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Title:

The added value of palliative day care centres: a full-population cross-sectional survey among clients and their family caregivers in Flanders, Belgium

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Conflicts of interest statement:

The authors declare that there are no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Data availability statement:

The data that support the findings of this study are available from the authors upon reasonable request.

Authors contribution statement:

Study conception and design: KC, KB. Data collection, data analysis, drafting the article: SD. All authors interpreted the results, revised the manuscript critically for important intellectual content and approved the final version of the manuscript.

ABSTRACT

In addition to palliative care delivery at home or in hospital, palliative day care centres occupy an in-between position in palliative care. In palliative day care centres multidisciplinary teams provide holistic care and support for people with (chronic) life-limiting conditions, or clients, in a homely surrounding, allowing them to remain living at home while attending a specialist palliative care service. This study aims to evaluate palliative day care centres from a user perspective. We conducted a full-population cross-sectional survey of clients (N=86) and their family caregivers (N=63) in all five palliative day care centres in Flanders, Belgium from January until December 2019. We used validated instruments supplemented with self-developed items to measure participants' reasons for use, support provided, unmet support needs, and added value to other (palliative) care services across palliative care domains i.e., physical, psychological, social and spiritual care. Response rate was 77% for clients and 81% for family caregivers. The most often indicated reasons for use were that the client needs social contacts (clients: 73%, caregivers: 65%), to enable the client to live at home as long as possible (resp. 58%, 55%), and to reduce the family caregiver's mental burden (resp. 42%, 65%). Three out of four family caregivers felt better able to combine daily activities with caring for the client (77%) and felt better able to perform their family caregiving tasks (77%) because the client attends the palliative day care centre. Thirty-six per cent of clients had received support for social needs exclusively in the palliative day care centre and not from any professionals outside palliative day care. Palliative day care centres seem to be of added value for those care domains to which often less attention is paid in other settings, particularly social and emotional support, both for clients and family caregivers.

KEY WORDS

Palliative Care, Day Care, Cross-Sectional Survey, Health Services Evaluation, Family Caregivers

What is known about this topic?

- In addition to providing the usual nursing and medical care, palliative day care centres provide psychosocial support and organise social and creative activities.
- Evidence suggests that palliative day care is beneficial for the well-being of both people with chronic life-limiting illness and their families.
- While most prominent in the UK, palliative day care centres exist in many countries across Europe.

What this paper adds

- Both clients and family caregivers indicated several reasons to use palliative day care centres in addition to other (palliative) care services.
- A remarkable proportion of clients exclusively received support for social and emotional needs in the palliative day care centre.
- Family caregivers felt supported by the day care centres both through direct attention and indirectly by means of respite.

INTRODUCTION

Palliative care is an approach that aims to improve the quality of life of people with advanced illness and their families by addressing physical, psychological, social and spiritual care needs (*WHO Definition of Palliative Care*, 2020). In addition to palliative care being delivered at home, e.g., via multidisciplinary home care teams, or in hospital, e.g., via mobile multidisciplinary teams or in palliative care units, palliative day care centres occupy an in-between position in the palliative care landscape.

In palliative day care centres multidisciplinary teams, including nurses, nursing assistants, physicians, occupational therapists, psychologists, social workers and volunteers, provide holistic care and support for people with (chronic) life-limiting conditions, to whom we refer further as 'clients', in a homely surrounding (Moore et al., 2013). In addition to providing the usual nursing and medical care, they provide psychosocial support and organise social and creative activities, with a high variance in service provision across centres (Davies & Higginson, 2005; Stevens et al., 2011). Palliative day care centres allow clients to remain living at home while regularly attending a specialist palliative care service (Kernohan et al., 2006; Kilonzo et al., 2015). Additionally, palliative day care centres support clients' informal caregivers by providing some time-off from informal care duties (Low et al., 2005; Vandaele et al., 2017).

Evidence is growing that the involvement of palliative care services in the care of people with chronic life-limiting illness is beneficial for the well-being of both clients and their families. It has been suggested that attending palliative day care centres positively impacts clients' quality of life by reducing isolation, increasing social support and encouraging communication (Bradley et al., 2010b; Stevens et al., 2011). Clients particularly value the social contacts with caregivers and other clients, taking part in a range of activities and having symptoms assessed when required (Bradley et al., 2010b; Davies & Higginson, 2005; Kennett & Payne, 2005; Low et al., 2005). In this, palliative day care centres help clients cope with their illness and its consequences (Bradley et al., 2010a). In terms of benefits for

family caregivers, research suggests that palliative day care reduces caregiver burden by providing much needed regular respite (Bradley et al., 2011).

