


Integrated palliative care networks from the perspectives of patients: A cross-sectional explorative study in five European countries

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Abstract

Background: Although examining perspectives of patients on integrated palliative care organisation is essential, available literature is largely based on administrative data or healthcare professionals' perspectives.

Aim: (1) Providing insight into the composition and quality of care networks of patients receiving palliative care and (2) describing perceived integration between healthcare professionals within these networks and its association with overall satisfaction.

Design: Cross-sectional explorative design.

Setting/participants: We recruited 157 patients (62% cancer, 25% chronic obstructive pulmonary disease, 13% chronic heart failure, mean age 68 years, 55% female) from 23 integrated palliative care initiatives in Belgium, Germany, the United Kingdom, Hungary and the Netherlands.

Results: About 33% reported contact with a palliative care specialist and 48% with a palliative care nurse. Relationships with palliative care specialists were rated significantly higher than other physicians ($p < 0.001$). Compared to patients with cancer, patients with chronic obstructive pulmonary disease (odds ratio = 0.16, confidence interval (0.04; 0.57)) and chronic heart failure (odds ratio = 0.11, confidence interval (0.01; 0.93)) had significantly lower odds of reporting contact with palliative care specialists and patients with chronic obstructive pulmonary disease (odds ratio = 0.23, confidence interval (0.08; 0.71)) had significantly lower odds of reporting contact with palliative care nurses. Perceptions of main responsible healthcare professionals or caregivers in patient's care networks varied across countries. Perceived integration was significantly associated with overall satisfaction.

Conclusion: Palliative care professionals are not always present or recognised as such in patients' care networks. Expert palliative care involvement needs to be explicated especially for non-cancer patients. One healthcare professional should support patients in understanding and navigating their palliative care network. Patients seem satisfied with care provision as long as continuity of care is provided.

Keywords

Delivery of healthcare, integrated, patient navigation, cross-sectional studies, palliative care

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What is already known about the topic?

- Although there have been major improvements in the development of (specialist) palliative care services during the last decade, accessibility to services is still often unevenly distributed across countries and disease groups.
- It can be challenging for patients with cancer to have an overview of their care and to know who their key worker is.

What this paper adds?

- Although patients were recruited from integrated palliative care initiatives, it was uncommon for many of them to report on specialist palliative care professionals within their care networks, especially for patients with chronic obstructive pulmonary disease and chronic heart failure as well as patients from generalist palliative care initiatives.
- This international study shows that patients may have different understandings of the organisation of their care (network) than healthcare professionals. Therefore, it can be challenging for patients to have insight into who is involved in their care network, what are the specific roles of healthcare professionals (e.g. palliative care specialists) and who is the main healthcare professional responsible for their care.
- Notwithstanding differences in the organisation of care networks between different integrated palliative care networks or diagnostic groups, patients generally seem to be satisfied especially with their relationships with palliative care professionals and with care provision as long as continuity of care is provided.

Implications for practice, theory or policy

- The study suggests that palliative care professionals are not always present in care networks or recognised as such by patients. Therefore, the involvement of expert palliative care needs to be explicated, especially for non-cancer patients.
- The roles of different healthcare professionals in patients' palliative care networks need to be clear for patients as well as who is their first point of contact in case of needs.
- One healthcare professional working in the integrated palliative care initiative should have an overview of the patient's palliative care network and support patients in navigating through this network should they need this.

Background

Integrated palliative care is increasingly recognised as a beneficial approach both in terms of patient outcomes^{1,2} and costs.³ However, the best way to organise it is still a point of discussion.⁴ Since patients are the direct users of palliative care services, examining their perspectives on integrated palliative care organisation is essential. Although literature about palliative care organisation is available, this is largely based on administrative data or the perspectives of healthcare professionals (HCPs).

For example, the European Association for Palliative Care has published a White Paper providing a normative framework for hospice and palliative care in Europe including requirements for palliative care services.^{5,6} The Paper distinguishes between a general palliative care approach and specialist palliative care. A general palliative care approach would be used in settings and services that occasionally or even frequently treat palliative care patients, but do not provide palliative care as the main focus of their work. Specialist palliative care is provided by specialised palliative care professionals who treat patients with more complex problems.^{5,6} In addition to this framework, several studies evaluated the current integration and developments of palliative care services in European countries and beyond. Examples are Pivodic et al.,⁷ Centeno et al.,⁸ Woitha et al.⁹ and Tanuseputro et al.¹⁰ They found that

there have been major improvements in the development of (specialist) palliative care services during the last decade, but that accessibility to services is still often unevenly distributed across countries and disease groups.

