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Background:

- Around 500,000 of the 6,500,000 unpaid family carers in the UK provide support and care within the context of an end of life phase.
- It is recognised that caring can be a positive and rewarding experience for some carers, but for others this may not be the case. (Cohen *et al.*, 2002)
- Carers at the end of life phase are at risk of developing Prolonged Grief Disorder (PGD) - also known as 'complicated grief', 'abnormal grief', 'chronic grief' and 'distorted grief'.
- Inadequate preparation and support prior to death is amongst the risk factors for PGD. (Barry *et al.*, 2002)
- Carers, concerned about wasting the time of their doctor, can be reluctant to make an appointment for issues relating to bereavement. (Nagraj & Barclay, 2011)
- Carers are often 'assumed to have no unmet support needs.' (Aoun *et al.*, 2012: 843)

Aim:

The aim of this study was to explore the needs of carers in relation to **Prolonged Grief Disorder (PGD)** to understand more fully their experiences supporting someone who is approaching end-of-life.

Methodology:

This was a mixed-method evaluation consisting of two phases:

- 1) **Qualitative phase** 2 focus groups with carers (n= 16)
- 2) **Quantitative phase** Electronic survey with health and social care professionals

Analysis Qualitative data were subject to content analysis to identify themes. Quantitative analysis explored frequencies from 62 respondents.

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You couldn't go to these things that were offered to carers because you couldn't be released from your caring. It's got to be built in. There's no point having a session . . . if you haven't got help to cover your absence. F3FG2

My wife . . . would not have anybody come and sit with her so that I can go out and do the shopping . . . we never asked any outside carers for help, my wife didn't want that. M1FG2

We had no friends, in fact one of [our] friends said "I can't do this again, I can't come and see him" . . . and I told him where to go, really. F2FG2

Results (selected):

- The caring role was experienced as demanding and time consuming. Feelings of isolation, fear and being overwhelmed were common.
- Many carers felt unable to prioritize themselves and time limitations often meant they were unable to access available support.
- Some carers were often discouraged from accessing support for the caring role by the person who was ill.
- Whilst in some cases peer support had proved invaluable, for other people social contact had reduced since taking on the caring role.
- 44% (27 survey respondents) felt that support services offered to carers prior to experiencing bereavement were either poor or fair; around
- 27% (23 survey respondents) believed that post-bereavement care was poor or fair.
- 41% (24 survey respondents) reported encountering PGD, significantly higher than estimates in most of the published literature.
- Only 20.3% (12 survey respondents) felt accurately able to predict future occurrences of PGD in family carers.
- 72% (42 survey respondents) felt that the implementation of an alert tool would be worthwhile.

Conclusion:

The needs of carers, both pre and post-bereavement, are complex and varied, with a range of barriers frequently preventing appropriate support being accessed or delivered. To counter this, and to ensure timely and appropriate intervention, there is broad support amongst carers and health and social care staff for the development of an alert tool to help identify those at risk of experiencing an adverse grief reaction. Consistent with the findings of other studies, our work suggests that further research into this area is warranted, and as such, work to develop an alert tool is planned.