendly', 'polite' and 'lovely people', particularly by those with a mild to moderate CI. Interestingly, participants with a severe CI were less superlative about staff relationships and less inclined to refer to staff. In general, the three groups of residents were less forthcoming about their relationships with fellow residents. Few appeared to have made new friends in the NH. A small number of those with a mild CI had taken on a surrogate role as carer to fellow residents they deemed more disabled than them. A few, particularly those with a mild to moderate CI, complained about their fellow inmates. These complaints often centred around difficulties tolerating other residents' idiosyncrasies, particularly when sharing rooms or having to interact with others over mealtime or during activities. Those with a moderate to severe CI appeared to be far less aware of their fellow residents and, not surprisingly, made no complaints. 375 380 385 390 395

Attachment

This attachment theme focused on the extent to which participants felt 'at home' in the NH and/or connected

Table 1. Selection of quotes from the theme Social Contact.

 Sub-themes: family, staff and residents
Mild CI

'Seeing them (*my children and grandchildren*) makes my happy. (...) the children can come and see me (...) (Staff) are respectful. They are nice, they do anything you ask'. (female, 82, MMSE = 21)

'The care here is very good. They bring me food and help me in the toilet. Some are Indian and most of them are not local, Irish. They are very nice, they all respect me. (...) I like the staff and (name of the Director of Nursing)'. (female, 90, MMSE = 23)

'There are a few annoying, there is a chap, I cannot understand him. I let him go. He always wants the TV on and wouldn't change the channel. I just let him go there is no point in fighting'. (male, 88, MMSE = 26)

'I get on very well, I sit in the piano room which is quieter and say hello to everybody'. (female, 84, MMSE = 22)

Moderate CI

'My family still come to see me' (...) 'One or two of staff are not nice, rough. When I am getting up in the morning I am slow, they get me out, put me on the commode. Leave me there for a while'. (female, 81, MMSE = 16)

'Staff are very obliging. It is a warm feeling of people. They are very nice. The manager is a very kind, human person. They could not be nicer'. (female, 89, MMSE = 20) sometime the priest. There are only one or two odd people here'. (male, 74, MMSE = 14)

'Well there is nobody here much besides myself and whoever is working here and We (residents) don't have much talk but they are ok'. (female, 89, MMSE = 12)

Severe CI

'I have a family, they don't bother visiting' (female, 87, MMSE = 1)

'I miss my family'. (female, 92, MMSE = 5)

'They (staff) are a little bit secretive'. (female, 84, MMSE = 4)

'I don't know anybody in here. I spend my day in the bed'. (female, 92, MMSE = 9)

'I hate having nobody here... I'd like to know where they all are'. (female, 83, MMSE = 3)

Table 2. Selection of quotes from the theme Attachment.

 Sub-themes: feeling at home/missing home, connectedness
Mild CI

'I feel this is my home and nobody else's. (...) I used to live in (*name of the borough*) very near to this NH, I know all the shops. The lad in the shop up the road, I go there and have a laugh with him' (male, 88, MMSE = 26)

'I like to live here, this is my house. I've been here 9 years now' (female, 84, MMSE = 22)

'Yes relatively, it is my second home (...) I want to go back home once I finish my treatments. (...) I have another home out there and I want to go home before I die' (male, 93, MMSE = 22)

'I've nothing here, none of the things I want around me. I have no dog. My daughter looks after the dog' (male, 71, MMSE = 26)

'Big shock to me from own home (...) you sit with your mouth closed all day' (female, 85, MMSE = 26)

Moderate CI

'I am very happy here. You bring yourself wherever you go (...) It is very important to me where I live. To have a nice house and garden' (female, 95, MMSE = 13)

'I have been living here for quite a while now. Is the kind of place you come for a long while'. (female, 96, MMSE = 13)

'Personally is what I want, peace and quiet. (...) In general it is quite good (...)

