Abstract  The goals of the work described in this paper were to describe palliative day care from the patient’s perspective. Five palliative day care centres in the UK are described. The study subjects were new referrals to the five palliative day care centres, which provided facilities for medical and nursing assessment and also for social and therapeutic activities. This reflects the range of palliative day care services provided in the London region. Three interviews were carried out with each patient over a 3-month period. The descriptive data were examined for content, and the themes were analysed for the frequency of responses within and between interviews. The responses were also examined within three different models of day care (defined by the services). In all, 120 day care patients were recruited from the five centres. Patients attending for day care were mainly white, over 65 years old, retired, and with a cancer diagnosis. These were a representative sample of day care patients in the London region. Patients attended day care to ‘meet people’ and ‘get them out of home’ and found the environment ‘nice and friendly’. The relationships with the staff and volunteers were also important, and they enjoyed the various activities. At each interview the most important theme identified was ‘meeting people’. For this to be supported it would mean encouraging the activities within day care that provide patients with an environment in which they can meet people. This will mean different things to different people, as highlighted in the different philosophies obtained at individual centres.

Keywords Palliative day care · Patient perspective · Multi-centre · UK
An extensive literature search (1966–2000) identified abundant descriptive accounts of individual centres. There were eight studies from the UK [9, 10, 11, 12, 13, 14, 15, 16, 17] and four studies describing palliative day care services in the US [2, 4, 5, 7]. The published literature highlights the differences in services provided at individual day centres. In general the day care service provides care from 10 a.m. to 3 p.m. on 4 days per week, although variations exist, with some centres opening for 5 or 6 days per week. The activities provided are similar at each centre: arts and crafts, personal care, baths, cooked meals, massage and relaxation [9, 11]. Researchers have highlighted the variability in the aims and organisation of the different services [16, 17] and suggested that variations in services depend upon the interests and motivations of those who run the centres rather than local need [13].

It is suggested that there are at least two models: ‘medical’ and ‘social’ [8, 18]. However, Higginson et al. found few differences between the types of staff or activities in centres that were described as medical or social [16]. This calls in question the definition of day care as medical or social, although this divide is the health professionals’ definition and not the patients’ perception. This paper aims to evaluate palliative day care, from the patients’ perspective. It will focus on patients attending five specialist palliative day care centres in the London Region.

London has the largest and most diverse range of ethnic minorities in the UK [19]. Most cancers have a higher incidence in the white population [20], with the exception of prostate cancer, which has a higher incidence in Black Caribbean and Black African populations. This reflects the sociodemographic characteristics of the patients accessing palliative care services. This is one hurdle that needs to be overcome in palliative care services, ensuring the service is accessible to the nonwhite [19, 20] and noncancer population [21].

Methods

Study design

This survey was part of a larger prospective comparative study evaluating the effectiveness of palliative day care for new referrals to day care. Day care patients were compared with a comparison group over time (reported elsewhere). All patients received the usual palliative care services, but the comparison group did not attend day care. This paper concentrates on the group of patients attending day care and describes palliative day care from the patient’s perspective.

Data collection

Setting

The five palliative day care centres provided facilities for medical and nursing assessment of all patients. A variety of social, recreational and therapeutic activities were available, and the centres often employed such specialists as art therapists and aromatherapists. The centres reflect the range of activities and types of palliative day care provision within the London health region [16].

Each of the centres described the philosophy of care it provides in a survey carried out in 1998 [16]. Three of the centres described themselves as ‘medical/social’ (mixed), one as a ‘social’ and one as a ‘medical/therapeutic’ model of care.

Patient sample

The patient sample was made up of consecutive new day care referrals to the five centres.

Eligibility criteria were: age over 18 years, general condition good enough to allow patient to be interviewed (for approximately 35–45 min), absence of obvious confusion/severe cognitive impairment.

Interview

Three interviews were carried out, at baseline (within 2 or 3 visits to day care as it was not possible to identify patients before they attended day care), after 6–8 weeks, and after 12–15 weeks. The interview schedule included measures of quality of life and family burden (to be reported elsewhere; paper submitted) and semi-structured questions about day care. This paper presents the data elicited by two main questions: ‘What is day care like?’ and ‘What is the most important thing about day care?’ Patients were also asked ‘Is there a downside to attending day care?’ This provided a patients’ perspective of the variety of palliative day care services.

Analysis

The descriptive data were examined for content, and the themes were analysed for the frequency of responses within and between interviews, and then within the three different models of day care (defined by the services). This process was carried out by one analyst (D.G.), who consulted with a second analyst (H.-R.D.) to check the themes that had emerged and the clustering of the data into themes.

Multi-centre (MREC) and local (LREC) research ethics approval was obtained.

Results

Data collected

Of 251 new referrals to four of the centres (missing data at one centre) 104 (41%) agreed to participate. The main reasons for not participating were that the patient attended as an out-patient (27%), the patient was not eligible—usually too unwell to complete an interview (25%) and the patient refused (24%).

From the five day centres, 120 day care patients were recruited. Of these 102 (85%) completed baseline interviews, but only 59 (49%) completed a second and 40 (33%) a third interview. Attrition was due mainly to patients’ saying they felt too unwell (10% at each interview) and to death (10% at each interview). Refusal was the least common reason once patients had agreed to participate in the study (n<5 at each interview).