

An evaluation of the domiciliary occupational therapy service in palliative cancer care in a community trust: a patient and carers perspective

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In the past 20 years there has been considerable growth in the provision of palliative care services. The shift in emphasis from hospice and hospital care to the development of community services has been significant. This enables people to be cared for at home and is in keeping with Government agenda. While this may be beneficial for the patient and fit in with the wishes of the family, it is likely to put heavy demands on the coping resources of individual carers. The views of service users are of paramount importance when discussing service evaluation and patient, family and carer empowerment. This research presents the findings of an evaluation of the domiciliary occupational therapy service provided for patients in the palliative stage of cancer care in North and West Belfast from the perspective of the patients and carers. For the purpose of this study, the palliative stage of cancer care is defined as the point from which the patient is no longer responsive to curative treatment, until death. A sample of 30 patients and their primary informal carers were selected using purposive sampling. A structured interview was carried out with both the patients and their carers to obtain views. Results suggest that although both patients and their carers value the service provided and report high levels of satisfaction, there are gaps identified in service provision and a lack of clear information among patients and their carers about the role of the occupational therapist and the range of services they can provide. There is a need to build upon the good work being done by domiciliary occupational therapists in the area of palliative cancer care and increase education and resources to ensure that a patient-centred, holistic, approach to care is used, addressing both the needs of the patient and their carers.

Keywords: occupational therapy, palliative care, cancer, community, service users.

INTRODUCTION AND BACKGROUND

Cancer care is a high priority for development and reform in the Government's plan to provide a health service fit for

the 21st Century. In September 2000 the National Health Service Cancer Plan was published and this sets out the first comprehensive national cancer programme for England. Its aim is to save lives and ensure that people with cancer get the right professional support and care as well as the best treatments. It also aims to streamline cancer services around the needs of the patient (Department of Health 2000).

Cancer services have been the focus of attention since the 1995 review in England and Wales and the subsequent Campbell report in Northern Ireland in 1996. The Camp-

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bell report reviewed the local implementation of cancer services as recommended by Calman and Hine (1995). This review was stimulated by evidence that the incidence of cancer was rising and within the United Kingdom there were geographical variations in treatment outcomes (Calman & Hine 1995; Campbell 1996). Both the Calman and Hine (1995) and Campbell (1996) reports stress the importance of the primary care team in the future of cancer management and emphasize the need for a multidisciplinary approach to care. In the document *A Framework for the Multiprofessional Contribution to Cancer in Northern Ireland*, emphasis is placed on the contribution made by all healthcare professionals to ensure the well-being and quality of life of patients with cancer (DHSS 1996).

As a recommendation of the Campbell (1996) Report, a regional review of palliative care services was established (Department of Health, Social Services and Public Safety 2000). Palliative care is defined as 'the active total care of patients and their families by a multiprofessional team when the patient's disease is no longer responsive to curative treatment' (Higginson 1997). The emphasis on palliative care has been to support both the patient and his/her carer and to maintain their involvement through the patient's illness and death.

Life threatening illness profoundly affects people's occupational functioning, yet continuing occupational engagement seems vital to their well-being (Lyons *et al.* 2002). Occupational therapy is unique in the way it views patients. No other profession studies the occupations of people (Dawson 1982; Cooper 1992; Dawson & Barker 1995; Penfold 1996). The occupational therapist plays a key role in assisting each individual to attain the occupational roles that are perceived by the individual and the caregivers to be important, given the limitations of time and physical ability (Lloyd 1989; Dawson 1993). Occupation is the daily activity that people carry out in their lives and involves the complex interaction of biological, psychological and environmental factors. The ability to carry out normal daily living activities is often the primary objective for those patients with a life threatening illness. When this is not possible, powerlessness, loss of control and lack of choice are just a few of the factors that can undermine efforts to boost morale (Fisher & McDauid 1996; Wilcox 1998; Yerxa 1998).

The role and contribution of the occupational therapist in palliative cancer care is both diverse and challenging. Many authors have indicated that a rehabilitative approach is appropriate to palliative patient care (Broadwell 1987; Strong 1987; Hopkins & Tookman 2000; National Council for Hospice & Specialist Palliative Care Services 2000). However, Eva (2001) suggests that patients with advanced cancer do not make the kind of progress

that can be expected in more traditional rehabilitative settings. They progressively deteriorate in terms of their functional independence, often requiring a significant amount of care from others.

