

ORIGINAL ARTICLE

Who is the key worker in palliative home care?

Views of patients, relatives and primary care professionals

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Abstract

Objective. Palliative home care involves coordination of care between the professionals involved. The NICE guideline on supportive and palliative care (UK) recommends that teams, regardless of their base, should promote continuity for patients. This may involve nomination of a coordinating “key worker”. This study aimed to explore who acts as key worker and who ought to take on this role in the views of patients, relatives, and primary care professionals. Furthermore, it aimed to explore the level of agreement on this issue between study participants. **Design.** Interview and questionnaire study. **Setting.** Former County of Aarhus, Denmark (2008–2009). **Subjects.** Ninety-six terminally ill cancer patients, their relatives, general practitioners (GPs), and community nurses (CNs). **Main outcome measures.** Actual key worker as valued by patients, relatives, and primary care professionals; ideal key worker as valued by patients and relatives. **Results.** Patients, relatives, GPs, and CNs most often saw themselves as having been the key worker. When asked about the ideal key worker, most patients (29%; 95%CI: 18;42) and relatives (32%; 95%CI: 22;45) pointed to the GP. Using patients’ views as reference, we found very limited agreement with relatives (47.7%; $k = 0.05$), with GPs (30.4%; $k = 0.01$) and with CNs (25.0%; $k = 0.04$). Agreement between patients and relatives on the identity of the ideal key worker was of a similar dimension (29.6%; $k = 0.11$). **Conclusion.** Poor agreement between patients, relatives, and professionals on actual and ideal key worker emphasizes the need for matching expectations and clear communication about task distribution in palliative home care.

Key Words: Denmark, organisation and administration, palliative care, patient care, primary health care

Introduction

End-stage cancer patients and their families often have complex needs requiring a multidisciplinary approach [1–3] with involvement of a large number of professionals, e.g. general practitioners (GPs), community nurses (CNs), and staff in specialist palliative care teams (PCTs) [4].

Patients and relatives are particularly vulnerable when active, anti-neoplastic treatment is terminated. At this point, there is a risk that placement of responsibilities becomes unclear, causing the family to

feel “left in limbo” [5–7]. This risk emphasizes a need for open communication concerning the division of responsibilities [8–10].

The NICE guideline on supportive and palliative care [11] recommends that teams, whether hospital, hospice, or primary care-based, should develop mechanisms to promote clinical continuity for patients. This may involve nomination of a “key worker” who may take on tasks such as coordinating care and assessments and ensuring that patients know whom to contact for help or advice. Patients

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Coordination of care is of great importance to families receiving palliative home care. The GP is often considered the obvious coordinating key worker in palliative care pathways.

- This study demonstrates a marked disagreement between patients, relatives, and primary care professionals on who acts as the key worker.
- Most patients and relatives considered themselves to be the actual key worker but the GP to be the ideal key worker.
- Clear communication among families and professionals on expectations and responsibilities can improve care and collaboration in primary palliative care.

and carers value a key professional coordinating care [12], and evaluation of different models of the key worker concept is highly desirable [11].

In Denmark, the GP is expected to assume the role of key worker for patients with cancer [13] and palliative care patients [14], but it is unknown whether GPs are taking on this role actively.

In this study we aimed to explore who acts as key worker and who ought to take on this role in the views of patients, their relatives, and primary care professionals. Furthermore, we aimed to explore the level of agreement on this issue between study participants.

Materials and methods

The study design was a combination of structured interviews with end-stage cancer patients and questionnaires to patients' relatives, GPs, and CNs. A total of 96 patients were recruited from seven hospital departments and three PCTs from April 2008 to December 2009.

Setting

The study was conducted in the former County of Aarhus, Denmark, an area with approximately 660 000 inhabitants, two district hospitals and one university hospital. The Danish health care system provides free access to health care services financed through taxes. More than 98% of the Danish population is registered with a GP. GPs and home care nursing services provide a basic palliative treatment service. Multidisciplinary PCTs are affiliated to the major hospitals. GPs and hospital doctors can refer patients to PCTs for palliative support, including home visits, or they can ask for specialist advice.

Sampling

We included adults with advanced cancer, who had recently ended or refused further anti-neoplastic treatment, or for whom no treatment was available. Patients were excluded if they were cognitively impaired, had insufficient Danish skills or were about to be discharged to a hospice or nursing home.