A systematic review of 31 studies on palliative day care outcomes shows that most studies focus exclusively on clients' health-related quality of life (Stevens et al., 2011). Scarce evidence is available on palliative day care centres' role in other domains central to palliative care delivery, such as social, emotional and existential well-being, and administrative support (Payne, 2006; Stevens et al., 2011). More in-depth understanding of which support is provided in palliative day care centres, how they contribute to the holistic care of clients and their families, and their added value to other (palliative) care services is needed. Additionally, published literature of palliative day care is mainly based on research conducted in the United Kingdom (Andersson Svidén et al., 2009; Stevens et al., 2011). However, while most prominent in the United Kingdom, palliative day care centres have been identified in many countries across Europe (Arias-Casais et al., 2019).

In the Belgian context, the palliative care centre model is uncertain of survival as policymakers are yet to evaluate and fund palliative day care centres adequately (Federal Evaluation Cell Palliative, 2014; Federation of Palliative Care, 2018). The palliative day care centres in Flanders, the northern Dutch-speaking part of Belgium, are financed by the Flemish regional government through an annual subsidy depending on the average occupation of the previous working year and an allowance per day of stay of individual clients. In addition, clients pay a daily rate. Lastly, as government support is insufficient to cover all costs, the centres receive financial support from the Flemish-Belgian cancer society 'Kom op tegen Kanker'.

The present study aims to evaluate palliative day care centres in Flanders, Belgium from the perspective of people attending palliative day care centres and their family caregivers. A rigorous analysis and evaluation of the service is needed to identify the added value of palliative day care centres and opportunities for improvement. We address the following research questions:

- 1) What are clients' and family caregivers' self-reported reasons for attending palliative day care centres?

- 2) What is the perceived impact of attending palliative day care centres for family caregivers and which differences in perceived impact occur according to the family caregiver's profile?
- 3) For which existing needs do clients and their family caregivers receive support in palliative day care centres and what is the added value of palliative day care centres in addition to other (palliative) care services?
- 4) What can palliative day care centres do more in terms of support for clients and their family caregivers?

METHODS

We used the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement (Von Elm et al., 2014) to describe all relevant aspects of the study.

Study design, setting and participants

We conducted a multicentre prospective full-population cross-sectional survey of clients and their most important family caregiver in all five palliative day care centres in Flanders, Belgium. Participants were prospectively recruited from January until December 2019. Flanders is the semi-autonomous northern half of Belgium with approximately six million inhabitants.

Clients were eligible if they were 18 years or older, had attended the palliative day care centre at least three times, were Dutch-speaking and were capable of filling in the questionnaire independently as judged by the people working at the palliative day care centre. Family caregivers were eligible if they were 18 years or older, were Dutch-speaking, were capable of filling in the questionnaire independently and if their relative had attended the palliative day care centre at least three times.

Data collection

Clients and family caregivers were approached by a palliative day care centre employee who was either a psychologist, a nurse or social worker. They explained the aims of the study, obtained written informed consent, and if consent was obtained, gave the questionnaire to the client. The same method was used for family caregivers who visited the day care centre. For those who did not visit, the employee first contacted the family caregiver by phone to ask if they were willing to participate and delivered the questionnaire via the client. Respondents were asked to fill out the questionnaire at home and to mail the questionnaire to the researchers using a free-postmarked envelope. We asked participants to complete the survey at home, not in the presence of an employee of the palliative day care centre, to encourage them to respond honestly and to not feel pressured to give overly positive evaluations. Sociodemographic and clinical client data i.e., sex, age, and diagnosis, were collected by the palliative day care centre employees.

Follow-up of response and linking of sociodemographic and clinical client data, client questionnaires and family caregiver questionnaires was possible using unique identifiers for each client and each family caregiver. The researchers did not have access to nominal information of the client and the palliative day care centre staff did not have access to the completed questionnaires.

