RESEARCH ARTICLE

International Journal of
Geriatric Psychiatry **WILEY**

The impact of auditory hallucinations on "living well" with dementia: Findings from the IDEAL programme

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Abstract

Objective: To determine whether auditory hallucinations in community-dwelling people with dementia (PwD) living in the community impacted on quality of life (QoL), subjective wellbeing and life satisfaction.

Design: Cross-sectional cohort study.

Settings and participants: 1251 community-dwelling PwD and caregivers were included in this study.

Measures: Neuropsychiatric Inventory Questionnaire completed by caregiver interview. Mean differences between the absence and presence of auditory hallucinations were compared to scores on three validated measures of living well: QoL in Alzheimer's disease scale (QoL-AD), World Health Organization-Five Well-being Index and Satisfaction with Life Scale. Analysis of covariance determined the confounding contributions of cognition via Mini-Mental State Examination, depression via Geriatric Depression Scale-10, caregiver stress via Relative Stress Scale and whether antipsychotic drugs were prescribed.

Results: Auditory hallucinations were associated with lower scores for QoL ($p < 0.001$, $\eta^2 = 0.01$), wellbeing ($p < 0.001$, $\eta^2 = 0.02$) and life satisfaction ($p < 0.001$, $\eta^2 = 0.01$). After controlling for background measures, which were potential confounds, the relationship between auditory hallucinations and QoL ($p = 0.04$, $p\eta^2 = 0.01$) and wellbeing ($p < 0.000$, $p\eta^2 = 0.02$) remained significant but there was no significant association with life satisfaction.

Conclusion: Auditory hallucinations are associated with lower QoL and wellbeing in PwD living in the community. This has implications for targeted therapies in PwD with psychotic symptoms.

KEYWORDS
psychosis, quality of life, satisfaction with life, wellbeing

Key points

- Auditory hallucinations were significantly associated with reduced scores for quality of life (QoL), subjective wellbeing and life satisfaction

- The associations remained significant for QoL, wellbeing and life satisfaction after controlling for cognition, depression, antipsychotic prescription, and caregiver stress
- The finding that auditory hallucinations are important for people with dementia to live well provides a focused treatment target when developing therapies for psychotic symptoms in people with dementia

1 | INTRODUCTION

There are 45 million people living with dementia worldwide.[1] Whilst dementia is commonly thought of as a generalized disorder of cognition and functional impairment,[2,3] neuropsychiatric symptoms are nearly universal, and often include psychosis.[4] Psychotic symptoms are frequently distressing to the individual and those in close contact, including the caregiver,[5] and are associated with poorer disease outcomes, including accelerated cognitive decline,[6] more rapid progression of functional impairment,[7] increased hospital admissions,[8] earlier admission to institutional care[7] and increased mortality.[7,9] In addition, psychotic symptoms are often antecedent to or co-morbid with other neuropsychiatric symptoms such as agitation, aggression and depression,[10] further adding to the impact on the individual and others. It is estimated that up to 50% of people with dementia (PwD) will experience a psychotic symptom—delusions, hallucinations or both—during the course of the disease.[11]

Auditory hallucinations have received far less attention than visual hallucinations or delusions, but nevertheless have a prevalence of up to 12% in PwD, and prevalence is higher in people with Lewy body dementia.[12,13] Understanding the potential impact of auditory hallucinations on quality of life (QoL) and elucidating their importance as a specific treatment target is therefore an important gap in our current knowledge. QoL has been defined as describing individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.[14] Dementia, and symptoms resulting from dementia, have a key impact on a person's lived experience and perceived QoL.[15–18] Relatively few studies have examined the impact of psychotic symptoms such as delusions and hallucinations on QoL.[19–22] The few studies that have been conducted have concentrated on community-dwelling PwD with smaller number of participants and possibly as a consequence have generally not identified associations between hallucinations and impaired QoL.[21,22]

Whilst QoL measures have been most frequently used in evaluating subjective life experience in the presence of dementia, the inclusion of perceived wellbeing and life satisfaction may yield a more complete understanding of a person's ability to "live well."[23,24] Subjective wellbeing represents the appropriate balance of positive and negative emotions ascribed to one's current situation, and life satisfaction reflects a global evaluation of one's life up to the present circumstances.[16,25] Although QoL, subjective wellbeing and life satisfaction are interconnected, they include unique elements that

examine different facets of "living well."[16,26] Living well with chronic illness and disability has been defined as the best achievable health state that encompasses all dimensions of physical, mental and social wellbeing.[16,27] The specific effects of auditory hallucinations on different facets of a person's ability to live well have not yet been determined.

