Lung cancer, caring for the caregivers. A qualitative study of providing pro-active social support targeted to the carers of patients with lung cancer

PJ Ryan Hereford County Hospital, Hereford, V Howell Macmillan Cancer Relief, J Jones Carers Action, Hereford and EJ Hardy The Mental Health Research and Development Unit, University of Bath, Bath

Introduction: Carers of patients with lung cancer often have a short time to access the support they require. The Macmillan Carers Project (MCP) was set up to provide non-clinical social support targeted in the community to the carers of patients with lung cancer and this study describes its evaluation. Methods: Prospective case study using interviews with the carers, project workers and health and social care professionals to obtain qualitative data for thematic analysis. 81 patients' carers received support from the MCP; 20 carers, 2 MCP workers and their manager and 10 other professionals (chest consultant physician, lung cancer clinical nurse specialist, GP, four Macmillan nurses, hospice social worker and two community social workers) were interviewed. Results: Patients were predominantly male (62%), mean age 71 years and carers were predominantly female (70%) mean age 63 years. Carers identified the MCP as providing emotional support, more time, practical help, financial advice, information and back-up for a myriad of problems. Although there was some overlap with other services, the MCP was valued by carers and professionals as filling a gap in social care. Conclusions: The unique aspect of this study was support targeted to the carers of a single cancer site (lung) rather than generic cancer support. As lung cancer may progress rapidly, patients and their carers have a short time to gather new information, access services and adjust to their new circumstances and roles. By focusing on the needs of carers from the time of lung cancer diagnosis, we have shown that the MCP was a valued additional service, well received by carers, patients and professionals. Palliative Medicine (2008); 22: 233-238

Key words: caregiver; health service organisation; lung neoplasm; programme evaluation; qualitative research; quality of life; social support; social worker

Introduction

Lung cancer is the commonest cause of cancer death with a median survival from diagnosis of less than four months.1 Patients and carers have concerns regarding appointments, tests, treatments, care arrangements, work, changing roles, money and bereavement. Professionals, such as secondary care specialists, respiratory nurse specialists, GPs, district nurses, Macmillan nurses and social workers, try to deal with these. Support is usually focused on the lung cancer patient and support for the carers is often secondary and reactive rather than planned.

The Macmillan Carers Project (MCP) was created to respond to the emotional and practical needs of carers whose partner or close friend has been diagnosed with lung cancer. The MCP aimed to provide expert independent non-clinical advice and support for carers from the time of diagnosis and to provide a holistic personalized plan to meet the individual carers' needs. Support also included information, benefits advice, liaison, co-coordinating appointments, emotional support, assistance in accessing aids/equipment and bereavement counselling. It is a joint partnership between Macmillan Cancer Relief, Hereford Carers Action and Hereford County Hospital Respiratory Team.

Objectives

The evaluation aimed to assess: (1) whether the MCP aims were achieved; (2) the views of carers compared to professionals; (3) opportunities and barriers encountered in receiving and providing the service; and (4) whether the service improved the quality of life for the carer.

Methods

Design

Ethical approval was given by the Herefordshire & Worcestershire Ethics Committee. The research utilized a case
study design. Interviews were conducted with carers, project workers and other involved professionals. To sample the carer population, consecutive carers who met the inclusion criteria were approached and those who consented were interviewed. This was used for the majority of the recruitment but this failed to offer a range of cases, as hoped. Purposive sampling was employed in order to recruit carers with under-represented characteristics, which were: carers not living with the patient, the carer/patient relationship being between friends rather than intra-familial and employed carers with dependent families. However, the population failed to offer any consenting carers with these characteristics. The interview was structured around the aims of the MCP but with flexibility to allow unexpected issues and themes to emerge. Detailed notes were taken during the audio-taped interviews. Thematic analysis was used to collate themes and sub-themes into patterns. The Care Work Impact Appraisal Questionnaire was used to quantify carers’ experiences. The two MCP workers were also interviewed about their experience of working with each carer interviewed. Professionals involved with the MCP and the project workers manager were also interviewed. Validity was ensured by data triangulation (carers and professionals) and methodological triangulation (interviews, structured questionnaires and researcher observations and notes). EH and another independent researcher, who had no previous involvement with the research, separately used the interview transcripts to identify themes. They then devised a coding framework and applied it to each interview report. By working in an independent and joint sequential manner, the validity of the coding framework was strengthened.

