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Social objectives of palliative day care groups

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***Abstract**: This paper reports an evaluation by patients, staff and volunteers involved in different types of groupwork in a palliative day care centre; policy comment and research suggests that social as opposed to healthcare objectives in palliative day care are ill-defined. Staff and volunteers completed questionnaires (n=48) and patients were interviewed (n=37) about nine social objectives formulated from the palliative day care and groupwork literature. The results demonstrate agreement between patients, staff and volunteers about objectives, with most objectives assessed being positively identified as being helpful. Formal activity groups organised around creative arts, involving creation of an artistic object were more important to staff and volunteers, while patients gave equal importance to less formal social groups. Staff valued patients supporting each other about their illness and death, while patients were divided, with some preferring not to share. The researchers suggest that the staff and volunteers' focus on creative activities and outcomes led them to give less priority to specific efforts to engage patients in social skill development to combat social isolation.*

***Key words**: day care; palliative care; activity groups; hospice; groupwork*

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Introduction: Objectives of palliative day care groupwork

This paper reports an evaluation of views of patients, staff and volunteers about the social objectives of different kinds of group offered in the day centre at St Christopher's Hospice, London, a specialist palliative care service covering a population of about one million people. Firth (2000) describing her experience of groupwork in palliative care refers to a variety of groupwork interventions in palliative care settings, including an open group for cancer patients, a psychoeducational group providing information according to a structured programme in a supportive setting, a group for bereaved children, and work with staff groups. In a later publication, Firth (2005) suggests that a wide range of groupwork is practised in palliative care including:

- Self-help groups, where patients support each other calling on the trust that develops from sharing similar experiences
- Children's groups
- Groups for bereaved adults
- Groups for cancer patients
- Client or service user groups, to enable them to participate in service planning and feedback on their own experiences
- Caregivers groups.

Within such groups a range of work is possible. We would identify interventions designed:

- to assist people to deal with emotional and cognitive issues
- to offer information and practical assistance
- to enable people to take part in activities that achieve fulfilling experiences for them
- to enable people to have spiritual guidance and reflection.

A range of group activities and objectives is therefore possible. This evaluation focuses on activity groups and other group experiences taking place in the day centre. As with other similar settings, the entire programme of the day centre is organised in groups, but the programme is not intended to address directly therapeutic objectives in relation to the patients' symptoms or healthcare treatment. In that sense, they are typical of the use made of groups by many health and social care agencies. The group experiences form part of a wider programme that is intended to contribute to health and social care objectives formulated by the agency. Moreover, groups are often used as a vehicle for other activities carried out to meet the agency's purposes, and the success of groupwork is measured not in its own terms but as part of wider objectives

What might those objectives be? Palliative care offers holistic care for people dying of advanced illness, their families and carers and bereavement care (Sykes et al, 2004). It forms a specialist part of a healthcare system, in the UK the National Health Service (NHS), with even broader objectives in maintaining a politically acceptable level of response to health needs in society. Therefore, any groupwork offered might be evaluated according to the extent to which it meets healthcare objectives.

Within a palliative care service, Firth's (2005) analysis makes it clear that social care needs related to healthcare needs may also be relevant. Thus, a range of potential healthcare and social objectives interlock, and the groupwork programme may be affected by the wish to achieve many different kinds of outcomes. Healthcare outcomes are typically seen in terms of individualised patient cure or care, and achieving groupwork or social objectives may not be prioritised or well understood. The reason for carrying out the study was to focus on social and non-healthcare objectives, rather than individualised healthcare objectives, and to understand more clearly what social objectives were recognised by patients, staff and volunteers as relevant to their involvement in the day centre.

Palliative day care developed in the UK during the 1970s, being first reported by Wilkes at al (1978). It has increased from 30 units in 1985 probably providing fewer than 500 places in total to the point where nationally there are around 13,000 places (Eve, 2004). Recent literature reviews (Gysels and Higginson, 2004; Payne, 2006) identify a range of objectives including medical, nursing and other physical care, emotional care, spiritual care, social care, services for families and carers, and provision of opportunities to pursue creative arts.