The presence of other symptoms and features of dementia may serve as a possible confound to any interpretations associating auditory hallucinations with living well. Symptoms commonly related to dementia such as cognitive impairment and depression, and connected features such as antipsychotic prescriptions and caregiver stress, have been associated with lower QoL in PwD.[15,17,18,26,28,29] It is important to delineate the contributions of these factors when assessing the impact of psychotic symptoms in dementia.

The primary aim of this study was to determine the impact of auditory hallucinations on living well in PwD living in the community. We also aimed to elucidate the role of various possible confounds, such as depression, cognition, whether antipsychotic drugs were prescribed and caregiver stress, when evaluating the impact of auditory hallucinations on these outcomes.

2 | METHODS

2.1 | Study population

The study used data from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study, a longitudinal cohort study conducted across England, Scotland and Wales to investigate social, psychological and economic factors that may enhance the capacity to "live well" with dementia.[26,29] The IDEAL cohort at baseline comprised 1540 community-dwelling PwD and 1278 caregivers recruited between June 2014 and August 2016 through a network of 29 National Health Service sites. The present study used cross-sectional data from the IDEAL baseline assessment and the analysis was conducted on version 4.5 of the dataset.

All PwD had a clinical diagnosis of dementia and were in the mild-to-moderate stages as indicated by a Mini-Mental State Examination (MMSE)[30] score of 15 or above on entry to the study. For each person with dementia a family member or friend, subsequently referred to as a caregiver, who provided practical or emotional unpaid support was also invited to take part where available and willing. Informed consent was obtained from all PwD and caregivers. Researchers visited PwD and their caregivers in

their homes to conduct structured interviews. The caregivers were asked to complete questionnaires separately, and both acted as informants regarding the person with dementia and provided information about their own experiences. Data from PwD were included in the present study only if there was an accompanying caregiver to form a participant dyad and if the caregiver answered the question on auditory hallucinations from the Neuropsychiatric Inventory Questionnaire (NPI-Q).[31,32]

The IDEAL study was approved by the Wales 5 Research Ethics Committee (reference:13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014—11684). The IDEAL study is registered with the UK Clinical Research Network, registration number 16593.

2.2 | Measures

Auditory hallucinations: Caregivers completed the NPI-Q and were asked whether the person with dementia was experiencing symptoms in 12 discrete behavioral domains.[31] For the purpose of the present study, we only used the domain for auditory hallucinations. Specifically, presence of auditory hallucinations was defined as a caregiver's positive response to the question "Does your relative/friend act as if s/he hears voices? Does s/he talk to people who are not there?"[32]

Living well: Three self-report measures were completed by PwD to assess living well with dementia. These were the QoL in Alzheimer's disease scale (QoL-AD)[33] total score, the World Health Organization-Five Well-Being Index (WHO-5)[34,35] percentage score, and Satisfaction with Life Scale (SwLS)[25] total score. For each measure, a higher score indicates greater capability to "live well"; QoL-AD range 13–52, WHO-5 range 0-100, and SwLS range 5–35. For convenience the three measures together will be referred to as "living well" measures.