Setting
The study involved patients and their carers attending a single rural DGH lung cancer clinic and delivered additional support to carers in their own homes. The DGH serves several market towns and the surrounding countryside with a catchment population of approximately 200,000. Patients undergoing radiotherapy attend a cancer network facility in a neighbouring county (40 miles) and surgery in a regional centre (62 miles). Chemotherapy is given locally and in the network facility.

Participants
Patients and their carers were recruited from patients with a new diagnosis of primary lung cancer. A carer was defined as the person perceived by the respiratory team as delivering most care at that point in time. Inclusion criteria were: patient living at home; patient receiving informal care. Exclusion criteria were: patients referred for curative surgery; patient living in residential accommodation; main carer unable to give consent due to dementia or other mental impairment.

Aims and intervention
The MCP delivered additional pro-active non-clinical social support targeted to the carers of patients with lung cancer in the community. The project was intended to provide information (care options, accessing resources), liaison (medical staff, other family), emotional support, practical support (form filling, financial / benefit advice) and referral to other agencies from the point of diagnosis. This was provided mainly by home visits and telephone support. The aim of this intervention was to reduce psychological morbidity for the carers and ease the burden of caring. We hoped to improve the quality of the caring experience.

Results
One hundred and thirty-eight patients were diagnosed with lung cancer during the 18-month recruitment period; 22 patients were not referred to the MCP (referred for surgery, inconclusive test results, carer had dementia or long-term disability or patient was living in residential accommodation, no carer, patient missed) and 35 were referred to the MCP but declined. Of the 81 carers who received support from the MCP 20 were interviewed. Demographic details of participants are illustrated in Table 1. Spouse or partner (59%) and children (25%) accounted for the majority of carer-patient relationships (Table 2).

Qualitative data
(1) Caring for patients with lung cancer in general. Carers did not always identify themselves as ‘carers’, as often the patient was not dependent upon them, they were not doing anything ‘special’, it was not a role they chose and

Table 1  Age and sex of patients and carers

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Patients whose carers were interviewed</th>
<th>All carers</th>
<th>Carers interviewed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 116)</td>
<td>(n = 19)</td>
<td>(n = 117)</td>
<td>(n = 20)*</td>
</tr>
<tr>
<td>Male (%)</td>
<td>72 (61.5%)</td>
<td>10 (55.6%)</td>
<td>35 (30.2%)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Age (SD)</td>
<td>71 (10)</td>
<td>71 (12)</td>
<td>63 (14)</td>
<td>63 (12)</td>
</tr>
<tr>
<td>Range</td>
<td>45–97</td>
<td>50–97</td>
<td>29–92</td>
<td>37–88</td>
</tr>
</tbody>
</table>

*aOne patient had two main carers.*
Table 2 Relationship of carer to patient

<table>
<thead>
<tr>
<th>Relationship</th>
<th>All (%)</th>
<th>Research participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse/partner</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>20 (17)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Wife</td>
<td>45 (39)</td>
<td>10 (50)</td>
</tr>
<tr>
<td>Partner</td>
<td>4 (3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>20 (17)</td>
<td>5 (25)</td>
</tr>
<tr>
<td>Son</td>
<td>9 (8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Parent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>1 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Friend</td>
<td>2 (2)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Neighbour</td>
<td>1 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Sibling</td>
<td>5 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>1 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>1 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Cousin</td>
<td>1 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Nephew</td>
<td>1 (1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Niece</td>
<td>2 (2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Not known</td>
<td>3 (3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Total</td>
<td>116</td>
<td>20</td>
</tr>
</tbody>
</table>

Caring was a normal part of marriage (Box 1). The carers' roles and involvement varied greatly, but key features were seen by carers as providing a coordinating role, moral support and practical care. Many reported positive rewards from the caring role. Their concerns centred on their ability to provide the best care, juggling employment with caring, managing a reduced income and being alone physically when the patient died. The majority of carers identified their family and friends as sources of support, with some also identifying community resources, eg, church and a counsellor.

