

Understanding the barriers to identifying carers of people with supportive and palliative care needs in primary care

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Background

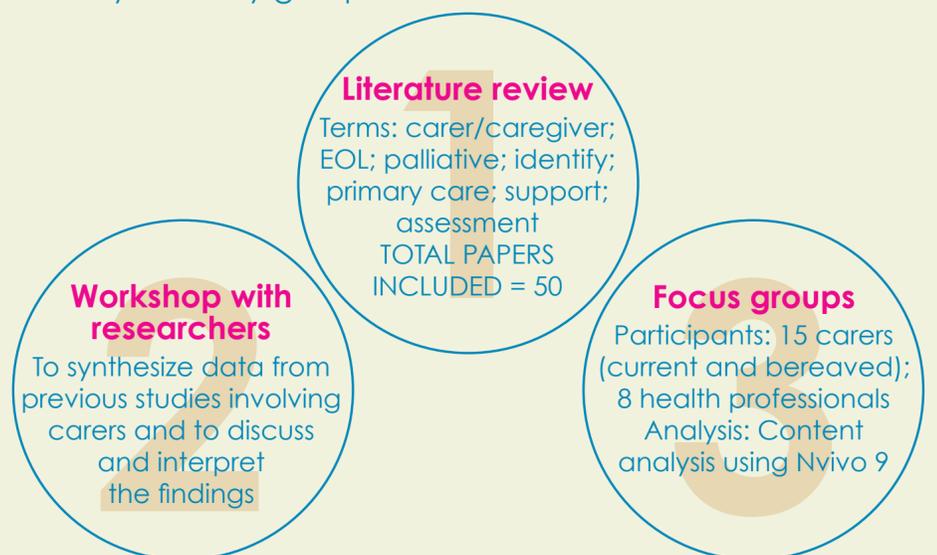
- Carers can experience poor physical and psychosocial wellbeing, but are often ambivalent about their own needs
- Policy suggests that carers should be considered equal partners in care
- Identifying carers is complex – primary care does not legitimise carer well-being AND carers are not self-identifying and asking for help

Aim

To explore the barriers to, and strategies for, identifying carers of people at the end of life in primary care, and to understand why carers do not self-identify.

Methods Triangulating 3 Data Sources

Findings were compared, contrasted and corroborated. Common themes were discussed with the steering group and lay advisory group.



Findings Barriers To Identification

1 THE GRADUAL PROCESS OF CARING

Carers did not always identify with the term 'carer'

"I feel the carer became what was the daughter. The carer part became more relevant when she [mother] lost that confidence" (Faye, caring for mother)

Relationships changed in the context of caring, which could affect the person's willingness to ask for support

"Like yesterday morning, I sort of had like been sort of, getting annoyed about things because he's a perfectionist and I said things just can't be perfect now" (Joan, caring for husband)

2 ENGULFED BY THE ROLE

The all-encompassing nature of caring compromised carers' sense of self

"I'd always had fairly wide interests, I found that I was losing interest in anything, in sport or politics or whatever" (Mike, caring for wife)

Carers struggled to manage competing demands of caring, work and family

"It's all about balance, this caring thing" (Shona, caring for parents)

3 LEGITIMISING THE NEEDS OF CARERS IN PRIMARY CARE

**Professionals' were perceived to lack knowledge about available services
Carers thought there was nothing available for them**

"I just don't feel there's... for me, I don't feel there's anything" (Pamela, caring for mother)

Professionals were described as reactive, rather than proactive, in supporting carers

Health professionals acknowledged that supporting carers was important

"Well, certainly as a GP, I would certainly see it as a very important part of my role to help someone who is a carer with that issue, but I think they would struggle to see it as the GP's role" (Health professional, GP)

Conclusions and Implications

- Identifying carers is important so that all carers can:
a) be acknowledged for their role; b) have their needs sensitively assessed; c) receive support that is right for them.
- Support for carers should be commenced early, which necessitates timely identification.
- Health professionals need to legitimise carer identification, assessment and support to ensure the experiences of carers are not overlooked.
- Legitimising carer support in primary care will hopefully encourage carers to self-identify.