In contrast to the above-mentioned literature, studies examining integrated palliative care organisation from the patient perspective are limited. Analysing care networks of patients enables examining the organisation of care as well as the quality and potential shortcomings from a patient perspective. A social network approach may be useful here. Social network analysis is based on the notion that individuals are embedded in 'thick webs of social relations and interactions'.¹¹ Therefore, studying the nature of relationships and interactions between individuals within a network enables explaining social phenomena or outcomes.¹² During the last decades, several approaches towards social network analysis have been developed ranging from merely technical procedures using mathematical methods to quantify networks dynamics and explain outcomes to qualitative approaches allowing for in-depth description of network dynamics and explanation for social phenomena.¹² A number of studies focused on the constitution of social support networks of patients^{13,14} or on continuity of palliative care for children.¹⁵ Furthermore, Jarret et al.¹⁶ extensively investigated palliative care networks of patients with cancer. They found that these can be very

complex and hence that it can be very challenging for patients to have an overview of their care and to know who their key worker is. However, this study was only conducted with patients in the United Kingdom. As patient's care networks in the last phase of life may differ across countries,⁷⁻⁹ due to, for example, regional organisation and development of palliative care, it is useful to consider the organisation of patients' care networks from an international perspective.

This article therefore aims (1) to provide insight into the composition and quality of care networks of patients receiving palliative care within several integrated palliative care initiatives in five European countries from a patient perspective and (2) to describe to what extent integration between HCPs within these networks is perceived by patients and whether this is associated with overall satisfaction with care provision.

Methods

Design

This explorative study uses a cross-sectional design. The study was part of a European multiple embedded case study (InSup-C).¹⁷ The STROBE (STrengthening the Reporting of OBServational studies in Epidemiology) checklist for observational, cross-sectional studies¹⁸ was used to report our data.

Participants and sampling

Patients were recruited from 23 eligible integrated palliative care initiatives in Belgium, Germany, the United Kingdom, Hungary and the Netherlands. Inclusion criteria for integrated palliative care initiatives have been published elsewhere.¹⁹ Patients were selected by their treating HCPs based on inclusion criteria: life expectancy of maximum 1 year, advanced cancer, chronic obstructive pulmonary disease (COPD) with Gold stage IV classification or chronic heart failure (CHF) with *New York Heart Association* (NYHA) classification stage III-IV. If patients expressed interest in participation, they received further information from the researcher who would collect the data. After providing written consent, participants took part in a semi-structured interview and completed questionnaires at baseline and after 3 months. For this study, we used only the baseline data from the questionnaires, because at month 3 there were too much missing data (response rate 53%) to do useful analyses. Attrition was mainly due to death and poor health of the patient. Because the InSup-C study addressed the topic of integrated palliative care, patients were recruited from a pre-selection of integrated palliative care initiatives where integration was already visible and not 'at random'. Therefore 'country' as a variable in the results section refers to the pre-selection of integrated palliative care initiatives in that country.

Data collection

Demographic data were collected at baseline. The Palliative care Outcome Scale (POS)²⁰ was used to measure patients' overall condition. Questions include 5-point Likert scales ranging from 0 to 4. To examine the organisation and quality of patients' care networks, we used a social network analysis approach.¹¹ Although the qualitative results of this study on the experiences of seriously ill patients and their family caregivers with the care they received from HCPs in the patients' care network have been published elsewhere,¹⁹ the focus of this study was to quantitatively explore the composition of patients' care networks, perceived integration and its relation to perceived satisfaction. Therefore, a basic approach of social network analysis was used. A social network analysis questionnaire was developed by the Dutch research team based on existing literature.²¹⁻²³ A preliminary version of the questionnaire was discussed, adjusted and subsequently approved within the international InSup-C research team. The questionnaire contains 12 questions about HCPs in the patient's care network, collaboration and continuity within the network and the quality of relationships with, and quality of care provided by, individual HCPs (Supplementary file). The questions include dichotomous answer categories, 5-point Likert scales ranging from 0 (*excellent*) to 4 (*poor*) and from 0 (*completely disagree*) to 4 (*completely agree*) as well as open answer questions. The social network analysis questionnaire served as the basis for semi-structured interviews as part of the previously mentioned qualitative study.¹⁹ In these interviews, the answers given to the social network analysis questionnaire were further explored. This study reports the results of the social network analysis questionnaire.

Perceived integration between HCPs in care networks was measured using social network analysis questions 5-9 (based on the Nijmegen Continuity of Care questionnaire²¹) containing statements about collaboration and continuity of care within the care network. Overall satisfaction with care provision was measured using the Canadian Health Care Evaluation Project Questionnaire Lite (Canhelp Lite).²⁴ The questionnaire includes five domains: Relationship with the doctors, Illness management, Communication, Decision-making and Feeling at peace. Questions contain 5-point Likert scales ranging from 0 (*very dissatisfied*) to 4 (*very satisfied*). For the analysis, we used the Canhelp Lite overall summary score which is the unweighted average of all answered questions.