Survey research in the 1990s (Higginson et al, 2000) explored the objectives and range of activities of palliative day care, identifying a debate about whether palliative day care met primarily social objectives, in which the researchers included creative arts provision, rather than medical or healthcare objectives. Their study suggests that there is a 'base layer' of 'physical, emotional and social care' with additional layers such as 'medical and creative therapies'; thus care aims were more important than therapeutic aims. A well-constructed study of outcomes (Goodwin, et al., 2003) found that it did not achieve symptom control or health-related quality of life objectives. The researchers comment:

> The study suggests that palliative day care was more than health-related QOL [Quality of life] … Therefore, future studies evaluating outcomes in palliative day care need to consider adding items of social contact or support to QOL measures, or using domain-specific measures of social support or coping strategies. (Goodwin et al, 2003, p.211)

What might those social contact or support measures be? Authoritative guidance to commissioners of services from the National Institute for Clinical Excellence (NICE, 2004, pp.130-131) describes the potential benefits of 'specialist day therapy' as enabling a range of services '… to be brought together in one setting. It also brings patients together, providing social support and access to facilities, and can offer respite to carers.'

Thus research and policy development throws doubt on the healthcare outcomes of palliative day care, while acknowledging that those patients that attend like it and that social objectives are relevant. Smaller qualitative studies have attempted to explore the social aspects of palliative day care. These have focused on informal interactions. For example, Langley-Evans and Payne (1997) found that social interaction in a day centre was valued by patients; it enabled them to rehearse in informal discussion the prognosis that they were soon to die and come to accept it. Kennett (2000) found that a range of creative and social activities fostered hope and self-fulfilment in a hospice day centre, and in a subsequent study (Kennett and Payne, 2005) that patients were enabled to deal with losses in social, community and family interactions, improve mood, and foster a sense of achievement, belonging and mutual support.

All these findings suggest that palliative day care aims to achieve primarily social, rather than healthcare, objectives, through interpersonal interactions in a group setting. The present study sought to build on such findings by examining what social objectives were accepted elements in the group interactions taking place in a day centre. Some one-to-one interactions took place through the centre, for example a regular nursing assessment, individual interviews with social workers and chaplaincy staff, clinics with doctors and sessions with complementary and arts therapists. However, because groups were the major vehicle for shared experiences, it seemed appropriate to focus particularly on whether the group experiences available in the day centre contributed to social objectives.

The day centre is based within St. Christopher's Hospice, London. Offering 20–25 places each day, totalling 100–120 per week plus attendance for any in-patient well enough to attend, the centre is staffed by a small nursing team who practise a 'key-worker' system each holding their own case load. Every day patients have the opportunity to be involved in three group activities: unstructured social time on arrival in the morning, the creative arts or other activity groups and sharing lunch together. The study sought views of patients, staff and volunteers about each of these activities separately.

Methods

For this study, it was decided to use a questionnaire with staff and volunteers and structured interviews, with patients, covering similar ground. This was because the research team wished to see if accounts of objectives expressed in both the palliative day care and general groupwork literature were understood and accepted by patients, staff and volunteers. A literature review seeking to identify social objectives of palliative day care (Payne, 2006) identified potential social objectives as follows:

- increasing social interaction;
- decreasing isolation;
- providing reassurance about future care arrangements in the Hospice, since the image of hospices as 'the place where you go to die' often prevents people from taking up the offer of help from a hospice;

- promoting personal growth;
- promoting a sense of control over the illness experience.