The role of the occupational therapist with this patient group, as suggested by Bye (1998), is in valuing their remaining life and helping them to live in the present, recognizing their right to self-determination and assisting in the preparation for the approaching death within ethical guidelines and the professional code of conduct. The intervention is based on a holistic patient-centred approach, which is flexible and constantly reassessed to meet the changing needs of the patients and their carers. It pays equal attention to the physical, psychological, social and spiritual aspects of care, assessing:

- the deterioration of the clients activity and role performance;
- the caregiving process and social support systems;
- the caregiving environment.

Bye (1998) suggests that the core phenomenon that guides occupational therapy practice with patients who are terminally ill is affirming life: preparing for death and has developed a provisional conceptual framework around this theory.

Occupational therapists have a key role in the treatment of terminally ill patients in the community as evidence from both population and patient surveys indicates that the majority of cancer patients would prefer to die in their own home (Townsend *et al.* 1990; Griffin 1991; Tong 2000; McClements 2001). Home care enables patients to live out their lives in dignity and privacy in familiar comfortable surroundings and to continue their familial relationships (Karlsen & Addington-Hall 1998). Despite these facts, only a quarter of cancer deaths in 1992 took place in the patient's home (Office of National Statistics 1996; Higginson 2000). Adequate provision of home nursing and support services, such as the provision of equipment is associated with people being able to achieve a home death (Karlsen & Addington-Hall 1998). UK government ministers have sought to prevent unnecessary hospital admissions and have seen the provision of good support services in the community as a key priority (Boateng 1998). Home care does, however, place increased duties and responsibility on family caregivers of people with cancer and to succeed in this role, they need support, information and education that is organized to enable them to apply a problem solving approach in the same way as healthcare professionals do (Bucher *et al.* 1999).

Evidence indicates that stress in family members caring for a loved one at home can be caused by dissatisfaction

with care received by the patient and themselves (Kristy-anon 1991; Fakhoury & McCarthy 1998). Higginson *et al.* (1990) concludes that in palliative care the needs of the carer may exceed those of the patient. This emphasizes the need for occupational therapists to assess not only the needs of the patient but also that of the carer to ensure that intervention is not counterproductive for either party if their needs are conflicting.

Healthcare workers can no longer practice on the assumption that they are delivering optimum care. The concept of clinical governance and evidence based practice coined in 1998 and referred to in the document *A First Class Service: Quality in the New NHS* (DOH 1998) is now central to current healthcare policy. Therefore it is necessary to evaluate the service provided to ensure best practice and user satisfaction.

The number of referrals received by the domiciliary occupational therapy service in North and West Belfast for patients in the palliative or terminal stage of cancer has trebled over the past 6 years (see Fig. 1). This demonstrates an increase in demand for the service, however, there has been limited research into whether domiciliary occupational therapy benefits this patient group and their carers. The body of literature on occupational therapy in cancer and palliative care is limited. In the literature that exists, occupational therapists suggest ways in which their intervention is of value to cancer patients (Cooper 1998; Rahman 2000). However, there is no indication of how the patient or their carers view the service provided. It is possible that patients could view occupational therapy as having a neutral or negative impact (Eva 2001). In order to ensure that care provision is responsive to patients needs, there is a need to know what constitutes good quality support from the patient's point of view (Grande *et al.* 1996). A patient-centred approach and seeking the users unique perspective is a constant challenge and is the hallmark of sound palliative care. The aim of this study is to evaluate the domiciliary occupational therapy service in a community Trust for patients in the

palliative stage of cancer from the patient and carers perspective.

METHODS

A single researcher, who was also the main author, carried out this research between September 2001 and January 2003. Structured interviews were completed between March 2002 and August 2002 using a pre-designed questionnaire for data collection to record patient and carer responses. No relevant published questionnaire was available. The content of the questionnaire was established using a review of the literature in both patient satisfaction surveys (Easi-Quest Patient and Staff Surveys, Reference Point Ltd), occupational therapy outcome measures (Oppenheim 1992; Stone 1993; Smith 1997a; Smith 1997b; Cooper 1998; Norris 1999; Eva 2001) and questionnaire design (Ballinger & Davey 1998).

During the development of the data collection instrument, occupational therapists in hospital cancer units and in the community were consulted about the content of the questionnaire to ensure that it included items considered relevant and valid to this expert group. A pilot study was carried out and ethical approval was obtained.

