

## Supporting carers of people affected by cancer and other long-term conditions at end of life

Investigators: David Nelson, Ros Kane, Anna Thomson, Ian McGonagle

University of Lincoln, School of Health & Social Care

Mental Health, Health & Social Care Research Group (MH<sub>2</sub>aSC)

### Introduction

- ❖ Caring for someone at end of life can be physically and emotionally demanding (Carduff et al, 2014; Collins et al, 2014).
- ❖ Carers are often ambivalent about their own needs and are reluctant to identify as a 'carer' in need of support (Carduff et al, 2014).
- ❖ The needs of informal carers are significant but remain largely unmet (Burns et al, 2010).
- ❖ Six in ten people caring for someone with cancer experience some kind of impact on their lives (Macmillan Cancer Support, 2015).
- ❖ The unmet needs of current palliative care carers has received little research attention (Ventura et al, 2014).
- ❖ Tailored and specific interventions for informal caregivers in palliative care are rare (Harding et al, 2012).

Since March 2012, Macmillan Cancer Support has funded an intervention in Lincolnshire to offer a bespoke package of support. The intervention established a Macmillan Carer Support Service (delivered by Carers Connect) to co-ordinate packages of support and communication to carers of palliative and end-of-life patients.

### Aims

(1) To explore the experiences of those in receipt of the intervention and (2) To inform the funders of particular strengths and areas for improvement of their service.

### Method

#### Design

A qualitative approach was utilised to allow for open discussion about participant's experiences of the intervention.

### Sampling and recruitment

We used purposive sampling to recruit informal carers (n=10) in receipt of the intervention.

### Data collection

All interviews were conducted between August and September 2014 in Lincolnshire (England).

D.N. performed all interviews with the carers; in two cases the person they cared for was present. Interviews ranged from 45 min to 90 min. All interviews were digitally recorded and transcribed verbatim.

### Analysis

Data were analysed based on the Framework Method of qualitative data analysis (Ritchie & Spencer, 1994).

### Ethical considerations

The study was approved by the National Research Ethics Service (NRES) Committee West Midlands (14/WM/0154) and locally from the Lincolnshire County Council (LCC) Research Governance Panel. We obtained written informed consent from participants at the time of interview.

## Results

### Characteristics of carers

The sample of carers consisted of ten participants, 8 of whom were female and 2 male. The majority (80%) of those interviewed were aged 65 years and over and cared for their spouse or partner. Participants were also not currently in employment, with 8 retired and 2 not employed or looking for work. At the time of interview, 8 of the participants were currently caring, whilst 2 were no longer providing care and in receipt of bereavement support.

### Summary of findings

Participants were most commonly referred into the service via health professionals, however some participants were not aware of how they were referred or (prior to the point of referral), of the service itself. The service appeared to be meeting a specific need of carers, in that it focused on the needs of the carer, something not being met elsewhere. A positive outcome was that the carer has felt reassured about having background support. All those interviewed reported that the personal attributes and specialist skills of the support team had influenced their satisfaction with the service. Participants also remarked on how they were signposted to a wide range of useful resources, which helped to streamline communication between the carer and other health and social care services.

### Recommendations

- ❖ Content and delivery of the intervention were highly valued; however, some of the on-going support could be delivered via carer support groups.
- ❖ Promotion must be incremental and targeted in order that the service can adapt gradually to any potential increases in demand. This will then need to be further evaluated.
- ❖ With regards to advertising, consideration should be given to the branding of the service and Macmillan's association be made more explicit. Given the high levels of satisfaction with the service it should be publicised more widely (locally and nationally) to emphasise the positive impact it is having on carers.
- ❖ Bereavement support is an important part of the service that was clearly valued amongst the bereaved carers. It is recommended that this continues to form part of the service. However, there needs to be further clarity as to when a case is closed. If the service is to meet any potential demand for new cases then there should be a clearly established cut off point where a bereaved carer is signposted on for further support, should they require it.
- ❖ An increase in demand will limit the capacity of the current service and potentially affect quality. Given that carer satisfaction was greatly influenced by the personality and skill set of the support team, similar traits will need to be considered for any training of current staff or future recruitment (should it be necessary).

### Conclusion

The evaluation found the Macmillan Carer Support Service to be a successful intervention within a social care setting. The participants had no overtly negative opinions on the service in its current format and held it in a high regard. This service is still developing and establishing itself within the wider provision of palliative care support. Further evaluation should be conducted once the service has become more fully established. This study provides important insight into a unique support service that has potential to be replicated both locally and nationally.

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