Seven departments recruited patients by assessing patients who were ready to be discharged according to the inclusion criteria, and introduced the patients to the study. The researcher informed patients thoroughly and obtained a signed statement of consent. The PCTs recruited newly referred patients by the same procedure.

All participating patients were asked for permission to send a questionnaire to their GP and CN and to indicate a relative who might be interested in participating in a questionnaire study.

Data from patients

The interview guide included EORTC QLQ-C15-PAL [15] and themes identified through literature studies, clinical experience, and a previous PhD study [8]. Structured interviews were carried out by the researcher, either in the hospital (29%) or in the patients' homes (71%) as close to hospital discharge as possible. Interviews took 45–60 minutes.

Data from relatives, GPs, and CNs

A questionnaire was sent to the relative the day after the patient interview. The relative also received a questionnaire two months after the patient's death. The GP and CN received questionnaires within two weeks after the patient's death. A direct, secure link from the Research Unit for General Practice to the Centralized Civil Register (CPR) made it possible for us to check once a week if the patients were deceased.

Key worker questions

A key worker was defined as "the person who coordinates care, treatment and cooperation between all persons concerned in the disease trajectory".

Patients were asked two questions: First: "Who do you feel has been key worker since you became ill?" (Primary key worker; see Table IV). Second: "If you were to point to a health professional that ought to take on the role of key worker from now on, who would it be?" (Ideal key worker; see Table V).

The relatives were asked the above questions in the first questionnaire. In their final questionnaire, after the patient's death, they were asked the

same questions in past tense, thus answering in retrospect. The GPs and CNs were asked: “Who do you feel has been the key worker in the patient’s disease trajectory?”

Analysis

We used the chi-squared (χ^2) test, *t*-test, and the Mann–Whitney U test, respectively, to assess the significance of the differences between the participants and non-participants. A significance level of 0.05 or less was used. Frequencies and percentages were calculated to describe the participants’ views.

The extent of agreement was measured by percentage of agreement and kappa coefficients. The strength of agreement measured by kappa was determined by the following criteria: kappa below 0: poor; 0.00–0.20: slight; 0.21–0.40: fair; 0.41–0.60: moderate; 0.81–0.90: substantial; and 0.81–1.0: almost perfect [16].

In calculating kappa, some categories were combined as the options for answers were not completely identical in the interview guide and questionnaires and only very few respondents had chosen specific options (see Tables IV and V). Data were analysed using STATA 11 [17].

Results

Participants

Ninety-nine of 160 patients approached agreed to participate. Three patients were excluded after inclusion because of having received palliative chemotherapy after inclusion, leaving 96 structured interviews for analysis (participation rate 60%). The participants and the non-participants were similar on most parameters, apart from a shorter survival time as from the time of screening ($p = 0.051$) and a significantly lower disposable income among

Table I. Characteristics of the 96 participants and the 61 non-participants.¹

	Participants (n = 96)	Non-participants (n = 61)
Gender (n (%))		
Men	56 (58)	33 (54)
Women	40 (42)	28 (46)
Primary cancer diagnosis ² (n (%))		
Prostate	25 (26)	6 (13)
Lung/pleura	17 (18)	8 (18)
Colon/rectum	12 (13)	8 (18)
Pancreas	5 (5)	3 (7)
Oesophagus/stomach	5 (5)	1 (2)
Breast	7 (7)	4 (9)
Female genital organs	8 (8)	4 (9)
Other	17 (18)	11 (24)
Age at time of screening for the study (mean, (95% CI))	68.7 (66.8;70.7)	70.2 (67.8;72.5)
Marital status (n (%))		
Married/living with partner	71 (74)	37 (61)
Single/divorced/widowed	25 (26)	24 (39)
Having children (n (%))		
No	19 (20)	10 (16)
Yes, children living at home	6 (7)	5 (8)
Yes, children have left home	71 (73)	46 (75)
Vocational education ³ (n (%))		
Unskilled	41 (44)	31 (51)
Short	34 (37)	22 (36)
Medium	15 (16)	8 (13)
Long	3 (3)	0
Yearly disposable income (n (%))		
<150 000 DKr	40 (42)	38 (62)*
>150 000 DKr	56 (58)	23 (38)
Survival time (mean, days (95% CI))		
from screening	108 (85;131)	74 (57;92)
from time of diagnosis	1029 (768;1290)	1012 (679;1345)

Notes: *Statistically significantly different from the 96 participants with p -value < 0.05 . CI = 95% CI: 95% confidence interval.

