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# Advanced cancer patients' self-assessed physical and emotional problems on admission and discharge from hospital general wards – a questionnaire study

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**Advanced cancer patients' self-assessed physical and emotional problems on admission and discharge from hospital general wards – a questionnaire study**

Most cancer patients receiving life-prolonging or palliative treatment are offered non-specialist palliative services. There is a lack of knowledge about their problem profile. The aim of this article is to describe the incidence of patient-reported physical and emotional problems on admission and discharge from general hospital wards and health staff's reported intervention. A prospective study was undertaken over 12 months, where advanced cancer patients completed a patient questionnaire, EORTC QLQ C15-PAL, on admission ( $n = 97$ ) and discharge ( $n = 46$ ). The incidences of the problems were dichotomised in intensity categories. The average number of 'clinically relevant problems' on admission was 5 (SD 2) and on discharge 4 (SD 2). A Wilcoxon signed rank test showed significant change in mean score for six out of nine problem areas, but the majority of the patients did not move to the lower intensity category. The highest concurrence was between patient-reported problems and reported intervention for physical function, pain, constipation and loss of appetite. Palliative cancer patients' self-reported problem profile on admission and discharge from hospital has not previously been described and the results indicate a need to focus on improvements to palliative services and for a special service for pain and constipation that could prevent some admissions.

*Keywords:* palliative care, EORTC QLQ-C15-PAL, hospital, advanced cancer, patients-reported problems.

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## INTRODUCTION

The World Health Organisation (WHO) emphasises that the existence of good palliative services presupposes early identification and intervention to address patients' physical, psychosocial problems to prevent and alleviate the patients' suffering and strive for the best possible quality of life (WHO 2002). The incidence and prevalence of cancer is rising and 30% more cancer-related deaths are

expected globally within the coming decades (WHO 2002). As a consequence of increased longevity, improved diagnostic methods and more life-prolonging treatments, cancer patients who do not recover can live longer with an advanced and progressive illness (Ahmedzai *et al.* 2004). This requires that health services offer effective palliative care (WHO 2004). The period before the terminal phase is preceded by a palliative (alleviating) course of care and treatment that can stretch over months or even years (Murray *et al.* 2005). Acute hospital admissions often occur in tandem with the progression of the illness and palliative services are not sufficiently available at home (Schneider *et al.* 2007). The patient is sometimes discharged before sufficient measures are taken in the home or before he/she is adequately prepared to manage at home and thus is re-admitted (Weaver *et al.* 2006). The development and organisation of palliative services varies considerably; however, across European countries and at specialist levels (in hospice, palliative teams and palliative wards) capacities are limited (Centeno *et al.* 2007). Specialist palliative care means a high standard of palliative care provided by a trained multi-professional team, unlike the majority of the palliative care services, at home and in hospital general wards, are provided by health staff with limited knowledge and lack of competence in palliation, defined as basic palliative care (Ahmedzai *et al.* 2004).

Cancer patients' physical and cognitive functioning is reduced in line with the progression of the illness, whereby preferences for palliative services changes (Radbruch *et al.* 2010). A targeted palliative service requires, therefore, that health staff have ongoing and sufficient knowledge of the patients' personal assessment of the current and potential physical and psychosocial problems as a starting point in arranging appropriate interventions (Rydahl-Hansen 2005). Identification and intervention can be included in the concept of continuity, defined as the patient's experience of concordance between their physical and psychosocial problems and the palliative services offered, both over short and longer periods (Haggerty *et al.* 2003). But what do we know about palliative cancer patients' problems profile and basic palliative service in relation to hospital admissions?

Johnsen *et al.* (2009) has described the incidence of physical symptoms and psychosocial problems identified in 977 patients with advanced cancer, of which the majority were not in contact with palliative specialist units. The most frequent patient-reported issues were fatigue (57%), reduced role function (51%), sleeplessness (48%) and pain (39%). Furthermore, the study showed that 19% of the patients with pain and 75% of patients with concentration problems had not received any help at all, even though they wanted it (Johnsen 2008). Doorenbos *et al.*

(2006) have studied cancer patients' experience of their problems in their final years and found that the most commonly seen physical and psychosocial problems are identical for patients who are treated at basic and specialist levels. Whether there were differences in the intensity of the problems in the two groups was not addressed in that study. Results from the specialist level suggest that neither doctors nor nurses adequately identify patients' physical and psychosocial problems (Nekolaichuk *et al.* 1999; Stromgren *et al.* 2001a,b; Horton 2002; Rydahl-Hansen 2009). One can suppose that, if the patients' problems are not sufficiently identified at specialist level, the same lack of continuity will be present at basic level. But results from the specialist level cannot be transferred uncritically to the basic level because the incidence of the patients' physical and psychosocial problems seem to vary in different treatment units (hospice, palliative wards, general wards and outpatient units), where palliative services are offered (Potter *et al.* 2003). The aim of this article is to describe incidence and degree of seriously ill cancer patients' physical and mental problems on admission and discharge from general wards where they have been admitted for more than 2 days, and to what extent there is concordance between the patient-reported issues and health staff's reported intervention in response to them.

## MATERIALS AND METHOD

### Patients

In all, seven wards (three medical wards, two acute reception wards and two surgical wards) were included in the study, based at two university hospitals in Copenhagen. The patients were included when it was clear in the medical record that they had an inoperable or metastatic cancer disease or when it was made known that treatment would be of a palliative character. Furthermore the patients should understand and speak Danish, have an expected stay >2 days and an expected remaining life span of at least three months, assessed by the patient's contact doctor. Patients who received treatment from a palliative specialist unit, had vision and/or hearing difficulties or were not in a position to give informed consent were not included in the study.