(Do you see this Nh as your home?) that will never happen; I only live up the road. Life (*here in the NH*) in general is not the same. You could not compare the two lives'. (female, 92, MMSE = 15)

'(What is important to you?) Go home. (...) No (*this is not my home*) I live at home in (*name of neighborhood*)' (female, 84, MMSE = 18)

'I miss home and my friends, the neighbors. Lived in (*name of neighborhood*) (...) I miss my friends' (female, 81, MMSE = 16)

Severe CI

'Do you see (this NH) as "home"? I do, yes (...) What helps you to see this Nursing House as home? Just look at it as it is. I think I am very lucky. I thank God I have this chance. (...) It is good for me and I am happy' (female, 76, MMSE = 10)

'Do you see this NH as "home"? No, I lived at home, but this is not, this is a house. (...) I like it because I get used to it, to live here' (female, 66, MMSE = 8)

'Do you consider (name of the nursing home) as your own home? NO!! (very strong)' (male, 63, MMSE = 3)

'We don't live here - only visit here' (female, 87, MMSE = 1)

'Do you see this NH as "home"? Not particularly now as my home (...) I am working here (female, 83, MMSE = 2).

400 to the environment where they now lived (Table 2). Different views were reported by these NH residents ranging from several, feeling that the NH was 'home'; they felt happy since they considered the facility

homely and felt lucky to be there, to another group strongly refuting the notion that the NH might be considered 'home'. Those who denied the NH was 'home' still wished and in some cases hoped to return

to their 'real' home. A smaller group of residents had more ambiguous feelings or were just resigned to living there.

410 Further analysis revealed that about one-half of residents with a mild CI (7 out of 13) felt at home in the NH, whilst only about one-third (6 out of 19) of those with a moderate CI, and even fewer, only about one-sixth (5 out of 28) of those with a severe CI felt
415 'at home' in the NH. The narratives of those with a mild CI clearly showed that most who felt 'at home' in the NH, did so because they had lived there for a long time, its location was close to where they/or other family members once lived, the atmosphere in the NH
420 was pleasant as were the staff and their relationships with staff members. Interestingly, residents who had previously lived in the area and those whose adult children presently lived nearby seemed particularly well adjusted. Having a private single room and being able
425 to enjoy some privacy helped many residents to feel at home.

Where these elderly men and women previously lived also remained very important to many. During the interviews, several spoke spontaneously about their
430 previous homes, mentioning by name the area where they used to live and some even gave a brief description of their house. Recollections of former homes were in most cases imbued with feelings of sadness. In some cases, homes had been sold and whilst in others, the
435 original home remained; these residents recognised that they were no longer able to live alone. Residents across all the three groups stated that they missed home but also often its locale, – the place where they used to live (neighbours, friends, local shops, etc.).
440 Among the severe group, we found the greatest number of reports of residents feeling disconnected and in search of home (15 out of 28 residents) – 'Home? No is not. This is not my home' (female, aged 95, MMSE=4). Several of those disorientated,
445 attempted to make sense of where they were now physically located, claiming that the NH was their work place or a home run by a relative or that they were merely visiting the place temporarily.

Pleasurable activities

450 Regarding structured activity programmes run by the NHs, analysis revealed how exercise classes and Bingo were cited by the majority as the most popular and enjoyable (Table 3). All residents with a mild CI and most with a moderate CI showed awareness about the
455 NH activities provided. Most residents reported that they enjoyed participation in these activities, although several of those with a mild-and-moderate CI complained of boredom and would welcome more regular stimulation – 'I don't think they organise activities, they do sometimes but not very often' (female, aged 89, MMSE = 12).

The main reason for liking activities was the pleasure derived from looking forward to, attending

and participating in them, except in the case of exercise where its health benefits were cited by several as
465 reasons for its enjoyment. Sadly, across each of the interviews conducted with those who had a severe CI, a distinct absence of awareness of NH-structured activities was noted, and most of these residents showed disinterest and indifference in discussions on this topic
470 – 'I never heard about it' (female, aged 92, MMSE=9), 'I can't say I know a lot about activities' (Male, aged 74, MMSE=10).