Cognition, mood and caregiver stress: The following additional measures from IDEAL were included in this analysis. The MMSE was used to measure cognition in PwD, with higher scores indicative of better cognition.[30] The Geriatric Depression Scale-10 (GDS-10) was used to measure depression in PwD, with higher scores indicating more self-rated depressive symptoms.[36] The Relative Stress Scale (RSS) measured the level of self-reported caregiver stress; possible scores range from 0 to 60 with higher scores indicating greater caregiver stress.[37]

Demographic data: Information on age and sex were obtained from PwD and caregivers. Additionally, information on education was obtained from PwD. Dementia diagnosis was provided by researchers from medical notes. Information about whether antipsychotic drugs were prescribed was obtained from a joint interview with the dyad using a pre-defined list of medications. Educational level was classified into four groups: no qualifications; school leaving certificate at age 16; school leaving certificate at age 18; university. Relationship with the participant was classified into two groups: spouse/partner

and other. Whether antipsychotic drugs were prescribed was coded as a binary yes/no variable.

2.3 | Planned analyses

All statistical analyses were carried out using SPSS Statistics v26. The main analyses used ANOVA to compare mean scores on measures of living well reported by those experiencing and not experiencing auditory hallucinations. Having conducted analyses on the three living well measures, a Bonferroni-adjusted alpha was used to correct for multiple comparisons; therefore, a p-value equal to/less than 0.016 was required to reach statistical significance. If a significant effect was found in the main analyses, further analyses were conducted using analysis of covariance (ANCOVA) to examine the confounding effect of cognition, depression, whether antipsychotic drugs were prescribed and caregiver stress on the association of the presence or absence of auditory hallucinations with living well. Effect size was calculated using eta squared (η^2) for ANOVA and partial eta squared ($p\eta^2$) for ANCOVA. Effect sizes were interpreted as follows; small (0.01 to 0.05), moderate (0.06 to 0.13), or large (≥ 0.14).[38]

3 | RESULTS

Among the 1278 eligible participant dyads, 27 caregivers did not answer the relevant question on auditory hallucination in the NPI-Q; hence the total number of dyads included in the analysis was 1251. Slightly more than half of the PwD were men (736%, 58.8%), with Alzheimer's disease (697%, 55.7%) being the most common diagnosis. Relatively few were prescribed antipsychotic drugs (26%, 2.1%). Prevalence of auditory hallucinations by dementia subtype was: Alzheimer's disease ($n = 37$) 5.3%; vascular dementia ($n = 5$) 3.6%: mixed Alzheimer's disease and vascular dementia ($n = 17$) 6.6%; , frontotemporal dementia ($n = 3$) 6.8%; Parkinson's disease dementia ($n = 13$) 31.0%; dementia with Lewy bodies ($n = 20$) 47.6%; and unspecified/other ($n = 2$) 6.5%. The sample characteristics are summarized in Table 1.

3.1 | Impact of auditory hallucination on living well

The first research question focused on whether there was an association between the presence of informant-rated auditory hallucinations and living well in PwD. Auditory hallucinations were significantly associated with lower scores for QoL, WHO-5, and SwLS, although effect sizes were small; see Table 2.

The second research question asked whether the difference between informant-rated auditory hallucinations and living well could be explained by cognition, depression, whether antipsychotic drugs were prescribed, or caregiver stress. ANCOVA suggested

TABLE 1 Characteristics of people with dementia and caregivers

Demographic information		n (%)
Characteristics of people with dementia		1251
Sex	Male	736 (58.8)
	Female	515 (41.2)
Age groups	<65	100 (8.0)
	65–69	156 (12.5)
	70–74	228 (18.2)
	75–79	298 (23.8)
	80+	469 (37.5)
Education	No qualifications	327 (26.1)
	School leaving certificate at age 16	222 (17.7)
	School leaving certificate at age 18	427 (34.1)
	University	244 (19.5)
	Missing	31 (2.5)
Dementia diagnosis	Alzheimer's disease	697 (55.7)
	Vascular dementia	139 (11.1)
	Mixed (Alzheimer's and vascular)	256 (20.5)
	Frontotemporal dementia	44 (3.5)
	Parkinson's disease dementia	42 (3.4)
	Dementia with Lewy bodies	42 (3.4)
	Unspecified/other dementia	31 (2.5)
Auditory hallucinations[a]	No	1155 (92.3)
	Yes	97 (7.7)
Antipsychotic medication	No	1226 (98.0)
	Yes	26 (2.0)
		Mean (SD); n
Mini-Mental State Examination		23.1 (3.7); 1187
Geriatric Depression Scale-10		2.7 (2.3); 1127
Quality of life in Alzheimer's disease		36.9 (5.9); 1139
World Health Organization-Five Well-Being Index		61.4 (20.5); 1228
Satisfaction with Life Scale		26.5 (5.9); 1217
Characteristics of caregivers		n (%)
Sex	Male	386 (30.9)
	Female	865 (69.1)
Age groups	<65	354 (28.3)
	65–69	206 (16.5)
	70–74	262 (20.9)
	75–79	219 (17.5)
	80+	210 (16.8)
Relationship to person with dementia	Spouse/partner	1018 (81.4)
	Other family/friend	216 (17.2)
	Missing	17 (1.4)
		Mean (SD); n
Relative Stress Scale		19.2 (9.8); 1187