¹83 participants and 55 non-participants died in the study period. Case data in study arise from the interviews, the questionnaires, and from formal health registers. Case data of non-participants stem from formal health registers.

²Diagnosis from 16/61(26%) non-participants is missing because of insufficient register information.

³Short: e.g. hairdresser, sales assistant. Medium: e.g. teacher, registered nurse. Long: academic education.

non-participants (Table I). Among the participants, we obtained a measure for symptom severity in the form of an EORTC-QLQ-C15-PAL score: pain: 45.2 (95% CI 38.2;52.2); fatigue: 57.7 (95% CI 52.0;63.5); physical functioning: 41.4 (95% CI 35.8;47.0); and quality of life 52.9 (95% CI 47.5;58.3).

Six (6%) patients were unable to appoint a relative. Thus, questionnaires were sent to 90 relatives and 75 (83%) returned this (see Table II). At the end of the study period, 83 patients had died. Five (6%) of the deceased patients were among those without a relative and eight (10%) relatives did not wish to receive the final questionnaire; hence, this was sent to 70 relatives and 62 (89%) returned this.

Three (3%) of the deceased patients' GPs did not wish to receive the questionnaire and one (1%) patient did not want the GP to receive a questionnaire. Thus, 79 questionnaires were sent to GPs and 70 (89%) returned this (see Table III).

Ten (12%) of the deceased patients did not have contact with a CN. Thus, 73 questionnaires were sent to CNs and 52 (71%) returned this (see Table III).

Key worker

Most participants considered themselves as having been the key worker (highlighted sections; see Table IV). Approximately a third of patients and relatives pointed to the GP as the ideal key worker (see Table V). Patients who were interviewed at home identified the GP as the ideal coordinator significantly more frequently (36%) than patients interviewed in hospitals (7%) ($p = 0.04$).

We observed a high level of disagreement between participants with low levels of kappa (see Tables IV and V). We also calculated kappa for each of the possible categories of answers, which all were below 0.35 (not listed in tables).

Discussion

Main findings

Patients, relatives, and professionals all tended to see themselves as having been the key worker. The GP was the professional singled out as ideal key worker by most patients and relatives. Our data show a high level of disagreement between participants on both actual and ideal key worker.

Strengths and weaknesses

A strength of the study is that we included participants who were all part of the same disease trajectory, allowing us to observe agreement on actual trajectories.

Table II. Characteristics of participating relatives (n = 75).¹

Gender (n (%))	
Men	19 (25)
Women	56 (75)
Relation to patient (n (%))	
Spouse/partner	56 (75)
Daughter	9 (12)
Son	2 (3)
Sister	2 (3)
Brother	3 (4)
Other	3 (4)
Age at time of questionnaire 1 (mean, (95% CI))	62 (60;65)
Marital status (n (%))	
Married/living with partner	69 (92)
Single/divorced/widowed	6 (8)
Having children (n (%))	
No	10 (13)
Yes, children living at home	11 (15)
Yes, children have left home	54 (72)
Vocational Education ^{2,3} (n (%))	
Unskilled	21 (38)
Short	22 (40)
Medium	9 (16)
Long	3 (5)
Disposable yearly income ³ (n (%))	
<150 000 DKr	28 (51)
>150 000 DKr	27 (49)

Notes: ¹Data arise from the questionnaires and formal registers.

²Short: e.g. hairdresser, sales assistant. Medium: e.g. teacher, registered nurse. Long: academic education.

³Educational status and disposable income from 20/75 (27%) relatives are missing because of insufficient register information.

Another strength is the high response rates compared with what is normally expected in palliative settings. Furthermore we were able to combine interview and questionnaire data with register-based data allowing us to make estimates of representativeness.