In discussion about activities, reference was often made by those with a mild or moderate CI to past
475 hobbies (knitting, crochet, gardening) and leisurely interests (golf, playing cards), some of which could no longer be pursued due to physical and cognitive disabilities. These residents by and large felt saddened about this – 'if I could play Bingo I would be a lot
480 happier' (female, aged 81, MMSE=18). The most important unstructured activities for residents, included reading, listening to music, watching TV, chatting to other people and playing cards.

Being taken out by relatives for the day or
485 afternoon was mentioned by many as an activity which provided much pleasure. A few complained about not being allowed to go out alone and felt frustrated because of this. For those with moderate CI, the garden and being brought outdoors was important
490 as it provided stimulation and pleasure. Interestingly, outings were not a relevant topic for those with a severe CI. Instead for this group along with those with a moderate CI, simple pleasures such as 'cups of tea', 'cigarette smoking', 'a sunny day', 'the odd chat' or
495 'someone giving me an ice-cream', bestowed much gratification.

Affect

This theme accounts for different positive and negative emotions which emerged from the analysis of residents' interview data (Table 4). Findings showed that feelings of happiness, sadness and loneliness were the three
500 predominant emotions which emerged across the interview data. Regarding happiness, results showed that several residents from each of the three groups reported feeling happy, and talked about being in good form, having fun and enjoying life in the NH. Some could provide details about what for them conferred happiness. Reasons included (1) the people they met in the NH, (2) the care received and (3) the respect,
505 dignity and privacy afforded to them. Others talked about their own particular bedroom conferring happiness. In cases like these, single bedrooms had ostensibly become their 'home' making them feel happy and content. Most feelings of happiness were reported by
515 residents with a mild CI.

Several residents talked about feeling sad, and a few claimed they were depressed. Feelings of sadness and depression tended most often to be associated with losses including deaths of family members, especially
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Table 3. Selection of quotes from the theme Pleasurable Activities.

 Sub-themes: structured vs. unstructured activities, outings and momentary pleasures
Mild CI

'We have Bingo, I like it (...) I had hobbies when I was at home, mostly gardening. I got kind of lazy. I need help for everything' (male, 93, MMSE = 22)

'We have question times, exercises and sonas' R73 (male, 71, MMSE = 26)

'My children bring me out for meals' (female, 82, MMSE = 21)

'(Staff) won't let me out as I am not fit to walk' (female, 85, MMSE = 26)

Moderate CI

'We play Bingo and all. I don't know (...) I play cards with some of them (other residents)' (male, 74, MMSE = 14)

'I miss knitting. We only have an exercise class. We go to on Tuesdays; hair takes up Wed. Church at the weekends' (female, 92, MMSE = 15)

'Don't seem to have any (activities) or else I am not with it' (...) 'Well I don't do anything here. I'd like to do some kind of activities. I'd like something to do. There don't seem to be any activities of any kind' (female, 80, MMSE = 12)

Severe CI

'Do you like the activities that (NH) organizes for you? I've never heard of any. I don't know of any' (female, 66, MMSE = 8)

'Do you like the activities that (NH) organizes for you? No I don't because I didn't pick these out' (female, 83, MMSE = 2)

'Do you like the activities that (NH) organizes for you? Don't mind, don't do anything here' (male, 86, MMSE = 6)

Table 4. Selection of quotes from the theme Affect.

 Sub-themes: happiness, sadness/depression and loneliness
Mild CI

'I am very happy with my life here and the people I met (...) I am happy, I am pleased (...) I am happy with the whole lot as it is' (male, 93, MMSE = 22)

'(Life is) great. I am very happy with my room' (female, 80 MMSE = 23)

'Sometimes I feel depressed, not often. That happens when I think back in my life, how my life was... my wife' (male, 88, MMSE = 26)

'I have no home, my home is gone. Everybody died and everything went to my nephew' (female, 90, MMSE = 23)

'My husband died, I would like to live with my family (...) I miss my husband and my family but I don't like to think about that. Is gone and it makes me feel sad' (female, 77, MMSE = 21)