Data were collected between June 2014 and August 2015. Review committee approvals were obtained in all participating countries, if required. Details of ethics approvals have been reported elsewhere.¹⁹

Data analysis

We examined differences in characteristics (gender, age, diagnosis, country, generalist versus specialist palliative

care initiative) of those who reported contact with a particular HCP compared to those who did not. Chi-square tests (or Fisher's exact tests if necessary) were used to determine statistical significance. For the relevant HCPs, we used multiple logistic regression (Enter method) to examine associations of these characteristics with the outcome 'having contact with a particular HCP'. To examine statistical significance of differences between means, we used *T*-tests and analysis of variance (ANOVA) tests.

To examine the association between perceived integration and overall satisfaction, we first examined bivariate associations between the individual determinants (social network analysis questions 5–9, age, gender, diagnosis, country, generalist vs specialist palliative care initiative, having contact with a particular HCP) and the outcome overall satisfaction. Subsequently, we conducted multiple regression analysis (Enter method) to find determinants for overall satisfaction. Overall, we used statistical significance level $p=0.05$. To support statistical analysis, we used IBM SPSS Statistics 22.

Results

Participant characteristics

The response rate at baseline was 100%. In all, 157 patients participated in the study of which there were 15 in Belgium, 34 in Germany, 35 in the United Kingdom, 42 in Hungary and 31 in the Netherlands (Table 1). The majority of patients had cancer ($n=97$, 62%), 39 patients had COPD (25%) and 21 patients had CHF (13%). In Belgium, Germany and the Netherlands, the majority of patients had cancer while in Hungary and the United Kingdom a substantial number of patients had COPD or CHF. The mean age of all patients was 68 years, and more than half were female ($n=87$, 55%). The time spent in bed or laying down during the daytime and POS mean sum scores indicate that patients' overall condition was reasonable at the time of the interview given their palliative background. Moreover, POS mean sum scores did not differ significantly between diagnostic groups ($p=0.517$) and countries of origin ($p=0.392$). The majority of patients were living at home ($n=144$; 92%) when completing baseline questionnaires. Integrated palliative care initiatives selected included specialised and general palliative care services based at hospitals, hospices or in home care in conjunction with primary and secondary care. The types of initiatives selected have been described elsewhere.¹⁹

Most frequently reported HCPs and caregivers in patients' care networks

Specialist palliative care. A third of all patients reported contact with a palliative care specialist ($n=51$; 33%; Table 2).

Almost half of the patients reported contact with a palliative care nurse ($n=75$; 48%).

General palliative care. Most patients reported contact with a general practitioner (GP) ($n=138$; 88%; Table 2). One-third reported contact with an oncologist ($n=55$; 35%) or with a specialist other than oncologist, cardiologist or pulmonologist ($n=52$, 33%). Less than one-fifth reported contact with a cardiologist ($n=26$; 17%) or pulmonologist ($n=28$; 18%). A quarter of the patients reported contact with a home care nurse ($n=39$; 25%).

Patients rated the quality of their relationship with physicians and the quality of care provision received from these physicians between reasonable and good. Relationships with palliative care specialists were rated significantly higher compared to other physicians ($p<0.001$). The quality of relationships with nurses and the quality of care provision received from these nurses were rated between good and excellent. We found no significant difference between patients' relationships with palliative care nurses and other nurses ($p=0.395$).

Additional care. Less than one-third of the patients reported contact with a physiotherapist ($n=41$; 26%). Between one-tenth and one-fifth reported contact with another HCP such as spiritual worker ($n=28$; 18%), psychologist ($n=22$; 14%) or social worker ($n=17$; 11%; Table 2). Patients rated their relationship with additional HCPs between reasonable and excellent.

Informal and voluntary care. Most patients reported having a family caregiver ($n=136$; 87%; Table 2). Patients rated their relationship with the family caregiver between good and excellent. Only 14 patients reported contact with a volunteer (9%) with whom they rated their relationship between reasonable and excellent.

Differences between diagnostic groups and countries for reporting contact with a particular HCP

Logistic regression (Table 3) confirmed the differences between diagnostic groups and countries for reporting contact with particular HCPs displayed in Table 2. Patients with COPD (odds ratio (OR)=0.16, confidence interval (CI) (0.04; 0.57)) and CHF (OR=0.11, CI (0.01; 0.93)) had significantly lower odds of reporting contact with a palliative care specialist compared to those with cancer (the reference group). Patients with COPD (OR=0.23, CI (0.08; 0.71)) had significantly lower odds of reporting contact with a palliative care nurse than those with cancer. Furthermore, patients with COPD also had significantly lower odds of reporting contact with a GP (OR=0.30, CI (0.11; 0.85)). However, patients with CHF (OR=3.96 (1.03; 15.31)) had significantly higher odds of reporting

Table 1. Baseline patient characteristics by country.