Table III. Characteristics of participating GPs and CNs (n = 70 and 52 respectively).¹

	GPs	CNs
Gender (n (%))		
Men	51 (73)	0
Women	19 (27)	52 (100)
Age (mean, (95% CI))	55 (54;57)	48 (46;51)
Years as MD/RN (mean, (95% CI))	27.8 (25.9;29.7)	22.4 (19.6;25.3)
Years as GP/CN (mean, (95% CI))	18.7 (16.5;20.8)	12.6 (10.4;14.7)
Postgraduate education in palliative care (n (%))		
Yes	51 (75)	21 (43)
No	17 (25)	28 (57)
Number of full-time GPs in the practice (mean, (95% CI))	2.3 (1.9;2.7)	–

Notes: ¹Data arise from questionnaires. MD = medical doctor. RN = registered nurse. GP = general practitioner. CN = community nurse.

Table IV. Actual key worker, patients', relatives', CNs', and GPs' retrospective views (highlighted figures are discussed in text).¹

	Primary key worker			
	Patients' views	Relatives' views	GPs' views	CNs' views
Patient (n (%),95% CI)	21 (24,15;34)	4 (8,2;19)	9 (13,6;24)	2 (5,0,6;17)
Relative (n (%),95% CI)	9 (10,5–19)	20 (40,26;55)	9 (13,6;24)	7 (17,7;32)
Patient and relative (n (%),95% CI)	44 (50,39;61)	–	–	–
GP (n (%),95% CI)	3 (3,0,7;10)	1 (2,0;11)	18 (27, 17;39)	3 (7,2;20)
Hospital doctor (n (%),95% CI)	2 (2,0,3;8)	0	5 (7,2;17)	1 (2,0;13)
Other hospital staff (n (%),95% CI)	4 (5,1;11)	3 (6,1;17)	1 (1,0;8)	2 (5,0,6;17)
Community nurse (n (%),95% CI)	1 (1,0;6)	10 (20,10;34)	4 (6,2;15)	22 (54,37;69)
Home care assistant (n (%),95% CI)	0	0	0	1 (2,0;13)
Staff in PCT (n (%),95% CI)	1 (1,0;6)	7 (14,6;27)	5 (7,2;17)	0
No one, no need (n (%),95% CI)	2 (2,0,2;8)	2 (4,0,5;14)	4 (6,2;15)	0
No one, but missed (n (%),95% CI)	1 (1,0;6)	1 (2,0;11)	1 (1,0;8)	1 (2,0;13)
Other (n (%),95% CI)	0	0	4 (6,2;15)	0
Don't know (n (%),95% CI)	0	2 (4,0,5;14)	7 (10,4;20)	2 (5,0,6;17)
Total (n (%))	88 (100)	50 (100)	67 (100)	41 (100)

Notes: ¹Data arise from structured interviews and questionnaires. 95% CI=95% confidence interval. GP=general practitioner. PCT=palliative care team. –=option not available in questionnaire. Agreement: patient–relative: 47.7%, kappa (95% CI)=0.05 (–0.02–0.15). Agreement: patient–GP: 30.4%, kappa (95% CI)=0.01 (–0.08–0.12). Agreement: patient–CN: 25.0%, kappa (95% CI)=0.04 (0.01–0.10). (In calculation of all kappa values the categories “Patient”, “Relatives”, and “Patient and relatives” were combined to form a “Patient/relative” category, “Community nurse” and “Home care assistant” were combined to form a “Home care team” category, “Hospital doctor” and “Other hospital staff” were combined to a “Hospital staff” category and finally “No one, no need” and “No one, but missed” to a “No one” category).

One limitation of our study is possible selection bias, as the hospital staff may not have invited some of the more vulnerable patients to participate, and some of the patients who declined may have had the heaviest symptom load. On the other hand, the EORTC-QLQ-C15-PAL scores of the participants compare well with scores in other samples of end-stage cancer patients [3,18].

We included only patients who were discharged to their own homes. We do not ascribe any significant bias to excluding patients who were discharged to a

hospice, as this group is not likely to have a great need for a key worker. We also left out patients who were discharged to a nursing home, and the opinions of these patients, relatives, and their primary care professionals are, therefore, undiscovered in this study.