Moderate CI

'I am happy and if I have growls or grumbles I don't make a thing about it' (female, 79 MMSE = 11)

'I feel happy when I am in good form' (female, 91 MMSE = 19)

'It is barely life, I have my own way. I don't like any fuss I wish I had someone with me for a day or two' (female, 79, MMSE = 11)

'Life is catching up on me (What makes you feel sad?) be sad (...) Life in general is not the same (...) I could not compare the two lives (before and now) (...) I miss knitting. Loss of all my people, ma, fa, brother (...) Life in general is not the same' (...) 'I admit it is a bit lonely' (female, 92, MMSE = 15)

'I have nothing to look forward to, only carry on till my life ends' (female, 87, MMSE = 12)

'There is not an awful lot of my life left to be important (...) My life is much in advance. I am in my 80's' (female, 88, MMSE = 17)

Severe CI

'I am happy when I see someone' (female, 94, MMSE = 4)

'Is good for me, the thing I am doing here is helping me and I enjoy it. I am very happy (Anything that makes you sad?) Nothing, honestly. I am a "happy" person

I just love being in here and I am so grateful. I don't have anything to be worried about' (female, 76, MMSE = 10)

'(...) I have no where to go, I am here because of that. (...) And what makes you feel sad? To think back, shops and all are gone. All my family is gone. (...) I have no teeth' (female, 95, MMSE = 6)

'I wont get very far in it (my life) I am afraid' (...) 'I hate having nobody here. It is nice if there is somebody that you could use' (female, 83, MMSE = 3)

'Sometimes I wish I was dead cause there's nothing in life for me at all. I can't make anything out of life. I am unlucky with my family' (female, 90, MMSE = 8)

'Yes, I will be glad to have more people coming in, but if the weather is bad there is nothing that you can do' (female, 84, MMSE = 4)

'There are a few items that I would like to change (in the NH). I'd like to be able to talk to people, where people gather in the community. (male, 74, MMSE = 10)

spouses and other first-degree relatives. Some felt sad about losing their home – 'I have no home, my home is gone' (female, aged 90, MMSE = 23) or about losing aspects of their physical independence which meant

that they were now reliant on others and unable to do the things they once enjoyed like hobbies. Some other residents, particularly those within the moderate CI group, expressed feelings of sadness in relation to their

age or being at the end of their lives – ‘my life is much in advance’. I am in my 80’s (female, aged 88, MMSE = 17).

In relation to loneliness, nobody with a mild CI reported they felt lonely, and only one resident with a moderate CI claimed she was lonely when she reflected back on her youth and remembered being able to ‘dance’ and when she remembered her deceased son. In contrast, loneliness, feeling lost, and at the extreme a feeling of abandonment and a quest for human contact was a striking sub-theme in data collected from residents with a severe CI. A large number of those with a severe CI seemed to be in quest of social contact – ‘I hate having nobody here, I’d like to know where they all are’ (female, aged 83, MMSE = 3).

Finally, a small minority of the participants revealed feelings of hopelessness ‘there is not a lot in my life to be important’ (female, aged 88, MMSE = 17), ‘I have nothing to look forward to only carry on till my life ends’ (female, aged 87, MMSE = 12) and at the extreme virtual despair, ‘sometimes I wish I was dead...’ (female, aged 90, MMSE = 8). Analysis showed that those who felt such extreme negative emotions had either a moderate or a severe CI.

Discussion

Overall, our findings support this growing body of literature on dementia and QoL (Dröes et al., 2006; Jonas-Simpson & Mitchel, 2005; Moyle et al., 2007; Train et al., 2005). Results demonstrate that for this NH sample, factors associated with a good QoL included positive social relationships, pleasurable activities, feeling at home, attachment to the NH environment and positive affect. In keeping with this literature, the family and particularly quality social interaction with family members had a very important positive impact on residents’ QoL (Byrne-Davis et al., 2006, Dröes et al., 2006, Jonas-Simpson & Mitchel, 2005). We also found that residents frequently believe there were insufficient activities in place in the NHs for their enjoyment (Harmer & Orrell, 2008). With the exception of exercise, results also show that whilst activities were deemed enjoyable (Harmer & Orrell, 2008; Train et al., 2005), residents themselves failed to identify their health benefits. Whilst previous studies have shown that PwD in long-term care frequently express a desire for more choice, freedom and independence (Dröes et al., 2006, Train et al., 2005), this was not a finding in our sample. This finding may result from cultural differences or from the fact that our sample was more severely cognitively impaired. Nor did spirituality or religion emerge as important to the sample, a finding somewhat surprising given the age and cultural profile of this Irish sample.

