

Meeting the social care needs of people affected by cancer in Lincolnshire

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Background

- ❖ People affected by cancer (PABC) can have a range of social and supportive care needs at different stages of the patient pathway. These may include **emotional, practical, personal**, as well as **information** and **financial** needs.
- ❖ The UK charity, Macmillan Cancer Support want to refocus their current social care provision and, (where need is evidenced) develop new services to address the needs of PABC in Lincolnshire.
- ❖ Macmillan together with the Bromhead Medical Charity has commissioned the University of Lincoln to undertake this research.

Aims

(1) To examine the social care needs of PABC in Lincolnshire (2) To provide recommendations regarding future service development and delivery.

Method

Qualitative study utilising in-depth interviews with PABC (n=10) across Lincolnshire. Data were analysed based on the Framework Method of Qualitative data analysis (Ritchie and Spencer, 1994)

Summary of findings

- ❖ All reported the need for emotional support (in particular around the initial diagnosis and surrounding period). This was fulfilled by friends, family, support groups and Macmillan health professionals.
- ❖ The need for practical and personal care support varied amongst those we interviewed with this often being dependent on the type and frequency of treatment. For most, family and friends shouldered the burden of this as opposed to social services.
- ❖ Some participants relied on personal income to pay for treatment and fund additional costs associated with their illness. Furthermore, expenses were also attributed to friends and family of the patient. We received reports of negative experiences when dealing with the Department of Work & Pensions (DWP) and claiming for Employment Support Allowance (ESA).
- ❖ Information and advice was important throughout the cancer journey; the preferred format (physical or online) was influenced by personal preference. For some, they felt well informed whilst others would have liked more information.
- ❖ Participants were often reluctant to apply for formal social support, in that, they felt they would be ineligible.

"I knew that when my husband was ill, he never got anything socially, he wasn't eligible because you've got money in the bank." (Participant 03)

"From outside, I think it maybe would have been nicer for my husband to have had someone to talk to...I think it's always worse for other people than the person who is ill." (Participant 02)

"...if you didn't have that emotional support especially in the beginning then it would have been a completely different story." (Participant 01)

"I was made to give up my job through the company I was with which was rather hard for me, I had no intention of ever retiring because I can't afford it but that's beside the point." (Participant 08)

"I was lucky my husband helped around the house...but I'm sure some people wouldn't be able to if they were on their own, I don't know how they would cope with running a home, doing the washing, ironing, and the cooking." (Participant 04)

"And quite frankly it was rather blunt the way the doctor told me, he said, 'well you've got prostate cancer'...he needs a different approach...if it was phrased slightly differently...but no it was just straight." (Participant 10)

"According to them (DWP) I went through 6 months chemo for the love of it, they said there's nothing wrong with you! I go for a medical and I'm not fit to work. I was on ESA but its due for renewal and I think they'll want to get me back to work." (Participant 07)

Good Practice

- ❖ Macmillan services (telephone and face-to-face) helped participants emotionally. Online and face-to-face support groups were effective in responding to some people's emotional needs.
- ❖ Services provided by other organisations, notably St Barnabas Hospice, the British Red Cross and Macmillan were effective in meeting some of the personal and practical care needs of the participants interviewed.
- ❖ Participants reported positive reports of Macmillan assisting with financial help, for example, with accessing benefits and paying utility bills.
- ❖ Macmillan literature (physical and online) and Macmillan professionals were a positive source of information and advice. In addition those who had used Macmillan's Information and Advice Centres found these particularly beneficial. Furthermore, support groups were also utilised as a way of informing some of the participant's about their condition.

Poor Practice

- ❖ For some, the manner in which doctors communicated the news of a cancer diagnosis was seen as insensitive and lacking in empathy.
- ❖ Perceived shortage of accessible information around cancer and employment. Furthermore, there was a lack of government support surrounding employment and finances, in particular around dealing with the DWP and accessing benefits such as ESA.
- ❖ Several of the participants reported that there was a perceived lack of information and emotional support for carers and partners of people with cancer.
- ❖ For some, health professionals (in particular doctors) would rarely discuss social or supportive care needs with patients. Consequently, there was a lack of signposting to social support.

Limitations

- ❖ Ethics – subject to considerable delay with obtaining ethical approval from several bodies (NRES West Midlands; LCHS R and D; ULHT R and D).
- ❖ Response Rate – the response rate was lower than originally anticipated and failed to deliver the target sample of twenty participants across all 4 stages of the cancer journey. The sample was inevitably biased predominantly consisting of people living with and beyond cancer and did not contain any palliative patients.
- ❖ Recruitment – winter pressure demands meant the CNSs we were recruiting through had limited time to help with the study and several did not report back whether they had sent out any invites. Several interviews had to be cancelled due to the participant being too ill to take part.
- ❖ Timeframe – as a result of the above limitations, the study has been over a longer time-frame than anticipated.

Conclusion

Final findings and recommendations will be available in late 2015. A University of Lincoln Research Report is currently in production.

Acknowledgements

We would like to express our gratitude to the participants who shared their experiences with us in the interviews. Furthermore, we are grateful to Macmillan Cancer Support, Bromhead Medical Charity & University of Lincoln for funding this research.