(2) To what extent the MCP aims were accomplished. Carers felt a non-medical, social work background was appropriate for the MCP workers and lack of medical knowledge was not a problem. Most were aware of the roles of the different professionals and could identify the most appropriate to help them with any medical queries. Several carers commented that the MCP provided 'old-fashioned' social work rather than 'care management', where there is limited contact and clients are referred on to appropriate services.

Project workers were flexible, sometimes supporting mainly carers, sometimes carer and patient equally. A few carers recognized the MCP as a pro-active service and appreciated being offered support, rather than having to seek it. Not all carers interviewed felt they required emotional support, although they were pleased to know that it was there. The main component of emotional support for the carers was having someone to talk to and listen to them. Some carers felt it was important to talk to someone outside of their family or friends, and the medical/nursing team (Box 1). A dominant theme was the time project workers were able to spend with carers. Carers felt the project workers' approach was more relaxed, compared with other professionals. Although other professionals recognized that carers need support, their remit and resources often ensured that this support was secondary and was curtailed when time became pressured.

Box 1 Comments about the Macmillan Carers Project

Caring in Lung cancer:

‘enjoyed the caring role as had become closer to father and had the chance to talk to him on his own’
‘an extension of my marriage vow “in sickness and in health”’

Project workers role:

‘it was nice to have someone not concerned with the medical aspects’
‘I suppose it sounds selfish but it is nice to know someone is thinking about me as well’
‘a health professional would be orientated towards health and health problems and not families, relationships, culture and environment’
‘the nurses are very busy and I appreciate the extra time the project workers are able to give’

Professional views:

‘ending the project would be detrimental to the patients, carers and us’ (Macmillan Nurse)
‘if the project workers are involved I don’t have to worry about everyone so much and check up on them, the project workers will let me know about any change’ (Lung cancer nurse specialist)

Bereavement:

‘it’s all very well having someone there at the time (of death), but you need someone there after, even two weeks after – she’s helped me cope’

Practical support was also delivered and covered a wide variety of areas including: organizing practical aids such as chairs and beds, arranging visits and links with the hospice, arranging day care, baby alarm, cordless phone, stair lift, arranging help with housework, assisting with a housing application and finding out phone numbers. Financial help was also provided by helping with Blue Badges (parking benefits for people with disabilities), attendance allowance, incapacity benefit, disability living allowance, income support, DSS1500 forms, Macmillan grants, employment advice, eg, compassionate leave,
insurance polices and access to 'incidental' money for dog walking and taxis etc.

Other themes developed from the interviews were that MCP workers provided information (about the illness, the investigation and treatment process, future care options), a useful point of contact (continuity was very important) and being a 'lifeline' (support described as 'lifeline', 'safety net' and 'back-stop').

(3) Compare the views of carers with those of professionals. Carers and professionals were very supportive of the MCP. The MCP workers both had social work training but were able to overcome the negative image carers had of social services.

Professionals reported that the MCP had benefit in either providing the carers with time and help that they themselves were unable to give and that it also freed up some time for them to deal with other matters or other clients.

(4) Explore the factors enabling carers to receive support and the care workers to provide it. Professionals identified carers who appeared to cope well as having the following characteristics: organized (eg, routines, lists, knowledge of where to seek information), in good health, financially secure, good family relations and support, supportive employment, self-sufficient, make use of available services, confidence to admit difficulty with coping and to ask for help, emotionally resilient, pro-active, good communication skills and ability to network, open and friendly personality that draws people to want to help them, realistic and practical approach to caring and death.

A key skill for the project workers was understanding the local network. As one professional stated: the most important attribute is an ability to network – to pick up the phone and involve people and let them know what is happening. A key quality of being a point of contact was the continuity of the project worker, compared with other services where the professional may be different with each meeting.