Our findings also build on and extend the literature on QoL and dementia since we attempted to unravel differences and similarities in QoL between the three

participant groups with varying degrees of CI, a topic the literature has not well addressed to date, and one we found at times challenging. As we were particularly interested in those with a severe CI, we only excluded from analysis, blank interviews of which there were five. In all other cases, we attempted to make sense of the data. We found that whilst it was not always easy to understand the verbal content of respondents particularly, that of those with very low MMSE scores, nonetheless by employing qualitative approaches (using a very simply constructed short questionnaire with open-ended questions) and by taking into account respondents’ non-verbal communication during the interviews (tone of voice, gestures, etc.), the majority of those with a severe CI (28 out of 33) could respond well and most of the data could be interpreted.

Our findings show preliminary and emerging differences between the groups, especially when we compared those with a mild and severe CI. In particular, the narratives of the severe group reflected an absence of social contact (be that authentic or not) with family members, other residents and staff and a lack of engagement in structured pleasurable activities. Instead for them, momentary pleasures such as ‘a cup of tea’ or ‘having an ice-cream’ were more relevant. People with a severe CI were also more likely to want to go ‘home’; they felt detached and believe that the NH was not their home.

This feeling of being dislocated and a quest for home is in keeping with the recent literature (Orulv, 2010) and can be interpreted as a search for security, safety and belonging to somewhere. In our sample, some of those with a severe CI who were ‘dislocated’ used different strategies to make sense of where they were physically located; some claiming, for example that the NH was their work place, or a place run by a relative, or simply justifying their disorientation by arguing that they had just arrived there. Orulv (2010) argued that disorientation had a social and existential dimension and showed that in some cases, interaction with other residents was very relevant for a positive co-construction and negotiation of the place. We did not capture this in our study where we found that for those with a severe CI, relationships and interactions within other residents were very rare. The narratives of these residents with more advanced dementia reflected greater degrees of loneliness, social isolation and a desire for human contact. These findings point to the need for NH staff to be cognizant of the multiple and unique needs of this group of residents with a severe CI. More resources need to be allocated to further promote these residents’ QoL.

Overall, our findings on QoL and what NH residents with a CI value most, have important policy and practice implications for NHs providing dementia care. Results which highlight the importance of family members’ visits for all three groups of participants, would suggest that open-door visiting policies should be encouraged whenever possible and private spaces

should be allocated in NHs to facilitate these visits. NHs should also strive to promote the involvement of family members and other community groups in the life and culture of the NH, as these were issues deemed very important to many participants. Our results which point to the importance of enjoyable activities for residents suggest that NH activities need to be wide ranging and tailored to individual past interests, life stories and needs. In particular, for those with a severe CI, momentary pleasures which are sensory stimulating may have an important role to play in promoting QoL. Underpinning each of these findings on QoL is the need for staff training in dementia care and the importance of on-going education on topics including assessment, communication, activities, challenging behaviour, palliative/end of life care and advanced dementia.

Limitations

As we did not include proxy (staff/relatives) perspectives on QoL, one limitation to this study is that we only have residents' viewpoints to report here. Accordingly, whilst their accounts may not concur with the proxy QoL accounts we have in this article attempted to report on what was real and relevant to these elderly people at the time. Thus, whether such accounts are orthodox or not, we believe they should be listened to and for the most part, seriously considered by NHs managers, relatives and staff.

