

Implementing Outcome Measures within an Enhanced Palliative Care Day Care Model

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Abstract

Context: Specialist Palliative Care Day Care (SPDC) units provide an array of services to patients and their families and can increase continuity of care between inpatient and homecare settings. A multidisciplinary teamwork (MDT) approach is emphasised and different models of day care exist. Depending on the emphasis of care, the models can be social, medical, therapeutic or mixed.

Objectives: We describe our experience of introducing an enhanced therapeutic specialist day care model and using both patient and carer rated tools to monitor patient outcomes.

Methods: Participating patients received MDT input over 8-week cycles of care. Validated tools used to monitor patients' progress were the Edmonton System Assessment Scale (ESAS), the Edmonton Functional Assessment Tool (EFAT), Part A of the McGill Quality of Life Index and the Palliative Care Problem Severity Scale (PCPSS).

Results: Seventy point six percent of patients showed an improvement in their ESAS symptom distress scores after one 8-week cycle. An improvement in EFAT scores occurred in 53% and remained unchanged in 13% of patients. On a scale of 0-10 the overall quality of life improved in 56% of patients, remained unchanged in 18% and worsened in 26%. PCPSS scores after an 8-week cycle improved in 58%.

Conclusion: This enhanced therapeutic model of SPDC allows for the tracking of progress towards specific goals and monitoring of patients symptoms, functional status, quality of life and complexity. Retrospective analyses of validated tools show SPDC results in both maintenance and improvement of all parameters.

Introduction

Specialist Palliative Care Day Care (SPDC) is defined as “a service that enhances the independence and quality of life of patients through rehabilitation, occupational therapy, physiotherapy, the management and monitoring of symptoms and provision of psychosocial support” [1]. SPDC units provide support to patients and their carers and aim to increase continuity of care between inpatient and homecare settings [2], and help patients remain at home for as long as they wish [3]. In recent years there has been a notable increase in the number of units providing this service [4-6].

Qualitative research has shown that patients value the social and psychological support provided by SPDC and the opportunity to participate in various activities [7-10]. Although the multidisciplinary teamwork (MDT) approach is emphasised in all SPDC units, observational studies have found that different models of day care exist.[4, 11] Traditionally, day care has been based on a social model, where the primary emphasis is on social interaction and carer respite rather than specific goal-orientated therapies. The aim is to provide an environment where patients have the opportunity to socialise with peers while participating in a range of recreational activities. In contrast, units operating a medical model place more emphasis on medical expertise and clinical surveillance. The therapeutic model of care focuses on active, goal-orientated therapies and rehabilitation. Specific clinical or psychosocial issues are highlighted during the referral process and the effectiveness of interventions reviewed after a pre-defined period. In practice however, a mixed model of care is common. A questionnaire survey of 40 UK day care centres, for example, did not find many differences in staffing or activities types offered between units describing their model as social or medical.[4]

Quantitative studies evaluating patient outcomes in SPDC units are scarce in the literature.[12] Patient reported outcome measures (PROMS) have increasingly been used in palliative care, both in research and routinely in healthcare settings.[12-14] A recent systematic review found evidence that capture and feedback of patient centred outcome measures improves symptom recognition and favourably impacts on care processes.[15] To date there are no published articles on the routine use of PROMS in the SPDC setting. In this article we describe our experience using a combination of both patient and carer rated tools to monitor patient outcomes in our SPDC unit which operates an enhanced therapeutic model.

Methods

Setting: The SPDC at Milford Care Centre, Limerick in the Mid-west of Ireland operates 2 days a week and accommodates 10 patients per day who have access to medical, nursing and allied health professional staff. It is attached to a 30-bed Specialist Palliative Care inpatient unit and a Hospice at Home Team that serves a population of 360,000 within a 70 km radius of Ireland's fourth largest city. Patients have access to a range of disciplines including physiotherapy, occupational therapy, complementary therapy and dietetics. In addition, patients can have support from a social worker and partake in various activities such as art therapy, music therapy and therapeutic horticulture.

An enhanced therapeutic specialist day care model was introduced at our SPDC unit in January 2012. This built on an already established social model. In this earlier model, patients were typically referred for social support obtained by interacting with other patients and staff. Where appropriate, participating patients received input from members of the MDT and relevant interventions performed. The core features of the therapeutic model are: (1) Clearly defined goals of care as referral criteria for admission to day care; (2) Identifying specific patient targets at the initial assessment; (3) MDT interventions delivered over energetic 8-week cycles of care (Table 1) and (4) Monitoring patient progress using newly introduced validated tools.