| | Belgium | Germany | United Kingdom | Hungary | The Netherlands | Total |
|--|---------|----------|----------------|---------|-----------------|----------|
| Patients, N | 15 | 34 | 35 | 42 | 31 | 157 |
| Age, years (N=153), mean (SD) | 69 (12) | 69 (12) | 66 (12) | 68 (8) | 70 (8) | 68 (10) |
| Gender, N (%) | | | | | | |
| Female | 8 (53) | 18 (53) | 22 (63) | 25 (60) | 17 (55) | 87 (55) |
| Male | 7 (47) | 16 (47) | 13 (37) | 17 (40) | 14 (45) | 70 (45) |
| Diagnosis, N (%) | | | | | | |
| Cancer | 12 (80) | 31 (91) | 18 (51) | 14 (33) | 22 (71) | 97 (62) |
| COPD | 3 (20) | 3 (9) | 10 (29) | 17 (41) | 6 (19) | 39 (25) |
| CHF | 0 | 0 | 7 (20) | 11 (26) | 3 (10) | 21 (13) |
| Time spent in bed or lying down during the daytime (N=156), N (%) | | | | | | |
| Hardly ever in bed | 7 (47) | 15 (46) | 8 (23) | 19 (45) | 7 (23) | 56 (36) |
| Less than half a day | 3 (20) | 10 (30) | 15 (43) | 9 (21) | 17 (55) | 54 (35) |
| More than half a day | 3 (20) | 5 (15) | 12 (34) | 11 (26) | 4 (13) | 35 (22) |
| All day | 2 (13) | 3 (9) | 0 | 3 (7) | 3 (10) | 11 (7) |
| POS sum score ^a (N=132), mean (SD) | 15 (7) | 14 (7) | 11 (6) | 12 (7) | 12 (6) | 12 (6) |
| Place of residence at baseline, N (%) | | | | | | |
| Home | 13 (87) | 31 (91) | 34 (97) | 39 (93) | 27 (87) | 144 (92) |
| Nursing home | 2 (13) | 0 | 1 (3) | 1 (2) | 4 (13) | 8 (5) |
| Hospital | 0 | 3 (9) | 0 | 0 | 0 | 3 (2) |
| Hospice | 0 | 0 | 0 | 2 (5) | 0 | 2 (1) |
| Type of integrated palliative care initiative, ^b N (%) | | | | | | |
| Specialised home care palliative care support service | 10 (67) | 0 | 0 | 0 | 0 | 10 (6) |
| Specialised palliative care service based in hospital in conjunction with specialised palliative home care services and/or other primary and secondary care services | 0 | 34 (100) | 0 | 12 (29) | 12 (39) | 58 (37) |
| Specialised palliative care service based in hospice in conjunction with primary and secondary care | 0 | 0 | 26 (74) | 12 (29) | 0 | 38 (24) |
| General palliative home care service in conjunction with specialised palliative care (support) service | 5 (33) | 0 | 8 (23) | 12 (29) | 4 (13) | 29 (18) |
| General palliative care nursing home service based in hospital in conjunction with secondary care | 0 | 0 | 1 (3) | 0 | 5 (16) | 6 (4) |
| General palliative care service based in hospital in conjunction with primary care | 0 | 0 | 0 | 6 (14) | 10 (32) | 16 (10) |

SD: standard deviation; COPD: chronic obstructive pulmonary disease; CHF: chronic heart failure; POS: Palliative care Outcome Scale; HCP: health-care professional.

Due to rounding up some percentages do not add up to 100%.

^aPOS sum score ranges from 0 (*good overall condition*) to 40 (*very bad overall condition*).

^b*Specialised* means that the majority of HCPs involved in the initiatives are palliative care specialists, while *general* means that of the HCPs involved in the initiative only a few are palliative care specialist or have received basic palliative care training.

contact with a home care nurse than those with cancer. Both patients with CHF (OR=4.83, CI (1.24; 18.79)) and COPD (OR=7.09, CI (2.47; 20.33)) had significantly higher odds of reporting contact with a physiotherapist than those with cancer.

Logistic regression (Table 3) also demonstrated that after correction for diagnostic group, patients from German (OR=86.84, CI (8.94; 844.06)) and Dutch initiatives (OR=11.31, CI (1.27; 100.59)) had significantly higher odds of reporting contact with a palliative care

Table 2. Most frequently reported people in patients' care networks from the perspectives of patients living at home or in a nursing home.