The questionnaire consisted of both open and closed questions designed to elicit information on service issues such as timeliness, information received and satisfaction with levels of contact. Questions were designed to identify problem areas for the client, intervention received from their domiciliary occupational therapist, communication, and if benefit was gained from the service. The interviews were carried out in the patients' own home and the same data collection tool was used to interview both the patient and the main informal carer separately. Interviews were pre-arranged by telephone and both the patient and the carer signed a consent form prior to the interview. The questionnaires were anonymized by the assignment of an identification code to each patient and carer. The interview procedure lasted approximately 1 h.

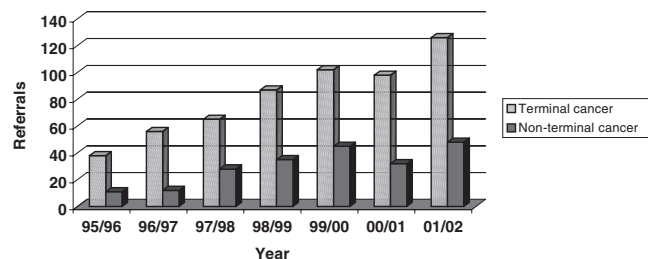


Figure 1. Referral pattern to North and West Belfast Health and Social Services Trust occupational therapy services from 1995 to 2002.

PARTICIPANTS

Thirty patients and their main informal carers were included in the study. This would give a representative sample of adequate size to give validity to the results obtained within the limited time allocated for completion of the research. Using the method of purposive sampling, a selection was chosen from patients, in the palliative stage of cancer care, referred to the domiciliary occupational therapy service in North and West Belfast Health and Social Services Trust (N&WBHSST). A range of

occupational therapists provided cases from which the researcher selected the appropriate participants according to predefined selection criteria. This sampling method was chosen as it provided the investigator with the opportunity to use their experience to select individuals considered to be representative, i.e. patients with non-curative cancer. This method can be used within small surveys, and there is no intention to generalize the findings beyond the chosen sample.

Inclusion criteria

- Referral to the domiciliary occupational therapy service in N&WBHSST in the palliative stage of cancer care.
- Patients willing and able to participate in the study.
- 18 years of age and over.
- Can understand written and spoken English.
- Have an informal carer.

Subjects were chosen from closed files, i.e. patients discharged from the service, there was a maximum of 2 weeks from the last occupational therapy visit and were the case notes indicated that the patient met the inclusion criteria. One hundred per cent response rate was achieved using this method of data collection.

SELECTED CHARACTERISTICS OF STUDY SAMPLE

The sample of patients was comprised of 20 (67%) women and 10 (33%) men. The mean age of patients was 65 years (range 34–87 years). The sample of carers was comprised of 19 (63%) women and 11 (37%) men with the mean age of carers being 53 years (range 28–80 years). All except two of the carers were related to the patient with 15 (50%) caring for their spouse. There was a wide range of referral agents; however, hospital occupational therapists were the referral source for 43% of the sample. The mean number of days between date of referral to the occupational therapy service and date of initial assessment was 13 days; however, 21 (70%) of the sample were assessed within 10 days of referral. Selected characteristics of the sample are shown in Table 1.

DATA ANALYSIS

The quantitative data was coded and analysed using EXCEL. The investigation used descriptive statistics for analysis and description of the data for example frequency distributions. A qualitative content analysis was per-

Table 1. Selected characteristic of study sample

Characteristics	Patients		Carers	
	%	<i>n</i>	%	<i>n</i>
Sex				
Male	33	10	37	11
Female	67	20	63	19
Age group (years)				
18–49	7	2	40	12
50–64	40	12	40	12
65+	53	16	20	6
Referral source				
General Practitioner	17	5		
District Nurse	13	4		
Hospital occupational therapy	43	13		
Hospice	13	4		
Social worker	7	2		
Relative	3	1		
Outside agency	3	1		
Number of days between referral and initial assessment				
0–10	70	21		
10–20	13	4		
20+	17	5		

formed on the open questions to determine the frequency and saliency of responses (Mason 1996). Interviews were transcribed verbatim and each transcript reviewed for identification of common themes, which described the views, or experiences of patients and their carers. In presenting the results, the range of responses obtained is demonstrated and italics are used to indicate verbatim quotations. No response was quoted more than once.

