

“I would imagine it needed a review...”

A qualitative study exploring the experiences of people with dementia and their informal carers of long-term condition reviews in primary care

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Introduction

Multimorbidity is common for people with dementia (PWD) and is associated with increased healthcare utilisation and poorer outcomes. Part of the management of long-term conditions (LTCs) occurs through annual LTC reviews conducted in primary care. Little is known about the experiences or needs of people with dementia and informal carers in regards to LTC reviews.

Aim: To explore the experiences of PWD and their informal carers of the review and management of LTCs in primary care.

Method

Qualitative research study, protocol informed by discussion with people with lived experience as an informal carer. Semi-structured interviews were conducted with PWD and informal carers recruited through Join Dementia Research and local (to Norfolk, UK) charities. Thematic analysis was undertaken with reference to Braun and Clarke (2006).

“She was taking an absolute cocktail of medicines [...] I do wonder whether it was just a case that things accumulated without an overarching plan.”

“It’s not knowing what’s available. It’s not knowing who to ask for what”.

“I don’t think she’s had a [...] review since lockdown”

“But it would be better for everyone if there was just a little more communication I think.”

“I hear from the care home rather than the GP”

“The GP seemed interested in what Dad actually wanted [...] we have a plan now”

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Results

16 participants were interviewed: two PWD, 10 informal carers and two informal care/PWD dyads. Our findings fall into four main themes:

1. What matters to people.

PWD and carers wanted LTC reviews to meet both medical needs (such as reducing polypharmacy) and their complex social care and wellbeing needs.

2. The experience of the review

Wide range of experiences of LTC reviews were described. Many expressed a lack of clarity and certainty as to whether a LTC review had taken place or not.

3. The importance of communication

The quality of communication between health care professionals and PWD and carers was key. Some had positive experiences. Others perceived that a review had occurred but described a lack of communication with a clinician or opportunity to be involved in the review. Communication issues were exacerbated when a patient lived in a residential home.

4. The involvement of PWD and carers in decisions

Poor communication could lead to lack of involvement of PWD and carers in decisions and no opportunity for shared decision making, including when the informal carer had Power of Attorney.

Conclusion

- Reviews are frequently not meeting needs of patients and informal carers.
- There is a need for clearer communication to enable shared decision making and patient centred care.
- Further research with other stakeholders such as clinicians is now needed to inform how long-term condition reviews could be optimised to meet needs