| | Specialist palliative care | | | | | General palliative care | | | | | Additional care | | | | | Informal and volunteer care | | | | | | | | | | | | | | | | | | | |
|---|----------------------------|-----------|------------------------|------------------------|---------------------|-------------------------|-----------------------|-----------------------------------|----------------------|---------------------|-----------------|------------------|--------------|---------------|------------------|-----------------------------|-----------------------------------|--|--|------------|--|-----------------|--|-----------------|--|------------------|--|--------------|--|---------------|--|------------------|--|-----------|--|
| | PC specialist | | PC nurse | | | All physicians | | GP | | | Onc | | Car | | Pul | | Specialist other than onc/car/pul | | | All nurses | | Home care nurse | | Physiotherapist | | Spiritual worker | | Psychologist | | Social worker | | Family caregiver | | Volunteer | |
| | PC specialist | PC nurse | All physicians | GP | Onc | Car | Pul | Specialist other than onc/car/pul | All nurses | Home care nurse | Physiotherapist | Spiritual worker | Psychologist | Social worker | Family caregiver | Volunteer | | | | | | | | | | | | | | | | | | | |
| Contact with actor, N (%) (N=157) | 51 (33) | 75 (48) | 151 (96) | 138 (88) | 55 (35) | 26 (17) | 28 (18) | 52 (33) | 122 (78) | 39 (25) | 41 (26) | 28 (18) | 22 (14) | 17 (11) | 136 (87) | 14 (9) | | | | | | | | | | | | | | | | | | | |
| Per country, N (%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Belgium (N=15) | 1 (7) | 11 (73) | 14 (93) | 14 (93) | 6 (40) | 2 (13) | 2 (13) | 1 (7) | 14 (93) | 12 (80) | 6 (40) | 4 (27) | 4 (27) | 1 (7) | 14 (93) | 3 (20) | | | | | | | | | | | | | | | | | | | |
| Germany (N=34) | 29 (85) | 22 (65) | 33 (97) | 32 (94) | 17 (50) | 2 (6) | 3 (9) | 8 (24) | 26 (77) | 5 (15) | 9 (27) | 7 (21) | 5 (15) | 5 (15) | 26 (77) | 3 (9) | | | | | | | | | | | | | | | | | | | |
| United Kingdom (N=35) | 2 (6) | 28 (80) | 35 (100) | 35 (100) | 17 (49) | 6 (17) | 6 (17) | 6 (17) | 35 (100) | 10 (29) | 1 (3) | 7 (20) | 5 (14) | 4 (11) | 29 (83) | 2 (6) | | | | | | | | | | | | | | | | | | | |
| Hungary (N=42) | 7 (17) | 0 | 41 (98) | 30 (98) | 7 (17) | 11 (26) | 11 (26) | 27 (64) | 22 (52) | 2 (5) | 18 (43) | 3 (7) | 7 (17) | 6 (14) | 39 (93) | 3 (7) | | | | | | | | | | | | | | | | | | | |
| The Netherlands (N=31) | 12 (39) | 14 (45) | 28 (90) | 27 (87) | 8 (26) | 5 (16) | 6 (19) | 10 (32) | 25 (81) | 10 (32) | 7 (23) | 7 (23) | 1 (3) | 1 (3) | 28 (90) | 3 (10) | | | | | | | | | | | | | | | | | | | |
| Per diagnostic group, N (%) | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Cancer (N=97) | 46 (47) | 58 (60) | 95 (98) | 89 (92) | 54 (56) | 5 (5) | 6 (6) | 25 (26) | 74 (76) | 23 (24) | 16 (17) | 20 (21) | 14 (14) | 9 (9) | 87 (90) | 10 (10) | | | | | | | | | | | | | | | | | | | |
| CHF (N=21) | 1 (5) | 7 (33) | 20 (95) | 19 (91) | 0 | 17 (81) | 0 | 10 (48) | 16 (76) | 6 (29) | 7 (33) | 2 (10) | 5 (24) | 1 (5) | 16 (76) | 0 | | | | | | | | | | | | | | | | | | | |
| COPD (N=39) | 4 (10) | 10 (26) | 36 (92) | 30 (77) | 1 (3) | 4 (10) | 22 (56) | 17 (44) | 32 (82) | 10 (26) | 18 (46) | 6 (15) | 3 (8) | 7 (18) | 33 (85) | 4 (10) | | | | | | | | | | | | | | | | | | | |
| Rating of quality of relationship with HCP, mean (SD) ^a | 0.8 (0.7) | 0.8 (0.7) | 1.2 (0.8) | 1.4 (1.0) | 1.1 (1.1) | 1.5 (1.2) | 1.7 (1.0) | 1.1 (1.1) | 0.9 (0.7) | 1.1 (0.9) | 1.1 (0.9) | 1.0 (0.9) | 0.9 (1.2) | 1.5 (0.9) | 0.4 (0.7) | 0.9 (0.8) | | | | | | | | | | | | | | | | | | | |
| Difference between relationship with respective HCP and PC specialist/nurse, p-value (95% CI) | n/a | n/a | <0.001* (-0.92; -0.37) | <0.001* (-1.06; -0.40) | 0.249 (-0.83; 0.23) | 0.141 (-0.25; 0.75) | 0.034* (-1.88; -0.12) | 0.088 (-1.24; 0.10) | 0.395 (-0.47; -0.19) | 0.193 (-0.83; 0.18) | n/a | n/a | n/a | n/a | n/a | n/a | | | | | | | | | | | | | | | | | | | |
| Rating of quality of care provision by HCP, mean (SD) | 0.8 (0.7) | 0.8 (0.8) | 1.1 (0.9) | 1.3 (1.0) | 1.1 (1.1) | 1.1 (1.1) | 1.5 (1.1) | 1.1 (1.1) | 1.0 (0.8) | 1.1 (0.9) | 1.2 (0.9) | 1.0 (0.9) | 1.0 (1.2) | 1.6 (1.1) | 0.4 (0.7) | 1.1 (1.0) | | | | | | | | | | | | | | | | | | | |