RESULTS

Results indicated high levels of client and carer satisfaction with communication and with accessibility to the domiciliary occupational therapy service. Twenty-five (83%) patients and 20 (67%) carers were aware of when the occupational therapist was visiting. Twenty-nine (97%) patients and 27 (90%) carers were provided with contact details from the therapist. Twenty-two (73%) of patients and 23 (77%) carers had no difficulty contacting the occupational therapist between visits if necessary. Seven (24%) patients and 6 (20%) carers had not needed to contact the therapist between visits. Twenty-six (87%) patients and 27 (90%) carers were satisfied with the frequency of therapist visits.

From a list provided, patients were asked to identify areas of difficulty and to grade on a scale of 0–4, the impact of each difficulty on their life. From the same list, carers were asked to identify the areas they felt were difficult for the patient and score from 0 to 4, the impact of each difficulty on their life as the carer. The difficulties were divided into four broad categories of physical, functional,

Table 2. The impact of physical, psychological, functional and social factors on patients and carers

	Patient		Carer	
	No problem (%)	Major impact (%)	No problem (%)	Major impact (%)
Physical				
Pain	43	57	27	60
Fatigue	7	93	3	83
Skin problems	53	27	63	13
Restricted movement	30	50	27	60
Muscle weakness	26	60	70	17
Incontinence	63	30	70	17
Psychological				
Stress	20	70	17	80
Fear	33	60	20	73
Not in control	30	70	20	73
Lack confidence	37	60	20	73
Worried about future	30	70	30	60
Maintaining life roles	13	87	27	63
Functional				
Walking indoors	37	63	23	57
Walking outdoors	10	87	10	83
Stair mobility	20	70	17	70
Bed	60	40	13	50
Bath	13	73	7	67
Chair	43	53	10	43
Comfort seated	33	57	20	33
Toilet	33	67	20	43
Feeding	97	3	50	23
Washing self	30	57	27	50
Dressing self	43	37	27	47
Cooking	13	50	7	73
Cleaning	39	50	10	73
Laundry	10	40	10	73
Social				
Social visits	27	60	17	67
Community activities	40	50	23	57
Hobbies and interests	30	60	23	50

social and psychological problems. Each of these categories was subdivided.

Table 2 demonstrates the percentage of patients and carers for whom each difficulty had a major impact on their lives, a score of 3 or 4 is considered to be of major impact. Pain, fatigue, restrictions in range of movement and muscle weakness were identified as problem areas, causing a major impact on the lives of a high percentage of both the patients and their carers. Fatigue was identified as having a major impact on 93% of patients and 83% of carers.

Difficulties with mobility, transfers and washing were identified as areas that significantly impacted on patients' lives. A high number of patients surveyed had difficulties with home management activities such as cooking, cleaning, shopping and laundry, however, the greatest impact of these difficulties was on the carer. Psychological factors such as stress, fear, lack of confidence and not feeling in control of one's life was reported to have a major impact on a high percentage of the population surveyed. Difficulty in social functioning such as visiting friends and

relatives, participating in community activities and maintaining hobbies and interests had a major impact on more than 50% of patients and carers.

Patients and carers were also asked to identify from a list provided what intervention they had received from the domiciliary occupational therapist (Fig. 2). Patients and carers were asked to indicate their response to statements concerning communication and interaction with the therapist (Table 3). The overall satisfaction with the service was measured on a 5-point Likert scale 0–4, where 0 indicates very poor and 4 indicates excellent (Fig. 3).