Questionnaire

We developed two questionnaires, one for clients and one for family caregivers, about their support needs and their reasons, wishes and expectations regarding the use of palliative day care. We also asked to what extent these needs, wishes and expectations had been met and what problems clients and family caregivers encountered when attending the palliative day centre. The questionnaires were based on a questionnaire used in a previous study of cancer patients' care needs (Beernaert et al., 2016). We developed the questionnaires within a multidisciplinary team, including a representative of the palliative day care centres, and pilot-tested them among three clients attending a palliative day care centre and two family caregivers. The questionnaires (in Dutch) are available upon request.

Client questionnaire. The questionnaire asked for the client's living situation, educational attainment, use of palliative care services other than palliative day care, and reasons for using palliative day care. Support needs were assessed using the EORTC QLQ-30 (Fayers & Bottomley, 2002). As the EORTC QLQ-30 does not contain elements related to existential issues and intimacy we added one item from the Sheffield Profile for Assessment and Referral to Care questionnaire (Hughes et al., 2015), three items from the EORTC QLQ-SWB32 (Spiritual Well-Being) (Vivat et al., 2017) and one self-developed item. For needs related to intimacy, we used one item from the EORTC SHQ-22 (Sexual Health) (Oberguggenberger et al., 2018) and 2 self-developed items. For each subscale we asked: 1) from which service the respondent had received support; 2) whether they had received support in the palliative day care centre; and 3) whether (more) support was desired.

Family caregiver questionnaire. The questionnaire asked for the respondent's sociodemographic characteristics (sex, age, employment situation, educational attainment, relationship with the client, living situation concerning the client) and the reasons for using palliative day care. Support needs were assessed using items from EORTC QLQ-30 (subscale emotional functioning) (Fayers & Bottomley, 2002), EORTC QLQ-SWB32 (spiritual/existential well-being, 2 items) (Vivat et al., 2017), SPARC (spiritual/existential well-being, 1 item) (Hughes et al., 2015), EORTC SHQ-22 (intimacy, 1 item) (Oberguggenberger et al., 2018), 1 self-developed item on spiritual/existential well-being, 2 self-developed items on intimacy and 3 self-developed items concerning financial, administrative and practical support needs. For each subscale we asked: 1) from which service the respondent had received support; 2) whether they had received support in the palliative day care centre; and 3) whether (more) support was desired. We also asked 14 statements to assess the perceived impact of palliative day care on a 5-point Likert scale ranging from 'completely disagree' to 'completely agree'.

Statistical analyses

We used descriptive statistics to report on the sociodemographic and clinical profile of clients and family caregivers, their reasons for using palliative day care, family caregivers' perceived impact of palliative day care, support provided to clients and family caregivers and unmet support needs. We used χ^2 association statistics to calculate bivariable p values to test differences in reported reasons for using palliative day care between clients and family caregivers and differences in family caregivers' perceived impact palliative day care depending on caregiver characteristics i.e., sex and living situation. Significance at $p=0.05$ or lower is indicated with an asterisk (*). We performed all analyses using SPSS software, version 27.0.

Research ethics and patient consent

Ethical approval was obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel (Study nr. 2018/397; December 3, 2018) and GasthuisZusters Antwerpen (Study nr. 190105ACADEM; January 8, 2019). All participants provided written informed consent.

FINDINGS

A total of 204 clients and 141 family caregivers attended the palliative day care centres during the 12-month study period (Figure 1). There were 120 clients eligible to participate, of whom 97 were invited to participate and 86 gave consent and received a questionnaire. In total 66 clients returned the questionnaire, resulting in a response rate of 77% (66/86). There were 100 family caregivers eligible to participate, of whom 70 were invited to participate and 63 gave consent and received a questionnaire. With 51 family caregivers returning the questionnaire, response rate was 81% (51/63).

Client and family caregiver profile in palliative day care centres

About one-third of the clients (33.8%) were between 18 and 64 years, 38.5% were 64 to 79 years and 27.7% were 80 years or older (Table 1). Most clients had cancer (56.9%) or neurological disorders

(18.5%) and were living alone (37.9%) or together with their partner without children (40.9%). While nearly two out of three clients (62,3%) did not use an additional specialist palliative care service at the time of completing the questionnaire, 29.5% of clients were supported by a palliative home care team and 8.2% used hospital-based palliative care. About one in three clients (35.9%) had attended the palliative day care centre 100 times or more (35,9%); while another third of clients (32,8%) less than 10 times.