PC specialist: palliative care specialist, which includes GP palliative care specialist from the palliative home care team, palliative care specialist/consultant and hospice physician; PC nurse: palliative care nurse, which includes nurse specialised in palliative care and nurse practitioner palliative care; GP: general practitioner; onc: oncologist; car: cardiologist; pul: pulmonologist; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease; HCP: healthcare professional; SD: standard deviation; CI: confidence interval.

*Percentages shown are percentages of the total number of patients (N) displayed in the first column.

^aRating of quality of relationship and quality of care provision could range from 0 (excellent) to 4 (poor).

*Significant at 0.05 level.

Table 3. Multiple logistic regression for the association between having/not having contact with respective healthcare professional and diagnosis as well as country.

| Determinant | Palliative care specialist | | Palliative care nurse | | General practitioner | | Home care nurse | | Physiotherapist | |
|----------------------|----------------------------|---------|-----------------------|--------|----------------------|--------|--------------------|---------|--------------------|---------|
| | OR (95% CI) | p | OR (95% CI) | p | OR (95% CI) | p | OR (95% CI) | p | OR (95% CI) | p |
| Diagnosis | | | | | | | | | | |
| Cancer | 1.00 | 0.005* | 1.00 | 0.038 | 1.00 | 0.065 | 1.00 | 0.106 | 1.00 | 0.001* |
| CHF | 0.11 (0.01; 0.93) | 0.042* | 0.63 (0.12; 3.34) | 0.586 | 0.85 (0.17; 4.34) | 0.849 | 3.96 (1.03; 15.31) | 0.046* | 4.83 (1.24; 18.79) | 0.023* |
| COPD | 0.16 (0.04; 0.57) | 0.005* | 0.23 (0.08; 0.71) | 0.011* | 0.30 (0.11; 0.85) | 0.023* | 2.11 (0.72; 6.16) | 0.173 | 7.09 (2.47; 20.33) | <0.001* |
| Country ^a | | | | | | | | | | |
| Belgium | 1.00 | <0.001* | 1.00 | 0.034* | n/a | n/a | 1.00 | <0.001* | 1.00 | 0.019* |
| Germany | 86.84 (8.94; 844.06) | <0.001* | 0.54 (0.13; 2.20) | 0.385 | | | 0.05 (0.01; 0.22) | <0.001* | 0.65 (0.17; 2.54) | 0.534 |
| United Kingdom | 1.24 (0.10; 15.21) | 0.866 | 1.90 (0.41; 8.78) | 0.410 | | | 0.07 (0.01; 0.31) | 0.001* | 0.02 (0.00; 0.21) | 0.001* |
| Hungary | 6.40 (0.67; 60.88) | 0.106 | 0.00 (0.00;) | 0.997 | | | 0.01 (0.00; 0.05) | <0.001* | 0.46 (0.11; 1.94) | 0.290 |
| The Netherlands | 11.31 (1.27; 100.59) | 0.030* | 0.28 (0.07; 1.16) | 0.080 | | | 0.10 (0.02; 0.45) | 0.003* | 0.32 (0.07; 1.39) | 0.128 |

OR: odds ratio; CI: confidence interval; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease.

To limit the number of variables in the regression model due to the small sample size and since age and gender were not significant for any of the healthcare professionals, we did not include these two variables in the final regression model.

Belgium was chosen as the reference group, since this was the first category within variable country.

^aCountry as a variable refers to the selection of integrated palliative care initiatives in that country, not directly to the whole country.

*Significant at 0.05 level.

Table 4. Top 3 'Who, do you think, is the main responsible caregiver of all caregivers you receive care from? (i.e. the person(s) who decide(s) how your care is being organised)?' by country.

| | Belgium | Germany | United Kingdom | Hungary | The Netherlands |
|---|--|--|--|--|--|
| 1 | More than one healthcare professionals ^a (n = 4, 27%) | Family caregiver (n = 12; 35%) | Nurse (n = 10, 29%) | Hospital specialist (n = 22, 52%) | Hospital specialist (n = 11, 36%) |
| 2 | Nurse (n = 2, 13%), GP (n = 2, 13%), family caregiver (n = 2, 13%) | Patient (n = 4, 12%) | Hospital specialist (n = 8, 23%) | More than one healthcare professionals ^a (n = 5, 12%) | More than one healthcare professionals ^a (n = 5, 16%) |
| 3 | – | GP (n = 3, 9%), palliative care specialist (n = 3, 9%) | More than one healthcare professionals ^a (n = 6, 17%) | Do not know (n = 4, 10%) | GP (n = 3, 10%) |

GP: general practitioner.