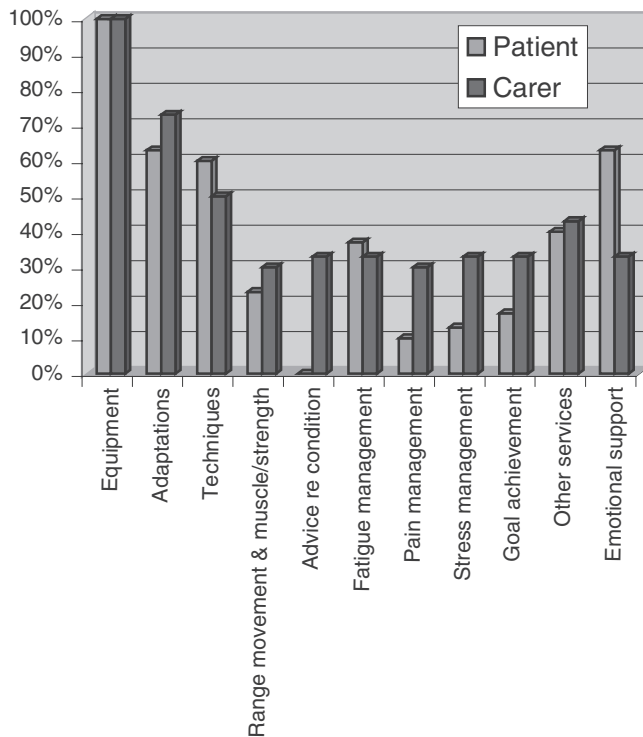
Qualitative results

Consistent with the pattern of quantitative results, patients and carers expressed high level of satisfaction with the domiciliary occupational therapy service provided.

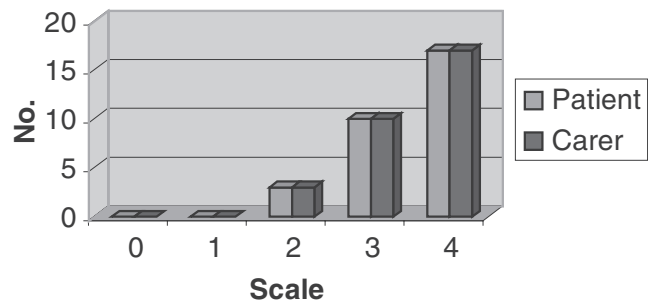
Patients and carers were also asked what they found most helpful, least helpful and how they felt that the domiciliary occupational therapy service could be

Table 3. Communication and therapist interaction

		Strongly agree (%)	Agree (%)	Disagree (%)	Strongly disagree (%)
I felt at ease with the occupational therapist	Patient	93	7	0	0
	Carer	66	29	0	3
I was given enough time to discuss the things I wanted to discuss	Patient	72	14	14	0
	Carer	60	31	6	3
I was involved in the decisions made about what help I needed	Patient	72	23	5	0
	Carer	54	40	3	3
I was given choices about ways in which the occupational therapist could help me	Patient	66	20	14	0
	Carer	47	40	10	3
The occupational therapist took my opinions and wishes into account	Patient	80	17	3	0
	Carer	58	25	17	0

**Figure 2.** Occupational therapy intervention.

improved. Specific findings are reported under thematic categories following content analysis. The categories which patients identified as being most helpful were equipment and adaptations provision, accessibility and speed of access to the service, quality of client and therapist interaction, helpfulness and understanding of needs and independence in activities of daily living. The thematic categories for carers were equipment and adaptations provision, accessibility and speed of access to the service, quality of carer and therapist interaction and reduced burden of care. The thematic categories for what patients and carers found least helpful were equipment and provision of information and the common theme in how patients and their carers felt the service could be improved related to the provision of information.

**Figure 3.** Overall satisfaction with service.

Equipment and adaptation provision

The provision of equipment and adaptations was highly valued by the patients and carers as they increased the patient's independence in activities of daily living and reduced the burden of care on the carers. One patient said, '*... I am able to have a shower independently. I can go to the toilet myself and be comfortable when sitting on the toilet, that is so important to me, I wouldn't have anyone taking me to the toilet ...*'.

A carer stated, '*... I felt that because of the things given to my daughter, it lessened my worry about her, she could be more independent and that helped me ...*'

Access and availability of the service

Prompt access and the availability of the service was identified by the patients and carers as being beneficial. This is evidenced by the comment from one patient, '*... things were done so quickly, whatever I asked for was immediately put into action and everything was provided so quickly ...*' Another patient stated '*... it was so good to know that she is there at the end of the telephone and I can contact her at any time if I need her, that gives me a lot of confidence and security ...*'. A carer's statement also supported this, '*... we were told we'd have to wait a year to see the OT but she was here within a week and got*

us everything we needed. She did her best to get everything straight away and if she couldn't get the stuff there and then, she would explain why and keep me updated . . .

Quality of client and therapist interaction

Reflecting on interactions with the occupational therapist, one patient said '*. . . she had a brilliant attitude and talking to her was a pick me up. She gave me lots of encouragement, her whole attitude was right . . .*'. Another said, '*. . . she was very kind in herself and the way she spoke to me, she put me at ease. She held my hand and wasn't afraid to touch me. Some people are afraid to touch you in case they get smitten or something . . .*'. The carers also valued interactions as this comment illustrates '*. . . her understanding of my situation and the fact that she was willing to sit and listen was most important to me . . .*'.