A survey of social work theory (Payne, 2005: 46-8) identifies a number of well-established potential objectives of social groupwork:

- remedial: to change existing patterns of behaviour;
- reciprocal: to develop mutual support;
- social goals: to achieve external social goals, such as education and information-giving;
- mediating: to achieve new external social roles in a safe environment;

The variety of theoretical models of remedial or mediating groupwork that exist, for example, cognitive-behavioural, humanist, psychodynamic and solution-focused groupwork, implement widely-used models of psychotherapy adapted to groupwork. Since the day centre does not attempt psychotherapy within its groups, it is not considered necessary or appropriate to apply such models in this project, and the remedial objective was therefore not relevant. However, these other broad social objectives were considered at least potentially relevant by the team.

Since groupwork in its various forms was the main activity of the day centre, the researchers hypothesised that objectives found in the literature ought to be recognisable by and relevant to the participants. The project was planned by the authors, one of whom is the manager of the day centre, the others being concerned with service evaluation. It was carried out during one week in May 2007. As a first step, the social objectives of palliative day care and the general objectives of groupwork taken from the literature were rephrased in a number of statements relevant to patients, staff and volunteers. Nine statements were offered to patients and slightly adapted for staff and volunteers. These were tested out on broadly representative groups of professionals within and outside the Hospice to ensure their comprehensibility and apparent relevance; the phrasing and number of objectives were amended following this advice. They are set out in Table 1, with an example in each case drawn from the respondents' comments to show how patients interpreted it.

The statements were included in questionnaires (for staff and

Table 1
Objective statements and patients' comments

Objective statement (prefaced by 'did the … group help …') *Patients' comment in italics*
To change the way you deal with or increase your control over how your life is affected by your illness. *It might seem little but it's a lot to me- I never thought of these things before.*
To provide support to others and gain support yourself by sharing your experiences with each other. *You've got to pick your moments. I don't even ask people why they're ill… I've been helped to feel more comfortable about the way I feel about the illness.*
To educate or inform yourself about your illness or your care *There's a lot I didn't know, when you start talking to people you really realize.*
To improve your life and relationships at home *When I left [home] this morning I was a miserable old sod, but when I get home I'm completely relaxed.*
To increase and improve your contacts with other people *You have contact with the nurses and volunteers. Social contact, a very good thing.*
To become more confident about ways in which the Hospice might help you in the future *You see a different side. All I know is someone gets to die but this hospice is about living.*
To enable you to have a fulfilling and interesting time *An opportunity to try something you haven't had time for in your working life. It's very important to let people come out of their own four walls at home. It's immensely valuable, a chance to do something you think you will never have an opportunity to do because you're ill.*
To take your mind off your illness and any troubles you may have *Definitely not because you tend to find every time you come that someone else has died. I'd rather not have that now.*
To produce something creative to take home or share with others *I can't wait to take it home, I've never done it before.*

volunteers) and in interview schedules (for patients). They were asked in turn whether they thought the statements applied to each of the three groupwork elements of the daily programme; the time in an unstructured group of attenders as they arrived for the day; activity groups undertaking craft and art activities, and a shared lunch. The staff and volunteers were asked whether they thought that the patients were helped in the various ways proposed by the statements for each of the three forms of groupwork, and patients were asked to say whether they were helped in those ways by each of the forms of groupwork. They were offered the alternatives of 'a lot', a little' or 'not at all' in responding, mainly to make the interviews reasonably short for very ill patients.

On each day during the week, staff and volunteers working that day were asked at the morning briefing meeting of the day centre to complete a questionnaire. During that week, all patients who attended the day centre were invited to take part in the project. As they arrived in the morning, they were given an information sheet about the project, and had the opportunity to ask a known staff member or volunteer about the project. If they agreed to take part they signed a form to consent to participating. After lunch, two staff members unconnected with the management of the day centre interviewed patients who were still willing and able to be interviewed until the day centre closed. At that point on some busy days, not all patients who had consented had been interviewed.