^aMore than one healthcare professionals mainly includes a combination of two to four of the following HCPs: family caregiver, patient, nurse (home care/specialised), GP, palliative care physician, hospital specialist.

Table 5. Social network analysis questions about perceived integration between healthcare professionals involved in the care networks of patients and Canhelp Lite questionnaire overall summary score.

| | Mean | SD |
|---|------|-----|
| 5 These caregivers appear to work together very well ^a | 3.0 | 0.9 |
| 6 The care given by these caregivers appears to be well-connected ^a | 2.9 | 1.0 |
| 7 These caregivers pass on information to each other well ^a | 2.9 | 1.0 |
| 8 These caregivers always know very well what the other caregivers have done ^a | 2.7 | 1.1 |
| 9 Sometimes, I perceive friction between caregivers ^a | 1.2 | 1.2 |
| Canhelp Lite overall summary score ^b | 3.0 | 0.6 |

SD: standard deviation.

^aScale ranges from 0 (*strongly disagree*) to 4 (*strongly agree*).

^bScale ranges from 0 (*not at all satisfied*) to 4 (*completely satisfied*).

specialist compared to those in Belgium (the reference group). In Hungarian initiatives, none of the patients reported contact with a palliative care nurse. In other countries, the odds of reporting contact with a palliative care nurse did not differ significantly from those in the Belgium initiatives. Furthermore, in all countries patients from the selected initiatives reported significantly lower odds of reporting contact with a home care nurse than those in Belgium. In addition, patients in the United Kingdom (OR = 0.02 (0.00; 0.21)) had significantly lower odds of reporting contact with a physiotherapist than those in Belgium initiatives.

Patients' perceptions of main responsible HCP or caregiver

We found large variations between patients' answers to the question 'Who, do you think, is the main responsible caregiver of all caregivers you receive care from? (i.e. the person(s) who decide(s) how your care is being organised)?' (Table 4). In Hungarian and Dutch initiatives, the largest proportion of patients reported hospital specialists to be responsible for organising their care. In German initiatives, most patients reported family caregivers to be the central person in their care network.

Patients from initiatives in the United Kingdom most often reported nurses or hospital specialists as the central HCP. Furthermore, a number of patients in Belgium, the United Kingdom, the Netherlands and Hungary perceived that more than one person (e.g. patient, family caregiver, nurse and GP) were responsible for organising their care.

Integration between HCPs and its association with overall satisfaction

Generally, patients perceived moderate to high integration between HCPs in their care networks and almost no friction. Furthermore, on average patients were quite satisfied about the care they received (see Table 5).

We did not find significant associations between overall satisfaction and generalist versus specialist palliative care initiative or having contact with particular HCPs. The multiple regression analysis in which we examined predictors for overall satisfaction with care showed a weak ($R^2 = 0.31$), but significant association between overall satisfaction and independent variables country, diagnosis, age, gender and perceived integration. The relation was mainly due to perceived integration (social network analysis questions 6 and 9) and country (Table 6).

Table 6. Multiple linear regression model for the association between overall satisfaction with care and diagnosis, country, age, gender and social network analysis questions 6 and 9.

| Determinant | B (95% CI) | p-Value |
|---|----------------------|---------|
| Diagnosis | | |
| Cancer | Reference | |
| CHF | 0.11 (−0.19; 0.41) | 0.470 |
| COPD | −0.08 (−0.32; 0.16) | 0.531 |
| Country^a | | |
| Belgium | Reference | |
| Germany | 0.51 (0.03; 0.98) | 0.037* |
| United Kingdom | 0.33 (−0.02; 0.68) | 0.068 |
| Hungary | 0.34 (−0.02; 0.70) | 0.067 |
| Netherlands | 0.00 (−0.36; 0.36) | 0.981 |
| Age | 0.00 (−0.01; 0.01) | 0.441 |
| Gender | −0.07 (−0.27; −0.13) | 0.479 |
| Social network analysis question 6 'The care given by these caregivers appears to be well-connected' ^b | 0.19 (0.08; 0.29) | <0.001* |
| Social network analysis question 9 'Sometimes I perceive friction between caregivers' ^b | −0.10 (−0.19; −0.01) | 0.030* |

CI: confidence interval; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease.

Belgium was chosen as the reference group, since this was the first category within the variable country.

^a'Country' as a variable refers to the selection of integrated palliative care initiatives in that country, not directly to the whole country.

^bThe separate social network analysis questions 5–9 significantly associated with overall satisfaction. However, since these questions mutually correlated we decided to only include questions 6 and 9 in the multiple regression model based on the highest coefficient of determination (R^2).