Family caregivers were predominantly women (75.5%) and had a median age of 61 years (Table 2). They were mainly 50 to 59 years old (31.9%) or 60 to 69 years old (38.3%) and were usually the client's partner (59.2%) or child (28.6%). Most were retired (44.9%), working part-time (20.4%) or on sick leave or disability (16.3%). Two out of three family caregivers (67,3%) were living together with the client.

Clients' and family caregivers' self-reported reasons for attending palliative day care centres

The most frequently mentioned reason for clients to attend the palliative day care centre is the need for social contacts (72.7%) (Table 3). This is also the most commonly indicated reason among family caregivers (65.3%). Other frequently indicated reasons are to allow the client to stay at home as long as possible (clients: 57.6%; family caregivers: 55.1%) and to allow the client to better process his/her situation (clients: 48.5%; family caregivers: 42.9%). Also, 40.9% of clients indicated the need for contact with people in similar situations. As for reasons related to the family caregiver, reducing the family caregiver's mental burden was an important reason in both clients and family caregivers (resp. 42.4% and 65.3%, $p=0.023$). Also, 46.9% of family caregivers indicated decreasing their physical burden as a reason for using palliative day care. Answers were congruent between client and caregiver, i.e., either both client and family caregiver ticked the reason or neither did, in 66.7% (to enable the client to better deal with his/her situation) to 84.6% (the care that was available for the client is insufficient) of client – family caregiver dyads.

Perceived impact of the use of palliative day care centres for family caregivers

More than three quarters of family caregivers agreed they feel more able to combine daily activities with caring for the client (77.1%) and feel better able to perform their family care tasks (77.1%) because the client attends the palliative day care centre (Table 4). Also, 72.3% agreed that caring for their loved one falls less on their shoulders and 61.2% says it is easier to let go of the situation now and then.

Female family caregivers more often than male family caregivers indicated their independence is less compromised because the client attends the palliative day care centre (58.3% vs 18.2%; $p=0.044$) and that they feel less pressured by the situation of the client (56.8% vs 30.0%; $p=0.038$) (not in table). Family caregivers who do not live with the client more often agreed that they feel less pressured by the client's situation because the client attends the palliative day care centre compared to family caregivers who live with the client (80.0% vs 37.5%; $p=0.025$).

Support received, unmet support needs and added value of palliative day care centres

Clients mainly report having been supported for their physical problems (physical functioning: 82.3%, physical symptoms: 79.7%) and emotional (77.6%), social (68.9%) and role functioning (78.1%) (Table 5). For some care domains clients indicated having only received support in palliative day care centres and not from professionals outside palliative day care. This is mainly the case for social functioning (36.2% only received support in palliative day care), intimacy (27.5%), role functioning (27.4%) and cognitive functioning (26.3%). Clients stated that they want more support in palliative day care mainly within the domains of cognitive functioning (18.6% want more support), spiritual/existential well-being (12.3%) and social functioning (11.5%). Some clients indicated that they did not want any support in palliative day care in a specific domain, ranging from 14.5% for physical functioning to 55.0% for financial, administrative and practical matters (not in table).

Family caregivers mainly received support in palliative day care for emotional functioning (42.9%). About one in ten family caregivers only received support in palliative day care for emotional

functioning (8,3%), spiritual/existential well-being (10.9%) and financial, administrative and practical matters (9.8%). A limited proportion of family caregivers would like more support, ranging from 10.6% for intimacy issues to 14.6% for spiritual/existential well-being. Family caregivers indicated not wanting any support in palliative day care ranging from 44.9% of family caregivers for emotional functioning to 76.6% for intimacy (not in table).

DISCUSSION

Main findings

This full-population cross-sectional survey study among clients visiting Flemish palliative day care centres and their family caregivers found that both clients and family caregivers indicate several reasons to use palliative day care centres in addition to other (palliative) care services. The main reasons for using palliative day care were that the client needs social contacts, to enable the client to live at home as long as possible and to reduce the family caregiver's mental burden. Family caregivers reported feeling more able to combine daily activities with caring for the client and to perform their family care tasks because the client uses palliative day care. One-third of clients reported to have received support for social needs only in the palliative day care centre.