Each member of staff and volunteer working during the week completed a questionnaire for each day they worked. There were 48 completed questionnaires from staff and volunteers. The total number of patients interviewed was 40, out of 82 patients attending that week and 47 consenting to be interviewed. Three were excluded for various technical reasons so results are based on 37 completed schedules. Patients' comments were recorded to provide additional more multifaceted interpretation of the results. The interviewers shared the work of transcribing, checking and analysing the data; disagreements were resolved by discussion. A more detailed report is available from the authors. Since this was an audit designed mainly to assist practice development, statistical tests were not applied to the results.

The research project was submitted to the relevant research ethics committee, which determined that it was an audit not requiring research ethics approval. The fact of submission to the committee and its determination means that the informed consent given by all participants was for an evaluation to contribute to more effective management within the centre; it was not considered ethically appropriate to manipulate the data to achieve research objectives outside the evaluation.

Results

Overall, the results show that patients, staff and volunteers thought that all these objectives were relevant to the help given by the day centre and mostly that they contributed a lot to that help. None of the objectives was rejected by any respondents. However, there were variations in the importance given to different objectives.

Table 2 shows the aggregated ratings for all objectives, except 'to produce something creative to take home or share with others', because this only applied to the activity groups. Patients were noticeably more likely than staff to make a negative judgement, but staff/volunteers more likely not to reply or see an item as not applicable. Because patients were interviewed, the researchers came to the view that they were less likely to refuse a reply or miss an item than staff/volunteers, who completed a questionnaire.

Table 2

Aggregated ratings of the importance of objectives

	Staff/volunteers		Patients	
	n	%	*n*	%
Positive	928	80.5	661	74.5
Negative	17	1.5	177	19.9
Not applicable/no reply	207	18.0	49	5.6
Total	1152	100.0	887	100.0

Tables 3 and 4 show in rank order how specific objectives were viewed by, in Table 3, patients and in Table 4 staff and volunteers.

While there are some variations, patients, staff and volunteers gave the objectives similar priority. Since staff/volunteers rarely rated any objectives as not contributing to help for patients at all, ranking of these negative ratings are not compared. However, one striking aspect of patient views is that one objective, 'educate/inform yourself about

Table 3
Percentage of patients rating objectives 'a lot', in rank order

Rank	Objective	Patients rating objective 'a lot' %
1	Fulfilling/ interesting time	73.9
2	Takes mind off illness/troubles	71.2
3	Understand ways the Hospice might help you in the future	65.8
4	Support/be supported by sharing experiences	62.2
5	Increase/improve contacts with others	60.4
6	Increase control over difficulties of illness	52.3
7	Improve life/relationships at home	52.4
8	Educate/inform yourself about illness	35.1

Table 4
Percentage of staff and volunteers rating objectives 'a lot', in rank order

Rank	Objective	Staff/volunteers rating objective 'a lot' %
1	Support/be supported by sharing experiences	70.8
2	Fulfilling/ interesting time	69.4
3	Increase/improve contacts with others	68.8
4	Takes mind off illness/troubles	61.8
5	Understand ways the Hospice might help you in the future	55.6
6	Increase control over difficulties of illness	43.1
7	Improve life/relationships at home	31.9
8	Educate/inform yourself about illness	31.9

Table 5
Patient, staff and volunteer ratings for 'taking home a creative product'

	Staff/volunteers		Patients	
	n	%	*n*	%
Positive	42	94	27	81
Negative. no response not applicable	0	6	1	19
Total	48	100	37	100

Table 6
Averaged views of different groups by patients.

	Positive	Negative	NA	NR	
Unstructured time	34.38	0.88	10.36	1.38	47.75
Sharing lunch	35.63	1.00	10.00	1.25	47.87
Activity group	45.00	0.33	1.33	1.33	47.99

Table 7
Averaged views of different kinds of groups by staff and volunteers

	Positive	Negative	NA	NR	
Unstructured time	28.01	7.76	0.125	0.125	36.02
Sharing lunch	26.00	7.88	0.875	0.375	36.13
Activity Group	26.34	5.89	4.67	0	36.9

your illness', is overall viewed as contributing 'not at all' rather than positively (38.74% rated it 'not at all' compared with 35.14% rating it positively).