Table 1: Details of services available during the 8-week SPDC programme	
Specialist Palliative Care Nursing Team	<ul style="list-style-type: none"> • Symptom review and management. • Psychological, emotional and spiritual support of patients and families. • Facilitate medical review in day care and the palliative medicine outpatient department. • Liaise with Hospice at Home team and primary care team.
Medical Review	<ul style="list-style-type: none"> • Clinical reviews and management by Palliative Medicine Consultant or Specialist Trainees. • Access to laboratory and radiology services. • Liaise with General Practitioners and referrals to other healthcare professionals.
Physiotherapy	<ul style="list-style-type: none"> • Palliative Rehabilitation • Individualised exercise programme. • One-to-one time with therapist.

	<ul style="list-style-type: none"> • Aerobic, resistance and balance exercises: 30-45 minutes duration once a week. • Lymphoedema management
Occupational Therapy	<ul style="list-style-type: none"> • Assessment of Activities of Daily Living. • Assessment for walking aids and referral for equipment. • Advice on energy conservation and breathlessness management.
Social Work Services	<ul style="list-style-type: none"> • Patient support and counselling. • Carer assessment. • Liaise with local resources and agencies.
Dietetics	<ul style="list-style-type: none"> • Provide specialised dietary advice and life style changes.
Creative Therapies	<ul style="list-style-type: none"> • Art Therapy • Music Therapy • Therapeutic Horticulture
<p>Other services offered: Complementary Therapy Pastoral Care Speech and Language Therapy</p>	

Patients are eligible to attend if they have a progressive, life-limiting illness and specialist palliative care needs. They include patients with non-malignant conditions such as degenerative neurological and chronic respiratory conditions. Those with communication or cognitive difficulties affecting their ability to complete the questionnaires were not excluded from attending if it was felt they would benefit.

Assessment Tools: The following tools were used to monitor patients' progress: Symptom and functional assessments were made using the Edmonton System Assessment Scale (ESAS) and Edmonton Functional Assessment Tool (EFAT) respectively. Part A of the McGill Quality of Life Index was used to monitor patients' quality of life. In addition, the Palliative Care Problem Severity Scale (PCPSS) was used to measure patient complexity. This scale produces a combined score that measures the patient's pain and other symptoms, psychological and spiritual problems and the extent of family or carer distress. Although unvalidated to date, this complexity-scoring tool is used by the Palliative care outcomes collaboration (PCOC) in Australia and has been the subject of a number of publications to date. [16-19]

Patient assessment and review: The multidisciplinary team meets weekly to assess new referrals to the SPDC service and discuss existing patients' progress towards their goals. Once a referral is triaged for appropriateness and urgency, a key worker is assigned to lead on the care plan for the patient. The key worker is the member of the team who will likely have the most input and interaction with the patient. So, for example, if a patient's needs are primarily rehabilitative and is being referred for physiotherapy, then a physiotherapist would be assigned as the patient's key worker.

The assessment tools are completed on initial review and after every 8-week cycle, at which time a patient is either discharged from the SPDC service if targets are reached or attend further treatment cycles if they might benefit. There is a compulsory rest period of at least 1 cycle after three 8-week cycles to prevent over-reliance on the service and to enable access for new patients. (Figure 1)

Figure 1: Flowchart showing SPDC assessment and review process. MDT- Multidisciplinary Team

Results

Demographics: A total of 152 new patients attended the SPDC unit over a 2-year period (January 2012 to December 2013). Baseline data was collected for 102 patients (67%). Cognitive impairment, dysphasia and absent documentation were reasons for missing baseline data (50 patients, 33%). Thirty-four patients (22%) completed at least one 8-week cycle and had outcome measures collected. Twice as many (68 patients, 45%) failed to complete an 8-week cycle mainly due to clinical deterioration, hospitalisation, death occurring at home or a terminal admission to the Specialist Palliative Care Inpatient Unit.

Table 2 shows the demographic information for patients who had completed at least one 8-week cycle of day care. The mean age was 69 years and over two-thirds (67%) had a malignancy, with the most common being lung cancer (N=7). There were approximately similar numbers of patients with chronic lung conditions as there were with progressive neurological conditions.

Table 2: Demographic information

Demographics	N=34	
Age in years		
Mean	69	(Range 47-89)
Gender		
Female (%)	19	(56%)
Carer		
Wife	7	(20.6%)
Husband	9	(26.5%)
Other	16	(47.1%)
No carer	2	(5.9%)
Primary diagnosis		
Malignancy	23	(67.6%)
Lung cancer	7	(20.6%)
Other cancer	16	(47.1%)
Non cancer	11	(32.4%)
Progressive Neurological diagnosis	6	(17.6%)
Chronic Lung diagnosis	5	(14.7%)

Table 3 shows baseline outcome measures. There were similar ESAS Symptom Distress Scores between those who were only assessed at enrolment (28.6/100) and those who completed an 8-week cycle (29.1/100). Average quality of life scores and PCPSS were also comparable.