Strengths and limitations

Strengths of this study include the use of a prospective full-population design and both the client and family caregivers' perspectives being investigated. This study has some limitations. Firstly, as a cross-sectional design was used, needs were measured at only one time-point while health condition and support needs of people with advanced illness and their family caregivers may fluctuate over time. Secondly, our findings may underestimate clients' and family caregivers' support needs as those with arguably the highest support needs may be underrepresented in the study. Persons with severe cognitive problems were not included in the study and in some cases, the client or family caregiver was not asked to participate by the palliative day care employee so as not to overburden these persons. In any case, it is unclear how such an underrepresentation might have impacted on the question of palliative day care centres' added value.

Interpretation

Our findings show that the majority of clients received ample support in palliative day care across all (palliative) care domains. This finding supports previous research (Bradley et al., 2011; Kennett & Payne, 2005; Stevens et al., 2011) and shows that palliative day care centres take on a holistic approach of care by addressing a broad range of care domains. In this sense, the palliative day care centres clearly propagate the palliative care philosophy. Moreover, the provision of support in palliative day care is generally considered satisfactory. This is in line with the finding of an international systematic review of palliative day care that clients generally report high levels of satisfaction with the care they received (Davies & Higginson, 2005). Nevertheless, the results indicate that there are still some opportunities for Flemish palliative day care to improve or optimize its service.

The results of this study show that support in palliative day care centres is of added value for both clients and family caregivers. Firstly, a significant proportion of clients received support for certain domains – such as social and emotional functioning – only in palliative day care. Palliative day care seems to have an important added value for these care domains to which typically less attention is paid in regular care settings. Our findings show that especially the social function of the palliative day care is highly appreciated by both clients and family caregivers by allowing clients to have social contacts in general and more specifically to meet people in similar situations. The importance of the social support function of palliative day care for clients, through peer support, social activities, meeting people in similar circumstances and enjoying a sense of community, is highly recognized in the international literature on palliative day care (Bradley et al., 2010b; Davies & Higginson, 2005; Hyde et al., 2011; Kernohan et al., 2006; Low et al., 2005; Payne, 2006). Secondly, family caregivers felt supported by the day care centres, both through direct attention and indirectly through respite. In addition to using palliative day care to reduce mental burden, family caregivers in our study indicate that they feel they function better in their role as informal caregiver using palliative day care and can more easily combine daily activities with caregiving tasks. The importance of the respite function of palliative day care has been highlighted in previous studies (Bradley et al., 2011; Kernohan et al., 2006; Low et al., 2005; Stevens et al., 2011) and, moreover, respite care has been proved effective in reducing

family caregiver's burden (Aoun et al., 2005; Koopmanschap et al., 2004). As provision of social and emotional support for clients and respite care for family caregivers are also considered core components of palliative day care in other countries (Bradley et al., 2010b; Douglas et al., 2000; Payne, 2006; Stevens et al., 2011), it is likely that our findings apply beyond Flanders, Belgium.

To identify and address areas for improvement we recommend that other palliative day care centres perform service evaluations similar to our study. Subsequent research can certainly add to this effort by providing more detailed descriptions and evaluation of the specific activities in palliative day care, through e.g., in-depth interview studies with both clients and family caregivers. As a further recommendation for research and policy, we believe it is important for palliative day care to be evaluated from a health economic perspective. The emerging picture in literature points to palliative day care having a clear added value in the (palliative) care landscape. In Flanders at least, this service type has remained marginal throughout due to a lack of evaluation. Considering their added value in the (palliative) care landscape, adequate funding of palliative day care centres may be considered. The next step is to evaluate the potential for upscaling and economic viability, in terms of cost effectiveness, cost efficiency and potential for 'return on investment' due to cost-saving in the last phase of life.