Table 5 shows the ratings for the remaining objective, which was only offered by the activity groups, and therefore could not be aggregated with other ratings. This was the objective '…to produce something creative to take home or share with others'. Staff saw the objective somewhat more positively than patients.

Tables 6 and 7 examine ratings of the different kinds of group, by patients and staff and volunteers. The percentages do not add up to the total number of respondent because they have been rounded up or down. Patients rated the activity group more positively than the other groups, staff/volunteers rated all the groups similarly.

Discussion

The response to the day centre programme as a whole was overwhelmingly positive, and the interviewers thought that this coloured the response to the specific objectives that the study focused on. Patients would say things like:

> *I can find no fault with it.*
>
> *Best thing that ever happened to me, coming here.*

Much of this positive feeling was generated by the experience of the activity groups. Examples of what patients said about these are:

> *It gives you back part of your life - I'd lost music, put it away when I couldn't dance any more, but now I listen to music all the time.*
>
> *It teaches me to be patient…. It keeps your mind together, your mind has to set on the things you're doing.*
>
> *It showed me I have a creative side I didn't know about. I'm now doing it at home! I like to do different things, it's extremely good, I've learned a lot.*

There were positive comments on other group experiences, on the unstructured time at the beginning of the day:

> *It provides me with relaxation after rushing and getting ready, and look forward to the rest of the day.*

and sharing lunch together:

> *The break before lunch is very important – it's civilising – brings you back to a 'normal' way of life.*
>
> *I was shocked [during my first attendance] when I saw the drinks trolley. It's like a gathering of friends, even though you're only acquaintances.*

Overall, patients accepted the objectives as relevant to the ways in which they were being helped but differentiated between them slightly more than staff/volunteers. Staff and volunteers also found them relevant (Table 2). Patients, staff and volunteers also had similar views about the comparative importance of the different objectives (Tables 3-4). However this had come about, patients, staff and volunteers agreed about the social objectives they were trying to achieve. Therefore, the evaluation shows that the day centre had achieved staff, volunteer and patient understanding of and agreement about its aims and these connected with the aims identified in the literature. The objectives that seemed most important were about the interpersonal experience at the day centre (such as having a fulfilling and interesting time, taking the patient's mind off the illness and any troubles they might have, and supporting others and being supported by sharing experiences). Both groups of respondents gave less importance to wider objectives, such as increasing the patients' feeling of control over difficulties presented by their illness, improving life and relationships at home and educating and informing the patient about their illness. It may be that the generality of these objectives make them seem less significant than objectives specifically related to the day centre programme.

There were, however, different views about the importance of some objectives. For example, staff and volunteers were more positive about the mutual support aspects of the groups than patients. The reason for this is that, when their comments are examined, patients were divided: some liked the mutual support derived from sharing experiences about their illness, while others preferred not to share or to put the illness aside. This was also reflected in the ranking of 'taking your mind off your illness and any troubles you might have', which came higher up the patients' ranking because some patients positively tried to achieve this. It seems to have been less important to staff and volunteers. Examples of patients' divided views taken from the comments are:

> *I shut my eyes to problems, the treatment here helps it go away.*
>
> *We don't discuss while doing the painting.*
>
> *We don't talk about each other. I don't talk about my illness all the time.*

and on the other hand:

You talk to people, and it does help you with your complaint. I looked into my illness and I could deal with it better.

I've found that since coming I'm more open.

I think it helps others more than it helps me.