Helpfulness and understanding of need

This theme was frequently expressed and one patient stated '*. . . she made me aware of everything I could get to help me, she seemed to know what I needed, mostly practical stuff. She couldn't have been more helpful . . .*'. Patients also placed great importance on the increase in their level of independence in activities of daily living following the occupational therapists intervention. One patient said '*. . . being able to get to the toilet and in and out of bed was worth anything for me, being independent and able to do things for myself . . .*'. This also appeared to have significant impact on the carers' burden as evidenced in the remark, '*. . . the help provided by the OT made life less stressful and more manageable for me, both physically and emotionally . . .*'.

Least beneficial

In contrast to the benefits gained by equipment provision, some patients reported that the equipment provided was of little use. One patient stated, '*. . . the recliner chair was not of any benefit, it was like getting out of bed to get into another bed and I don't want that for myself . . .*'. Another reported '*. . . the bed rail was no good, I couldn't use it . . .*'.

Service improvement

In content analysis of comments from both patients and carers on how the service could be improved, one com-

mon theme emerged as being the need for more information on the range of services the OT has to offer. One patient stated '*. . . if we knew a bit more about the range of things the OT could do, we may have availed of more from the service . . .*'. Another stated '*. . . I could have done with some help with relaxation techniques and managing stress but I really didn't know that that was the OT's role . . .*'. One carer reported '*. . . the OT seemed to concentrate on the physical aspects of my father's condition. This was fine with me as I thought that was what she was there for . . .*'.

DISCUSSION

The study set out to evaluate the domiciliary occupational therapy service for patients in the palliative stage of cancer care from a patient and carers perspective in one Trust area. The qualitative data and the richly detailed comments provided by many participants support the practice of including patient and carers perspectives in evaluations of occupational therapy services for both theoretical and methodological reasons (McKinnon 2000).

Results did suggest, both through the quantitative and qualitative data collected, the importance of accessibility and availability of the occupational therapy service to patient and carers level of satisfaction with the service. The importance of these factors is supported in the literature (Clumpus & Hill 1999; McKinnon 2000). Patient and carers high level of satisfaction with the speed and accessibility of the service is likely to have been due to the development of a Rapid Response Team in the Trust from which the sample was taken. The aim of this team is to prioritize and respond quickly and appropriately to the needs of urgent cases, which include palliative care patients. Patients and carers feel reassured by their ability to contact the occupational therapist when needed.

Communication and the relationship with the therapist are highly valued by both the patients and their carers. This is an essential component of palliative care (Grande *et al.* 1996; Fakhoury 1998; DOH 2000). A high level of satisfaction was found in communication and interaction with the therapist as demonstrated in Figure 3 and supported in the qualitative data. Research evidence indicates that 'a willingness to listen and explain' is considered by patients to be one of the essential attributes of a health-care professional (Fellowes *et al.* 2002).

This study does, however, highlight concerns about whether domiciliary occupational therapists are using a holistic approach in identifying and addressing the needs of the patients and their carers. Fifty-seven per cent of patients surveyed identified pain as a difficulty, which had

a major impact on their life; however, only 10% felt that they had received assistance from the occupational therapist in managing their pain. Many patients with cancer believe that pain is an inevitable consequence of their diagnosis. Although pain is one of the most common symptoms, occurring in about 80% of patients with advanced cancer, the majority of pain can be controlled by implementing simple guidelines (Doyle & Jeffrey 2000). The effect of pain on human performance is the legitimate concern of occupational therapy (Heck 1987). The occupational therapist can contribute to pain management by providing non-invasive techniques and purposeful activities that have been shown to potentiate physiological mechanisms associated with pain reduction.

Fatigue and weakness is another symptom reported by 93% of the patients surveyed as having a major impact on their lives; however, only 37% reported receiving advice or intervention in the management of fatigue. As evidenced in the literature, fatigue is increasingly recognized as one of the most pervasive problems likely to arise from having cancer and is likely to become more severe as the disease progresses (Krishnasamy 1997; Loge & Kaasa 1998; Richardson & Ream 1998). As cancer patients become too tired to participate fully in the roles and activities that make life meaningful, the most important effect of cancer-related fatigue may be in the realm of quality of life (Nail & Jones 1995). Occupational therapists have a significant role to play within the multidisciplinary team in the management of cancer-related fatigue through advice on energy conservation and adaptation of roles. Also by empowering patients to maintain control over decisions relating to their care, this can facilitate the patients' adaptation to living with cancer-related fatigue.