*Significant at 0.05 level.

R^2 of the model=0.31.

Discussion

This study examined perspectives of patients receiving care from several integrated palliative care initiatives in five European countries on the organisation and quality of their care networks. We found large differences between patient's reports on the organisation of their care networks for different diagnostic groups and countries of origin of the integrated palliative care initiatives involved. Notwithstanding, overall satisfaction was high and did not vary greatly. Moreover, patients' perceptions of integration between HCPs involved in their care networks significantly affected overall satisfaction.

Although patients were recruited from integrated palliative care initiatives, it was uncommon for many patients to report on specialist palliative care professionals within their care networks, especially for those with COPD, CHF and patients from generalist palliative care initiatives. Other studies found that palliative care is unevenly spread between disease groups and predominantly includes services for patients with cancer.^{7,10} However, differences found in this study also related to the type of integrated palliative care initiatives from which patients were recruited (generalist or specialist). For patients who were recruited from specialist palliative care initiatives, the involvement of a palliative care specialist in their care network was apparently more clear than for patients recruited from generalist palliative care initiatives.

Several studies show that palliative care is increasingly provided by generalist HCPs such as GPs^{7,25} or hospital clinicians.²⁶ However, patients may not always be aware of this, let alone that they know what palliative care means. This study shows that patients may have different understandings of the organisation of their care (network) than HCPs. Therefore, it can be challenging for patients to have insight into who is involved in their care network,¹⁶ what are the specific roles of HCPs, for example, palliative care specialists²⁷ and who is the main responsible HCP for their care. HCPs involved in integrated palliative care initiatives should be aware of potential needs of patients to clarify roles of specific key workers and to support them in navigating the health system.

Patients rated their relationships with palliative care specialists slightly higher compared to other physicians, and palliative care services seemed to be organised differently across countries. Nevertheless, overall satisfaction with care provision was not significantly different between diagnostic groups, HCPs, generalist versus specialist palliative care initiative and most countries. In addition, we did find a significant association between integration and satisfaction. These results suggest that it does not matter so much to patients who provides care or how their care is organised, as long as HCPs can provide continuity of care. A recent review²⁸ including 19 studies supports this finding showing that continuity of care aspects (being available as

an HCP and providing security) are essential for achieving positive patient experiences with palliative care.

Strengths and limitations

This study provides international insight into care networks of patients within several integrated palliative care initiatives in five European countries from the perspectives of patients. Since the results in this study are reported by patients themselves in different countries, they are limited by self-reporting bias and potential ambiguity in the interpretation of questions about roles and responsibility of palliative care or other HCPs and differences in the national healthcare systems. Nevertheless, we think these data are valuable, as patient perspectives about their care networks are likely to differ from that described by HCPs or family caregivers. Since patients probably do not always understand how their healthcare is organised, evaluating patients' views could identify gaps, for example, in their knowledge about the organisation or coordination of their care network and could therefore function as a trigger for improvement.

The association between integration and satisfaction was weak. Probably with only four questions to measure integration, we might not have captured integration completely. This confirms the literature suggesting that integration is only one among several aspects influencing satisfaction with care. For example, several review studies^{28–30} suggest that factors such as adequate symptom control, communication and shared care are crucial for satisfaction with palliative care.

The conclusions drawn from this study need to be taken with caution, since the sample included relatively small numbers that do not aim to be representative for whole countries with their varying healthcare organisations. This was an exploratory study in which we aimed to explore important features of the palliative care networks as reported by patients, rather than striving to test hypotheses. Analyses done are to be seen as an attempt to gain insight into the data within in this specific sample. Significant outcomes in this study should be therefore interpreted with care. Although the results are not representative for whole countries and diagnostic groups, these analyses provide information on how palliative care networks are built from a patient perspective and how they operate between different disease groups. A study with a representative sample of each country and diagnostic group, however, is needed in order to further investigate this topic.

Conclusion

This study provides insight into perspectives of patients with advanced cancer, COPD or heart failure receiving care by several integrated palliative care initiatives in five European countries on the organisation and quality of their

care networks. Notwithstanding differences in the organisation of care networks between different integrated palliative care networks or diagnostic groups, patients generally seem to be satisfied especially with their relationships with palliative care professionals and with care provision as long as continuity of care is provided. The study suggests that palliative care professionals are not always present in care networks or recognised as such by patients. Therefore, the involvement of expert palliative care needs to be explicated especially for non-cancer patients. Furthermore, the roles of different HCPs in patients' palliative care networks need to be clear for patients as well as who is their first point of contact in case of needs. One HCP working in the integrated palliative care initiative should therefore have an overview of the patient's palliative care network and support patients in navigating through this network should they need this.

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Data management sharing

Data from this study are deposited at the international database of the InSup-C project. These are available to a limited extent on request.


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