Comparison with existing literature

The importance of naming a key worker in palliative home care has been found in earlier studies [19–21] and the Cochrane collaboration recently attempted

Table V. Ideal key worker: patients' and relatives' views.¹

	Patients' view	Relatives' view
Patient (n (%), 95% CI)	2 (3%, CI 0;12)	–
Relatives (n (%), 95% CI)	2 (3%, CI 0;12)	3 (4%, CI 0.8;12)
Patient and relatives (n (%), 95% CI)	4 (7%, CI 2;16)	–
GP (n (%), 95% CI)	17 (29%, CI 18;42)	23 (32%, CI 22;45)
Hospital doctor (n (%), 95% CI)	5 (8%, CI 3;19)	14 (20%, CI 11;30)
Other hospital staff (n (%), 95% CI)	8 (14%, CI 6;25)	6 (8%, CI 3;17)
Community nurse (n (%), 95% CI)	4 (7%, CI 2;16)	4 (6%, CI 2;14)
Home care assistant (n (%), 95% CI)	2 (3%, CI 0;12)	1 (1%, CI 0;8)
Staff in PCT (n (%), 95% CI)	3 (5%, CI 1;14)	14 (20%, CI 11;30)
No one (n (%), 95% CI)	7 (12%, CI 5;23)	0
Other (n (%), 95% CI)	5 (8%, CI 3;19)	6 (8%, CI 3;17)
Total (n (%))	59 (100)	71 (100)

Notes: ¹Data arise from structured interviews and questionnaires. 95% CI=95% confidence interval. GP=general practitioner. PCT=palliative care team. –=option not available in questionnaire. Agreement: patient–relative 29.6%, kappa (95% CI)=0.10 (–0.05–0.25). (In calculation of kappa value the categories “Patient”, “Relatives”, and “Patient and relatives” were combined to form a “Patient/relative” category, “Community nurse” and “Home care assistant” were combined to form a “Home care team” category and finally “Hospital doctor” and “Other hospital staff” were combined to a “Hospital staff” category).

to review the evidence on organization of end-of-life care [22]. However, no studies met the criteria for inclusion in the review, indicating a need for high-quality research on organization of palliative care.

It seems that the patient's view on the identity of the ideal key worker is influenced by his/her situation at the time he/she was interviewed, as evidenced by the significant difference in whom the patients singled out for this role. This is hardly surprising, as the gap between hospital and home often feels wide to patients with a long-lasting contact with the hospital [23,24].

In our study, as in prior studies [10,25], both GPs and CNs pointed to themselves as the key worker, yet this conception was not shared by patients and relatives, so some professionals may have overestimated their own effort in coordinating care. Furthermore, it seems that the NICE guideline [11] does not relate to the reality as perceived by patients and carers, as this considers the key worker to be a professional.

Implications for future research and clinical practice

In developing the key worker concept, it is important to be aware of both the positive and the negative aspects for patients or relatives in taking on the coordinating role themselves. Hence, it may not be possible to make a uniform decision on who should be the key worker in palliative care pathways in general.

The high level of disagreement found is somehow surprising given the strong emphasis placed on having a key worker in palliative care [11,12,26]. Among both GPs and CNs, the position as key worker has been presented as a cornerstone in a successful palliative care pathway [14,19,25,27], and GPs usually express the opinion that coordination of palliative care is an essential task [28,29]. The observed disagreement has several possible explanations; first, in cases where several persons participated in coordinating care, it is likely that participants were not able to identify one specific key worker. Second, the disagreement could be based on a weak understanding of the concept among participants. On the other hand, the Danish word for key worker ("tovholder") is often used among laymen and professionals. Third, there could be real disagreement concerning role and task distribution. This seems the most plausible reason, such that we must interpret our results as evidence of a severe lack of explicit agreement on the distribution of roles among all involved in palliative home care. This calls for clear communication among patients, relatives, and professionals on expectations and responsibilities.

A general discussion on the key worker term and content of the role as well as more research on this subject is needed.

Conclusion

Poor agreement between patients, relatives, and professionals on actual and ideal key worker emphasizes the need for matching of expectations and clear communication regarding task distribution as a means to improve quality of care and collaboration in palliative home care. More research on the key worker term is needed.

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Conflict of interest statement

All authors declare that there are no conflicts of interest.

Ethics

According to Scientific Ethics Committee for the County of Aarhus, this study does not need the approval of the Scientific Ethics Committee (Report no. 16169). The study was approved by the Danish Data Protection Agency (J. no. 2007-41-1193) and was recommended by the Multi-Practice Committee of the Danish Society of General Practitioners and the Organization of General Practitioners in Denmark (MPU 24-2007).

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