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Table 1. Characteristics of clients in the study sample (N=66)		
	N	%
Sex[†]		
Male	31	47,7
Female	34	52,3
Age[†]		
18-64	22	33,8
64-79	25	38,5
80 or older	18	27,7
Primary diagnosis[†]		
Cancer	37	56,9
Neurological disorder	12	18,5
COPD	4	6,2
Heart failure	2	3,1
Dementia	1	1,5
General decline/accumulation of aging ailments	1	1,5
Other [‡]	8	12,3
Educational attainment		
Basic education	23	35,9
Secondary education	25	39,1
Higher education	16	25,0
Living situation		
Alone	25	37,9
With partner without children	27	40,9
With partner and children	5	7,6
With children	1	1,5
Other [§]	8	12,1
Use of palliative care initiatives other than palliative day care		
Palliative home care	18	29,5
Palliative support team in hospital	5	8,2
None	38	62,3
Entitled to higher reimbursement from health insurance (n=55)^{†¶}	21	41,2
Total number of visits to palliative day care since first visit[†]		
3-9	21	32,8
10-24	10	15,6
25-49	7	10,9
50-99	3	4,7
100-199	8	12,5
200-499	10	15,6
500 or more	5	7,8
Time since first visiting the day care centre[†]		
1 month or less	19	34,5
2-12 months	13	23,6
1-3 years	17	30,9
More than 3 years	6	10,9

Missings ranged from 1,5% to 16,7%.

†Data obtained from palliative day care centre employees

‡The deceased partner was a visitor of the day centre and continued to go after his death (n=2), scleroderma (n=1), HIV (n=1), renal failure (n=1), stroke (n=1), joint pain, spastic colon and anorexia (n=1), heavy metal poisoning (n=1)

§Lives with parents (n=2), lives with grandchild (n=1), lives with family of daughter (n=1), lives with (family of) brother/sister (n=2), in a retirement home (n=1), in a LAT relationship (n=1)

¶No data available for 1 palliative day care centre

Table 2. Characteristics of family caregivers in the study sample (N=51)		
	N	%
Sex		
Male	12	24,5
Female	37	75,5
Age, median (minimum, maximum)		
18-29	2	4,3
30-39	1	2,1
40-49	2	4,3
50-59	15	31,9
60-69	18	38,3
70-79	6	12,8
80-89	3	6,4
Employment status		
Retired	22	44,9
Working part-time	10	20,4
On sick leave or disability	8	16,3
Working fulltime	6	12,2
Unemployed	2	4,1
Homemaker/housewife	1	2,0
Change in employment status since client attends palliative day care (n=29) †		
None	20	83,3
Working less	4	16,7
Working more	0	0
Educational attainment		
Primary education	9	19,1
Secondary education	25	53,2
Higher education	13	27,7
Relation with client: family caregiver is...		
Spouse	29	59,2
Child	14	28,6
Sibling	4	8,2
Parent	2	4,1
Living together with client (yes)		
	33	67,3
Missings ranged from 3,9% to 9,8%.		
†Question was not asked in case the family caregiver was retired (n=22)		

Table 3. Reasons for using the palliative day care centre of clients (n=66) and family caregivers (n=51) [†]						
	Clients		Family caregivers	Congruence client - family caregiver§	Only indicated by client§	Only indicated by family caregiver§
	n (%)	n (%)	p-value‡			
Reasons related to the client: indicated at least one reason	62 (93,9)	46 (93,9)	>0,999			
To enable the client to continue to live at home as long as possible	38 (57,6)	27 (55,1)	0,850	71,8	15,4	12,8
The client needs social contacts	48 (72,7)	32 (65,3)	0,419	82,0	15,4	2,6
The client needs contact with people in similar situations	27 (40,9)	14 (28,6)	0,237	76,9	15,4	7,7
To enable the client to better deal with his/her situation	32 (48,5)	21 (42,9)	0,576	66,7	17,9	15,4
The care that was available for the client is insufficient	13 (19,7)	11 (22,4)	0,818	84,6	7,7	7,7
Reasons related to the family caregiver: indicated at least one reason	33 (50,0)	34 (69,4)	0,055			
To reduce the family caregiver's mental burden	28 (42,4)	32 (65,3)	0,023*	69,3	15,4	15,4
To reduce the family caregiver's physical burden	21 (31,8)	23 (46,9)	0,122	74,3	12,8	12,8
To give the family caregiver more time for themselves and/or other family members	23 (34,8)	19 (38,8)	0,699	74,3	17,9	7,7
Missings for two family caregivers.						
†The questions were posed in such a way that the reasons for both the client and the family caregiver were assessed from their own perspective. Percentages do not lead up to 100% as multiple answers were possible.						
‡P-value calculated with Fisher exact test for differences in reasons for using palliative day care between clients and family caregivers.						
§Congruence in answers (either both visitor and caregiver indicated the reason, or both did not) could be ascertained for 39 client-caregiver dyads.						