Table 3: Comparison of baseline outcome measures. ESAS SDS – Edmonton Symptom Assessment Scale Symptom Distress Score; EFAT - Edmonton Functional Assessment Tool; QoL – Quality of Life; PCPSS - Palliative Care Problem Severity Scale Scores		
	Patients only assessed at enrolment, N=68 unless stated	Patients who completed an 8-week cycle, N=34 unless stated
Average ESAS-SDS	28.6	29.1
Average EFAT Score	8.4 (N=18)	7.3 (N=15)
Average QoL Score	5.8	5.4
Average PCPSS	4.5	4.6

Edmonton Symptom Assessment Scale: Seventy point six percent of patients showed an improvement in their ESAS symptom distress scores after one 8-week cycle. Table 4 shows the breakdown in percentage improvement with 12 percent reporting over 50% improvement compared to their baseline.

Table 4: ESAS Symptom Distress Scores (N=34)	
Worse	9 (26.5%)
Unchanged	1 (2.9%)
Improved	24 (70.6%)

% Improvement	
< 10%	4 (11.8%)
11-20%	2 (5.9%)
21-30%	3 (8.8%)
31-40%	5 (14.7%)
41-50%	6 (17.6%)
>50%	4 (11.8%)

Edmonton Functional Assessment Tool: 15 patients had EFAT scores completed. An improvement in function was noted in 53% and EFAT scores remained unchanged in 13% of patients (Table 5). Of the 8 patients whose function improved, four had metastatic cancer, 2 had a diagnosis of a progressive neurological condition and 2 had end stage chronic obstructive pulmonary disease.

Quality of life: On a scale of 0-10 the overall quality of life improved in 56% of patients, remained unchanged in 18% and worsened in 26%.

Palliative Care Problem Severity Scale: PCPSS scores after an 8-week cycle improved in 58%, remained unchanged in 24% and worsened in 18% of patients (Figure 2).

Table 5: Edmonton Functional Assessment Tool, Quality of Life and Palliative Care Problem Severity Scale Scores			
	EFAT Scores (N=15)	QoL Scores (N=34)	PCPSS (N=34)
Worse	5 (33%)	9 (26%)	6 (18%)
Unchanged	2 (13%)	6 (18%)	8 (24%)
Improved	8 (53%)	19 (56%)	20 (58%)

Figure 2: Graphical representation of results. ESAS SDS – Edmonton Symptom Assessment Scale Symptom Distress Score; EFAT - Edmonton Functional Assessment Tool; QoL – Quality of Life; PCPSS - Palliative Care Problem Severity Scale Scores

Discussion

We report our experience of introducing and implementing both patient reported (PROM) and healthcare professional rated assessment tools in a SPDC unit. The primary aim of introducing these tools was to introduce a systematic assessment of patient need, facilitating the monitoring of progress made and robust evaluation of the new service. PROM assessments in clinical practice enable monitoring patient’s clinical state and can potentially detect symptoms, functional changes or psychological issues that might otherwise be missed.[20]

Fewer than a quarter of all new patients who accessed the SPDC unit completed one cycle and had both initial and 8-week assessment data collected. We hypothesise that the major reason for this low completion rate of all patients referred was due to patients being referred too late in their illness trajectory to be able to complete 8 weeks of ambulatory day-care attendance. The baseline outcome measures however, were similar between patients who completed a cycle and those who failed to do so. There was a significant (70.6%) improvement in ESAS symptom distress scores in the patients attending SPDC. This is in contrast to Goodwin et al study findings where in comparison to a control group, a group attending day care had significantly worse 'symptom control' Palliative Care Outcome Scale (POS) scores.[5] It is important to note however, that only a small percentage (14%) of patients in their day care group were referred for pain and symptom management. EFAT scores in our patients also improved but to a lesser degree (53%). We expected functional ability to deteriorate to some degree over time as all our patients had advanced progressive conditions. It is noteworthy therefore that this was maintained in 13% of the patients. So as not to overburden patients, Part A of the McGill Quality of Life Index alone was completed. Although this resulted in a less comprehensive quality of life assessment, we felt it provided a simpler overall measure for tracking purposes. This showed that 56% of patients reported an improvement in their overall quality of life. Finally, 58% of patients reported better PCPSS. This may reflect the holistic approach to patient care practiced in the unit, as it addresses both patient symptom and psychosocial distress, but also carer distress.

Although the described outcome measures were positive and the patients main palliative care input was the SPDC unit, we cannot attribute the changes to SPDC alone in the absence of a control group. We recommend routine use of PROMs in SPDC as a method of monitoring patients' progress and therefore improving care quality.

Conclusion

This enhanced therapeutic model of SPDC allows for the tracking of progress towards specific goals and monitoring of patients symptoms, functional status, quality of life and complexity with validated tools. Retrospective analyses of these tools show SPDC results in both maintenance and improvement of all parameters.

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