Other limitations to this study include the fact that the sample of NHs used was small ($N=3$) and each was private and Dublin based. We are also aware that the QoL instrument developed by us was short, simple and failed to investigate health-related domains. A further limitation is that some of these elderly men and women particularly those with a severe CI may have suffered from depression, anxiety or apathy and indeed other mental health problems which may have influenced their perspectives and narratives. The groups may also have differed in other features not addressed in this study. For instance, more detailed background information about the residents' differential diagnosis may have been relevant, as it is possible that the diagnosis sub-type may have had an impact on QoL and such could have helped to explain some of the differences in QoL emerging between the three participant groups.

Conclusions

As noted in the literature, the debate over the definition of QoL suffers from an absence of consensus on domains (Taillefer, Dupuis, Roberge, & LeMay, 2003). Building on the work of others (Dröes et al., 2006), we devised a short simple instrument which could be used with the three participants groups, namely those with a mild, moderate and severe CI. We found that whilst perceptions of QoL for those

with mild and moderate CI were quite similar, for those with severe CI, some important differences were noted. In particular, this group of participants appeared to be in quest of human contact, and a large majority reported feelings of isolation and loneliness. As noted in the literature (Harmer & Orrell, 2008), the social inclusion of PwD in NHs, particularly of those with severe dementia needs more careful consideration. Our findings point to the need for more research to be done to better understand the 'subjective world' of those with more severe CI with a view towards developing interventions which will improve their QoL. Finally, our findings add to the increasing evidence that people with CI and even those with probably advanced dementia can often competently communicate their views and preferences about what is important to them.

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Note

1. See 'Methods' section of earlier paper (Cahill et al., 2010).

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Appendix 1. Interview schedule

- 915 (1) Can you tell me briefly, what is it like for you living here in (name of NH)
- (2) What is important to your life now?
- (3) What makes you happy?
- 920 (4) What helps you enjoy your days here?
- (5) What makes you sad?
- (6) Do you see (name of NH) as ‘home’?
- (7) What helps you to see this Nursing House as home?
- (8) What prevents you from seeing (name of NH) as your home?
- (9) Do you have your own private room? Is privacy important to you? 925
- (10) Do you like the way staff in (name of NH) treats you?
- (11) Do you like the way other residents in (name of NH) treat you? 930
- (12) Do you like the activities that (name of NH) organizes for you?
- (13) What do you like most about living here?
- (14) What do you like the least about living here?
- (15) Is there anything that could be done to improve your life in (name of NH)? 935

Appendix 2

Table A1. Background characteristics of the three groups of participants.

		Mild (N = 13)		Moderate (N = 20)		Severe (N = 28)		Sample (N = 61)	
		N	%	N	%	N	%	N	%
Gender	Male	3	23	4	20	6	21	13	21
	Female	10	77	16	80	22	79	48	79
Marital status	Never married	4	31	6	30	6	21	16	26
	Married	2	15	1	5	3	11	6	10
	Separated	0	0	1	5	1	4	2	3
	Widowed	7	54	12	60	18	64	37	61
Last occupation	Housewife	3	23	7	35	13	46	23	38
	Employed by others	5	38	9	45	11	39	25	41
	Self employed	1	8	1	5	1	4	3	5
	Do not know	4	31	3	15	3	11	10	16
Reasons of admission	Living alone, unable to manage	6	46	5	25	11	39	22	36
	Family could not manage	2	15	8	40	6	21	16	26
	Dementia	1	8	1	5	4	14	6	10
	Medical reasons (falls, depression, immobility, alcohol, etc.)	3	23	4	20	5	18	12	20
	Others	1	8	2	10	2	7	5	8
Age (years)		84.17 (72–94)		84.7 (62–96)		86.3 (63–100)		85.3 (62–100)	
MMSE mean score		23.3		15.2		5.75		12.6	
NH1 (N = 19)		6		4		9		19	
NH2 (N = 19)		2		8		9		19	
NH3 (N = 23)		5		8		10		23	
Length of stay (years)		3.1		2.2		3.3		2.9	