Table 4. Family caregivers' experience of using palliative day care (n=51)			
	(Totally) disagree (%)	Neutral (%)	(Totally) agree (%)
Because my loved one visits the palliative day care centre...			
Physical functioning			
... I experience fewer problems with my physical health (e.g., less often sick, less tired, less physical overload, ...)	14,3	55,1	30,6
Social functioning			
... it is easier to combine my daily activities (e.g., work, housekeeping, study, hobbies, ...) with caring for my loved one.	8,3	14,6	77,1
... I experience less conflict at home and/or at work.	10,2	51,0	38,8
... I feel better able to perform my family care tasks.	0	22,9	77,1
... I feel more recognized, seen, heard as a family caregiver.	10,6	42,6	46,8
... my independence is less compromised.	2,1	50,0	47,9
... I can participate more in society again.	18,3	42,9	38,8
Emotional functioning			
... I feel less pressured by my loved one's situation.	14,6	35,4	50,0
... caring for my loved one is less on my shoulders.	14,9	12,8	72,3
... it is easier for me to let go of my loved one's whole situation every now and then.	14,3	24,5	61,2
... I can deal better with the emotional burden of family care tasks.	10,2	38,8	51,0
Financial, administrative and practical issues			
... I feel less pressure because people take over tasks (financial tasks, administrative help, ...) from me.	46,9	34,7	18,4
... I feel less pressure because of the support with practical matters, such as transport.	18,7	41,7	39,6
... I am better informed about the possibilities regarding financial benefits to which I am entitled as a family caregiver.	22,9	31,3	45,8
Missings ranged from 3,9% to 7,8%.			

Table 5. Support received and unmet support needs among palliative day care clients and family caregivers

	Clients N=66				Family caregivers N=51			
	Received support†			Wants more support in day care centre§	Received support¶			Wants more support in day care centre††
	Professional support outside day care centre‡	In day care centre	<u>Only</u> in day care centre		Professional support outside day care centre‡	In day care centre	<u>Only</u> in day care centre	
Support domain	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Physical functioning	52 (78,8)	51 (82,3)	7 (11,3)	5 (8,1)	‡‡	‡‡	‡‡	‡‡
Symptoms (physical)	45 (73,8)	47 (79,7)	10 (17,5)	5 (8,5)	‡‡	‡‡	‡‡	‡‡
Emotional functioning	41 (66,1)	45 (77,6)	14 (24,6)	5 (8,6)	32 (65,3)	21 (42,9)	4 (8,3)	7 (14,3)
Social functioning	23 (37,7)	42 (68,9)	21 (36,2)	7 (11,5)	‡‡	‡‡	‡‡	‡‡
Role functioning	38 (59,4)	50 (78,1)	17 (27,4)	2 (3,1)	‡‡	‡‡	‡‡	‡‡
Cognitive functioning	22 (35,5)	31 (52,5)	15 (26,3)	11 (18,6)	‡‡	‡‡	‡‡	‡‡
Spiritual/existential well-being	30 (51,7)	36 (63,2)	13 (24,1)	7 (12,3)	25 (52,1)	15 (31,3)	5 (10,9)	7 (14,6)
Intimacy	13 (23,6)	23 (41,1)	14 (27,5)	6 (10,7)	16 (37,2)	8 (17,0)	0	5 (10,6)
Financial, administrative and practical issues	26 (43,3)	25 (41,7)	7 (12,3)	4 (6,7)	19 (42,2)	10 (22,7)	4 (9,8)	6 (13,6)

†Missings ranged from 3,0% to 16,6%.

‡General practitioner, specialist physicians in a hospital, home nurse, nurse in a hospital, palliative home care team, psychologist, social worker, physiotherapist, occupational therapist or speech therapist

§Missings ranged from 6,1% to 22,7%.

¶Missings ranged from 3,9% to 13,7%.

††Missings ranged from 5,9% to 19,6%.

‡‡Not included in the questionnaire.

Figures

Figure 1: Participant flow chart