It is important to note, however, that although few patients reported having received intervention in the areas of pain management, fatigue management, advice on muscle strength, range of movement and goal setting, most patients reported intervention in equipment provision, home adaptations and advice on techniques to assist in carrying out activities of daily living. This intervention can assist in goal achievement and pain and fatigue management. Nail and Winningham (1995) suggest that depending on the nature of the fatigue or weakness, the use of mobility and safety aids may be necessary, the occupational therapist can teach new ways of performing specific tasks and environmental modifications may be needed to provide support in the home. Therefore, the patient and carers perception of help received may be influenced by their understanding of the terms used to describe the intervention. This research does, however, demonstrate that gaps do exist between the service pro-

vided and the needs patients identified from both their perspectives and the perspectives of their carers.

Both the patients and the carers identified functional problems as having a significant impact on their lives. Evaluation of both the qualitative and quantitative data indicates that the intervention of the occupational therapist was valued in this area, in assisting the patient to increase their independence and ease management for the carers. This is also reflected in research undertaken by Rahman (2000) and Armitage and Crowther (1999) who stated that increasing independence in the areas of mobility, transfers and personal care can increase the patients self-worth and self-esteem and encourage a sense of mastery and control over their daily life. This can also ease the burden of care for the informal carer and create a safe environment, reducing fear for the patient and carer concerning being at home, which is a high priority. This study shows that the difficulties which patients have in maintaining the ability to carry out home management activities has a major impact on the life of their informal carers who must assume this role.

Within the findings of this study, psychological factors had a major impact on both the patients and their carers. However, although 63% of patients felt that the occupational therapist had provided emotional support, only 13% reported being given assistance or advice in stress management. Meeting the psychological needs of patients in the palliative stage of cancer care is difficult to assess and measure; however, the psychological element of patient care must be addressed in order to provide holistic patient care (Johnston 1997; Henn 1999; Norris 1999; Doyle & Jeffrey 2000). Grande *et al.* (1996) suggested that patients were reluctant to bother health professionals with psychological or emotional issues, as they perceived their time and resources as being limited and other patients as being more in need of help. This was reflected in the qualitative findings of this study, patients and carers perceived the role of the occupational therapist to be focused on meeting their physical and functional requirements rather than their psychological needs.

Healthcare professionals do not appear to adequately identify psychological distress and tend to focus on physical concerns rather than psychological concerns in disease management (Brunelli *et al.* 1998; Henn 1999). This may be due to huge problems of time constraints faced by healthcare professionals. Evidence to date shows that current staffing levels are not meeting the requirements of Calman and Hine, and that there is a lack of specialist staff available (Wood 1999). The majority of cancer care carried out in the community is delivered by generic staff with little or no specialist skills or training in the area of

cancer or palliative care. This is not a criticism of the care given by general staff, but highlights the need for education and training to provide staff with knowledge and confidence to deal with the special needs of cancer and palliative care patients in their own home.

Often there is disparity between patients and their carers' estimations of symptoms in general (Richardson & Ream 1998) and this is evidenced in this study (Table 2). It is also important to note that carers and patients might have different perceptions of problem areas and different expectations and therefore, a satisfied patient does not necessarily mean a satisfied carer and visa versa (Fakhoury 1998). Higginson *et al.* (1990) suggested that this may cause conflict not only between the patient and carer but also between the carer and therapist. Often the needs carers may exceed those of the patient. Within this study, only 33% of the carers surveyed felt that the occupational therapist had provided them with emotional support (Fig. 2). Previous research indicated that health professionals generally treat carers as co-workers rather than co-clients. Caregivers often assume a subservient role to that of the patient and ignore or deny their own needs for emotional support. Their relationship with health professionals is often limited to discussion of care and management of the ill person, rather than their own needs (Payne *et al.* 1999; Smith 2000). This would indicate that there is a need to develop effective ways to offer emotional and physical support for carers, not only to sustain them in their role, but also to maintain their mental and physical health.