The researchers hypothesise that staff and volunteers may be committed to sharing and mutual aid values in the groups, while patients are divided between those who are mutually sharing and supportive about their illness experience and those who are more inhibited about this objective. The study did not examine length of time in the day centre, and it may be that new patients need time to share. A future study might examine what helped people to share and what hindered sharing. Also, staff and volunteers may not put such a high priority on 'taking your mind off things' as some patients did. This might be because of an ethos in palliative care that values openness and sharing about illness, or because they valued patients' achievements in the activity groups very positively and perhaps did not like to see them used merely as a diversionary activity. For practice development, therefore, the researchers suggested that practitioners might usefully be explicit in providing leadership on the social development aims of the day centre's groupwork. The researchers thought that their emphasis on artistic achievement and self-fulfilment underplayed the possibility of learning skills in social interaction so that patients could explicitly develop mutual support as an aspect of their engagement in the activity groups.

These two points together may suggest that in a mixed programme, activity groups may come to be seen more positively because what they are about may be clearly understood. Patients may not wish to share and provide support to each other about their illness, but it may also be that patients needed to be helped to make use of opportunities to develop or renew social skills. Positive achievements in the activity groups concealed the need to make more explicit the social objectives of the less clearly structured parts of the programme.

Responses to the activity groups, and particularly creative products from them, also varied. The staff and volunteers overwhelmingly (nearly 94%) viewed 'taking a creative product home' positively, whereas nearly 20% of patients found this objective not relevant or 'not at all' helpful. Staff/volunteers viewed all the groups as similarly helpful, but more patients regarded the activity group, with creative work as helpful. These findings supports a hypothesis that because staff give overwhelming importance to the activity groups and their product, perhaps influencing patients to see it as more important than unstructured activities. Alternatively, the focus on activities may identify it to patients as the main function of the day centre, and they have not seen, as staff/volunteers do, that the unstructured activities are as important. Therefore, as a practice development, the researchers suggested that staff and volunteers need to make clear the social value of the unstructured activities and perhaps model to patients and provide education in improving social skills in talking about illness and impending death. There is evidence that some patients use these social skills to improve relationships and reduce social isolation at home and with other social contacts (Langley-Evans and Payne, 1997).

Only one patient commented specifically about using group experiences in the day centre to develop social skills to use at home, She said, about the experience of sharing lunch with others:

> *[It helps me in] finding other strategies to use with your family. I observe what happens here, then take it home and try it with my family.*

It may be that the focus by staff and volunteers on the self-fulfilment objective and artistic achievement means that patients who did not focus on sharing and mutual support were not specifically helped through the groupwork programme to develop the skills that might help to reduce their social isolation outside the day centre experience.

Conclusion

St Christopher's Hospice day centre runs a number of groups as part of its programme, and this study enquired about the ways in which participants found them helpful, or not in relation to nine social objectives identified in palliative care and groupwork literature. They were asked about three types of groups that take place in the day centre, unstructured social time at the beginning of the day, the activity group and sharing lunch together.

The evaluation demonstrated a very positive response from patients to their group experiences in the day centre, and showed that there were shared objectives among patients, staff and volunteers. The positive experience is focused on both the creative arts work in the activity groups with their artistic achievements and also good social experiences within the centre. However, the study offered some pointers for further thought about how their practice might develop.

The social objectives explored were recognised and largely accepted by patients, staff and volunteers; thus the social objectives identified in the palliative day care literature do provide a basis for understanding social objectives in at least this day centre. However, there were some indications that a strong commitment to activity groups in a wider programme may have dominated staff/volunteer perceptions, and this in turn may have affected patients' views. Some patients seemed to feel that less clearly articulated social objectives such as educating or informing patients about their illness and social skill development, both of which may have helped them in their wider lives outside the day centre, were not fulfilled so well. The researchers suggested that to achieve such objectives, staff and volunteers need to devise aspects of the programme targeting these social skills development objectives explicitly and creatively to help patients with this area of their lives. This may also be true of many day centre settings where attention is focused on activity groups rather than wider social learning opportunities.

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