

Patients' and carers' experiences and perspectives of the pharmacological management of anxiety and depression in people with dementia: Analysis of an online discussion forum

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Introduction

Dementia is a progressive condition characterised by a gradual decrease in cognitive functioning. Up to 90% of people with dementia (PwD) are affected by non-cognitive symptoms, the most clinically significant of which include depression and anxiety.¹

These can lead to significant changes in patient behaviour, contributing to carer burden and negative patient outcomes, such as reduced quality of life and institutionalisation.

Despite being recommended in certain circumstances only, pharmacological management options, such as anxiolytic and antidepressant medications, are commonly prescribed in PwD and may contribute to potentially inappropriate prescribing.²

A better understanding of how to optimise the management of these symptoms in PwD could reduce carer burden, prevent the need for institutionalisation, and inform future intervention development.

Study aim

To understand patients' and carers' experiences and perspectives of depression and anxiety in PwD and the pharmacological management of these symptoms, through a thematic analysis of an online discussion forum for those affected by dementia.

Ethical approval was received from the Queen's University Belfast Faculty of Medicine, Health & Life Sciences Research Ethics Committee (MHLS 22_75) in May 2022 and permission was granted from the Talking Point Community Manager.

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Methods

Setting

- Online discussion forum: Talking Point, hosted by the Alzheimer's Society.
- Comprises 1,811,339 unique posts and 74,489 members
- Allows registered members to create threads, edit posts and receive replies.
- Rich source of data.

Data selection

- A total of 59 search terms such as "depression", "anxiety", "antidepressant", "anxiolytic", "SSRI" were used to identify relevant threads/posts using the advanced search facility.
- Searches ran from date of inception to May 2022.

Data extraction

- Relevant posts were copied into Microsoft Word verbatim.
- All usernames are being assigned a unique study identification number, e.g. TP001.
- Duplicate, similar and irrelevant posts and threads are being removed.

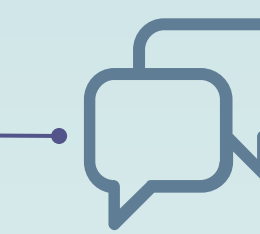
Analysis

- Inductive thematic analysis³ will be used to code the data and identify pertinent key themes.
- Study will be reported according to the consolidated criteria for reporting qualitative research (COREQ) checklist.⁴
- Appropriate illustrative quotations are being used to support interpretations.

Results

In total, 3,539 posts were extracted from 931 registered Talking Point users. Analysis of the data is ongoing. Preliminary findings show that depression and anxiety appear to be commonly experienced by PwD, and many forum users described the difficulty in differentiating between depression and dementia at the early stages of the condition, particularly where the patient had a previous history of depression:

Differentiating depression from dementia



"Initially my wife was treated for depression and anxiety but that soon changed to MCI [mild cognitive impairment], then dementia..." [TP019]

Forum users described their experiences of the use of a number of different medications to manage symptoms of depression and anxiety, and this appeared to be a case of trial and error in order to optimise symptom control:

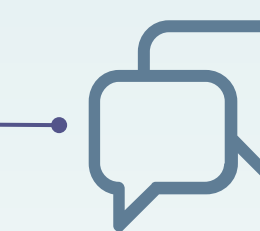
Medication use a process of trial and error



"The GP gave her sertraline but that didn't work so now on mirtazapine. Only been 10 days and really makes her sleep just with half a tablet but now crying again." [TP022]

Forum users described a range of signs and symptoms that patients had experienced:

Impact of depression and anxiety on patients and carers



"My FIL [father-in-law] says he just wants to end it quite a lot, even had the carving knife out of the drawer threatening to slash his throat a couple of times. Can't imagine how he must be feeling to say and do this." [TP722]

A range of different healthcare professionals were referred to by forum members as providing support with symptoms of depression and anxiety and their management, including general practitioners (GPs), community psychiatric nurses, and specialists in geriatrics and psychiatry.

Conclusion

This study will provide important data on patients' and carers' experiences of the pharmacological management of anxiety and depression in PwD and will inform further qualitative work with key stakeholders, such as carers, GPs, and pharmacists. Analysis of online fora can provide additional data not accessible through traditional qualitative research methodologies. Whilst the search terms used were comprehensive, it is recognised that these may not be exhaustive and may not include posts that contained typographical errors made by forum members.

References

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3. Braun A, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; **3**(2): 77-101.
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