[a]Symptoms indicated by caregiver via the Neuropsychiatric Inventory-Questionnaire.

TABLE 2 Relationship between auditory hallucinations and scores on measures of living well

	Auditory hallucinations	No auditory hallucinations			
	Mean (SD); n	Mean (SD); n	F statistic	p	Effect size
Quality of Life in Alzheimer's Disease scale	34.57 (6.10), 83	37.12 (5.87), 1056	(1,1137) = 14.44	<0.001	0.013
World Health Organization-Five Well-Being Index	52.34 (20.07), 94	62.21 (20.40), 1134	(1,1226) = 20.39	<0.001	0.016
Satisfaction with Life Scale	24.61 (6.50), 95	26.71 (5.82), 1122	(1,1215) = 11.13	<0.001	0.009

TABLE 3 Relationship between auditory hallucinations and scores on measures of living well adjusted for covariates

Covariate	Df	F statistic	p	Effect size
Quality of Life in Alzheimer's Disease scale				
Antipsychotic medication	1	0.47	0.495	0.000
Cognition	1	0.99	0.411	0.001
Caregiver stress	1	9.91	0.002	0.010
Depression	1	747.03	<0.001	0.440
Auditory hallucinations	1	4.12	0.043	0.004
Error	952			
$R^2 = 0.473$ (adjusted $R^2 = 0.470$)				
World Health Organization-Five Well-Being Index				
Antipsychotic medication	1	2.97	0.085	0.003
Cognition	1	4.23	0.040	0.004
Caregiver stress	1	1.08	0.299	0.001
Depression	1	645.66	<0.001	0.390
Auditory hallucinations	1	16.46	<0.001	0.016
Error	1008			
$R^2 = 0.409$ (adjusted $R^2 = 0.406$)				
Satisfaction with Life Scale				
Antipsychotic medication	1	0.26	0.610	0.000
Cognition	1	1.49	0.221	0.001
Caregiver stress	1	3.84	0.050	0.004
Depression	1	384.53	<0.001	0.277
Auditory hallucinations	1	3.00	0.084	0.003
Error	1002			
$R^2 = 0.302$ (adjusted $R^2 = 0.299$)				

that for QoL-AD scores the main effect of auditory hallucinations remained statistically significant after controlling for a priori confounding variables, but effect sizes were small; see Table 3. ANCOVA also indicated that for WHO-5 scores the association between auditory hallucination and wellbeing remained statistically significant. The ANCOVA did not find a statistically significant main effect of auditory hallucinations on life satisfaction scores. The results show that the association between auditory hallucinations and reduced QoL and wellbeing remained significant after controlling for a priori covariates but not life satisfaction.

Depression was a significant confounding variable with large effect sizes.