When asked about ways of improving the service provided by the domiciliary occupational therapist, both patients and carers responded with the need for more information about the role of the occupational therapist and the service that they can provide. This is a common theme in the literature where information provision is a major area of concern especially for carers (Beaver *et al.* 2000). Patients and carers indicated that they were unable to identify their needs in relation to occupational therapy, as they were not well informed of their role. This would indicate the need for domiciliary occupational therapists to explain their role more fully and provide accurate and relevant literature to the patient and their carers in order to ensure a more holistic approach to patient care.

The need for a multidisciplinary approach with good communication is essential to all areas of healthcare, and palliative care is no exception (Department of Health, Social Services & Public Safety 2000). There is a need for an understanding of the value of other disciplines to encourage joint assessment and treatment and a clear

understanding of when and who to refer patients to, when realizing the limitations of our role (Wood 1999).

ETHICAL CONSIDERATIONS

Although people with a terminal illness or in the palliative stage of cancer care can be considered vulnerable, it is important to gain their view of services to ensure that their needs are being met. However, whether this vulnerable group should be involved in research studies is open to debate (Beaver *et al.* 1999). Issues such as approaching potential participants without adding to their stress and anxiety and obtaining consent without coercion need careful consideration. Consideration must also be given to how and who will deal with issues arising during the research (Johnston & Plant 1996). This problem did arise during data collection as there may have been deterioration in the participants' condition and the unmet need researcher identified. Permission was gained from the participant for the researcher to bring this unmet need to the attention of the occupational therapy service.

LIMITATIONS OF THE STUDY

As this research was carried out in one Trust area, it cannot be considered representative of all domiciliary occupational therapy services for this patient group. A larger sample group taken regionally would have given a more representative sample. The sampling method used may also be a limitation of the study as the selection of participants is made by human choice rather than at random. This, however, was considered to be the most appropriate method of sampling for this study as the population was highly unique.

Both patients and informal carers may feel under pressure to provide socially desirable answers to sensitive questions and the reluctance of recipients of care to criticize providers of care is well documented (Wilkinson *et al.* 1999). While such factors may mean that negative aspects were less likely to come to light, there is no doubt that patients generally valued the support provided. The lack of negative statements should have no influence on the positive aspects patients chose to emphasize.

CONCLUSION

The role of the occupational therapist is increasing within palliative care and a major opportunity exists for occupational therapy in this area. Baum (1993) believes that efforts must be made to review what occupational therapists are currently doing and what they could be doing to

build a structure for future activities and training. This study, although small, does suggest that patients and carers do value and have a high level of satisfaction with the domiciliary occupational therapy service provided, which is encouraging. However, gaps have been identified in the service provided to this patient group and their carers. These gaps must be addressed if a truly holistic approach to care is to be realized. Occupational therapists should emphasize their wider role in enhancing and enabling occupational performance and should resist having their contribution measured solely in terms of patients' independence in activities of daily living (Eva 2001). Occupational therapists working in palliative care need to adopt the conceptual framework of affirming life: preparing for death suggested by Bye (1998). Only then can they know that they are making a difference relative to the needs of the clients, and feel satisfied that their work has meaning.

Carers have needs, which must be recognized and addressed, and supporting the carer both emotionally and physically is essential for home care to succeed.

Patients in palliative care may not be in control of the progressive nature of their illness; however, occupational therapists must work to enable them to gain control over their lives and work in partnership with both patients, relatives and carers to develop high quality palliative care services for the future. *'In palliative care, time is of the essence and the dissatisfied dead cannot noise abroad their discontent. It is a once and only experience for most palliative care users and their own agenda, not ours, will be uppermost'* (Oliviere 2001).

RECOMMENDATIONS

- To increase education and training both at undergraduate and postgraduate level in oncology and palliative care, in order to provide occupational therapists with the knowledge and skills to meet the holistic needs of this client group, within a multiprofessional environment.
- The appointment of research occupational therapists in partnership with commissioners, voluntary sector and educational institutes in order to audit service provision province wide and inform evidence-based practice.
- Development of a clinical resource pack to provide information and support for relevant staff working in this field.
- Increased specialization to deal with more complex cases, promote service development and improve multidisciplinary working.
- Increase staffing levels within domiciliary occupational therapy. This will provide time and support

allowing a more holistic approach in the treatment of patients and their carers.

- Better co-operation and co-ordination in service planning and delivery ensuring the involvement of both patients and carers in order to guarantee that their needs are identified and addressed.

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