Patients and professionals recognized there was potential for different agencies to duplicate some services. Both accepted that this occurred to a minor degree. The project workers felt that the success of the project depended on several factors, which included: good networking skills, a good relationship with the respiratory team, attendance at the lung cancer MDT, being informed about all patients and both stand to benefit from recognition of the carer's role. 10 Bakas, et al. found that in caring for lung cancer patients, the most time-consuming tasks were providing emotional support, transportation and monitoring symptoms, and the most difficult tasks were emotional support, behavioural management, monitoring symptoms and household tasks.11

Thomas and Morris feel this has 'legitimised carers as persons who are affected by cancer in profound ways. The carer is constructed as an actual or potential 'co-user' or
Table 3  Care Work Appraisal Questionnaire^a

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Number of completed questionnaires</th>
<th>Possible range</th>
<th>Mean (SD)</th>
<th>Comparator group – carers of elderly patients^a (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care work strain</td>
<td>18</td>
<td>13–91 (high score = low strain)</td>
<td>52.4 (18.2)</td>
<td>34.5 (20.4)</td>
</tr>
<tr>
<td>Care work satisfaction</td>
<td>17</td>
<td>6–42 (high score = low satisfaction)</td>
<td>18.7 (10.4)</td>
<td>28.5 (9.2)</td>
</tr>
<tr>
<td>Relationship dissatisfaction</td>
<td>18</td>
<td>7–49 (high score = low dissatisfaction)</td>
<td>37.7 (8.1)</td>
<td>18.4 (9.8)</td>
</tr>
<tr>
<td>Care lifestyle satisfaction</td>
<td>18</td>
<td>5–35 (high score = low satisfaction)</td>
<td>21.9 (8.1)</td>
<td>16.7 (6.7)</td>
</tr>
</tbody>
</table>

^aThe questionnaire used a Likert scale, where ‘agreement’ with the statement was scored as a low number and ‘disagreement’ as a high number.

Lung cancer, caring for the caregivers

'co-client' of services^1,2 As service users in their own right, consideration has been given to carers' own needs and levels of psychological distress^3,4 and they have been the subject of studies considering psychological interventions to aid their coping.5–7 A study by Harding, et al. demonstrated that a short-term intervention of generic support and information-giving targeting cancer carers was well received though uptake was only 25%.8

The NHS Cancer Plan recognizes that: 'Patients, families and carers need access to support from the time that the cancer is first suspected through to death and into bereavement'.9 This study shows that there is currently an unmet need for better social support to the carers of patients with lung cancer. Despite many health professionals accepting the philosophy of treating the whole family, when stretched by lack of time and resource they mostly focus on their primary aims, which tend to be diagnosis and treatment for doctors and nursing care and symptom control for nurses. The holistic social support that encompasses giving emotional support and practical support to carers is often the first casualty when time is short. For lung cancer there is the additional pressure that there may only be a few weeks or months to get this support right.

It is sometimes assumed that the needs of cancer patients and their carers are broadly similar across all cancer sites. This is not always the case and the network of professionals for each cancer may be very different. Using social workers dedicated to supporting carers of one type of cancer, rather than all cancers, allowed a close network of contacts to be established and used. This site-specific model may have benefits over a generic service, or perhaps a more cost effective model might lead to an individual supporting the carers of two or three sites, eg, upper and lower gastro-intestinal cancers.

Commissioners of health and social services, as well as charitable organizations such as Macmillan, still need to know where to deploy resources and their cost-benefit when compared with other interventions. Objective measurement of change in the quality of carers' and patients' experience is very difficult. More easily quantifiable outcome measures such as reduced hospital stays or reduced health care contacts will probably continue to drive government health-related spending. Though there are some signs that a target-led health service is changing to address quality issues.

We believe that we have shown that we were able to improve the caring experience for those looking after lung cancer patients. However, to secure long-term funding, future research will need to focus on a number of areas including: the cost-benefit, quality of life and exploration of the needs of other illness groups, which may benefit from planned carer-targeted support.

References