4 | DISCUSSION

The present study examined the associations of auditory hallucinations with self-reported QoL, wellbeing and life satisfaction in community-dwelling PwD. To our knowledge, this is the first study to use data from a large cohort to examine the relationship between auditory hallucinations and living well in community-dwelling PwD. Auditory hallucinations were associated with significantly lower scores on measures of living well, and these findings remained significant for QoL and wellbeing measures after adjusting for cognitive impairment, depression, antipsychotic usage and caregiver stress, confounding factors known to affect QoL in PwD.[15,17,18,28,29] The prevalence of auditory hallucinations in this cohort (7.7%) was similar to that found in previous literature[11,13] which suggests that prevalence of auditory hallucinations in community-dwelling people with mild-to-moderate dementia is likely to be around 10%. We found prevalence to be higher in PwD with Lewy bodies and Parkinson's disease dementia, which is consistent with previous research.[12,13]

No significant associations were detected for prescribed antipsychotics or cognitive impairment. Importantly, relatively few PwD in this cohort were prescribed antipsychotic medication (2.1%) as compared to previous studies that had detected an association between poor QoL and antipsychotic prescription,[15,19] and therefore the statistical power to detect associations with antipsychotic usage was low. Caregiver stress had a small effect on QoL for the person with dementia, but not wellbeing and life satisfaction, which is consistent with previous literature where caregiver stress has a stronger association with informant-rated living well rather than self-rated living well in PwD.[17]

As highlighted in previous literature, depression is a frequent co-morbidity in PwD with psychosis.[10] In the current study it was a key covariate alongside auditory hallucinations and associated with lower QoL, wellbeing and life satisfaction in PwD. Furthermore, depression had the largest effect size on all three living well measures of any of the co-variates. This result aligns with previous studies, in which depression has been a common predictor of poor QoL.[15,17,18,28,29] Importantly, the large effect size of depression detected in our analysis along with evidence from previous literature may indicate a potential association chain with depression having substantial

influence on reduced QoL, and limits interpretations of the relationship between auditory hallucinations and QoL.

The main strengths of the present study are the novel focus on auditory hallucinations, the breadth of measurement covering not just QoL but also wellbeing and life satisfaction, and the size of the cohort which gives good statistical power to examine the associations with living well. Additionally, the use of self-reported outcome measures in this study provides direct insight into the perspectives of PwD regarding their perception of living well. The study was limited by the slight reduction in sample size in the ANCOVA due to missing data, and the unavailability of NPI-Q data in a small number of cases, although the sample was still much larger than in previous studies. Small numbers of participants with rarer types of dementia reduced our ability to further investigate the effects of auditory hallucinations among people with these diagnoses. Additionally, the cross-sectional nature of the study restricted any causal interpretation, although this will be addressed once longitudinal data are available.

An important implication of these findings is to identify auditory hallucinations as an important treatment target in community-dwelling PwD. Given the potentially harmful effects of antipsychotic drugs,[39] the development of effective psychological therapies for key psychotic symptoms that include auditory hallucinations in PwD should be a priority. Importantly, our findings indicate that auditory hallucinations significantly impact the QoL and wellbeing of PwD living in the community, and therefore represent a key treatment target. Of note, there are a number of evidence-based psychological therapies for people with schizophrenia and auditory hallucinations[40] which could potentially be adapted to treat these symptoms in PwD.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

ETHICS STATEMENT

The IDEAL study was approved by the Wales 5 Research Ethics Committee (reference:13/WA/0405) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014—11684). The IDEAL study is registered with the UK Clinical Research Network, registration number 16593.

AUTHOR CONTRIBUTIONS

Aaron served as principal investigator of the research, designed the study, conducted data analyses, and took the lead in writing the manuscript. He is responsible for the data analysis and interpretation, and for drafting the article. Linda conceived and designed the IDEAL programme and contributed to the design and conduct of the current analysis, interpretation of findings and writing the manuscript. Anthony, Clive and Robin are co-investigators in the IDEAL programme and contributed to the design and conduct of the current study, interpretation of findings and writing the manuscript. Rachel contributed to the design and conduct of the current study, interpretation of findings and writing the manuscript. All authors have provided final approval of the version to be published.

DATA AVAILABILITY STATEMENT

IDEAL data were deposited with the UK data archive in April 2020 and will be available to access from April 2023. Details of how the data can be accessed after that date can be found here: http://reshare.ukdataservice.ac.uk/854293/.

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