### Instruments

In order to identify and evaluate the patients' physical and mental problems, patient questionnaire EORTC QLQ-C15-PAL was employed, which consists of 15 questions to cancer patients who are in receipt of palliative

services (Groenvold *et al.* 2006a). QLQ-C15-PAL is a shortened version of the well-validated and often used questionnaire EORTC QLQ-C30 that measures cancer patients' health-related life quality in 30 questions. The scheme was developed by the European Organisation for Research and Treatment of Cancer (EORTC) and translated into Danish according to EORTC's guidelines [European Organisation for Research and Treatment of Cancer (EORTC)]. QLQ-C15-PAL items and scales have been chosen and prioritised by cancer patients and professionals at palliative specialist level from six European countries, and covers nine problem areas: physical function, emotional function, which is related to the mental problems of tense and depression, dyspnoea, pain, fatigue, nausea, reduced appetite, constipation and sleeplessness. Physical and emotional function, fatigue and pain are multi-item scales, while nausea, appetite, dyspnoea, constipation and sleeplessness are individual-item. The questionnaire is validated on palliative cancer patients and the Danish translation directly follows the original questionnaire, QLQ-C30 (Aaronson *et al.* 1993; Osoba *et al.* 1994; Hjerstad *et al.* 1995; Kaasa *et al.* 1995; Groenvold *et al.* 1997; Suárez-del-Real *et al.* 2011). Multi-item scales from QLQ-C30 are reduced by Item Response Theory without significant loss of reliability (Petersen *et al.* 2006). Results are therefore comparable with results from studies with the original questionnaire QLQ-C30 (Groenvold *et al.* 2006b). In this study the questionnaire questions about general life quality were omitted as this is not relevant to the study's aim. The patient completes the questionnaire him/herself, and it can also be answered as a structured interview with the use of the questionnaire's answer categories. In responding to the questionnaire the patient assesses problems and strengths on an adjectival scale with four answer categories: 1 (not at all), 2 (a little), 3 (quite a bit) or 4 (very much) (Streiner & Norman 2003). The validated screening instrument, Palliative Performance Scale (PPS) is used to measure the patients' physical functioning upon admission (Anderson *et al.* 1996). The data collector evaluates five function areas: mobility, activity and signs of illness, performance of personal care, food and liquid intake and level of consciousness on a 10% interval scale from 0% to 100%, where 0% represents death and 100% represents no signs of illness. The function area mobility is the primary variable that indicates the patient's physical functioning level.

### The process

The study was reported to the Danish Data Protection Agency, J.nr. 2009-41-3357. In Denmark questionnaire

studies do not need to be reported to the Central Scientific Committee, but the study was carried out in accordance with internationally applicable ethical guidelines (World Medical Association 1964). All patients gave written informed consent after receiving oral and written information about the study's aim and process, and they were informed of their right to unconditionally withdraw from the study at any time. The patients answered the questionnaire in the first instance within the first 2 days of their stay, where the patient was contacted by the researcher and completed the questionnaire immediately after having given written informed consent. A few very weak patients took up the offer of responding to the questionnaire in the form of an interview, where the questions were read aloud in the same order as they were listed on the questionnaire without interpretation of the questions or the patients' responses. The patient was to be contacted on the ward the day before planned discharge, or the patient received the questionnaire with a franked addressed envelope to answer the questionnaire at home immediately after discharge. The registration of which of the questionnaire's problem areas that were described and acted upon during the patients' stay took place in a retrospective medical record and nursing record reading after the patients' discharge. In addition socio-demographic and clinical background variables were collected: age, gender, marital status, type of accommodation, education, employment, contact with the primary sector, PPS, type of cancer, co-morbidity, reason for admission and length of stay. As a control of confounders the following were also registered: whether the patient was currently receiving palliative oncological treatment, whether he/she was treated by a pain specialist during their hospital stay and whether any illness-related complications or those of a social nature arose during the stay.

### ANALYSIS

All data were doubly input in the Epidata programme by two different individuals and thereafter transferred to the statistical programme, Statistical Analysis System. The absolute scores from the questionnaire QLQ-C15-PAL were transformed to a linear scale from 0 to 100, based on average values from multi-item scales, and grouped in nine problem areas (Groenvold & Petersen 2006). The following conversation scale for response categories were used in the original measurement scale: 1 (not at all) = 0–16.9, 2 (a little) = 17–33.9, 3 (quite a bit) = 34–66.9 and 4 (very much) = 67–100. As the threshold for a 'clinically relevant problem', where intervention can be expected, we chose >34 (Stromgren *et al.* 2001a). The two function

scales, physical and emotional function, have in contrast this value scale: 0–33.9 = 4 (very much), 34–66.9 = 3 (quite a bit), 67–82.9 = 2 (a little), 83–100 = 1 (not at all) and the threshold for a clinically relevant problem is <67 (Groenvold & Petersen 2006).

The number of observed problem areas and scores on admission and discharge, and the concordance between the patient-identified problems and the problems that doctors and nurses had intervened upon were calculated in frequency tables. The change in the patients' scores (0–100) from admission to discharge were tested using the Wilcoxon signed rank test, based on scores on discharge minus scores on admission. A negative number hereby indicates an improvement. In addition the incidence and changes to the intensity of the problems calculated in relation to the original measurement scale (1–4). The results are presented as mean and standard deviation (SD) and per cent (%). The chi-squared test and Wilcoxon signed rank test were used for response analysis.

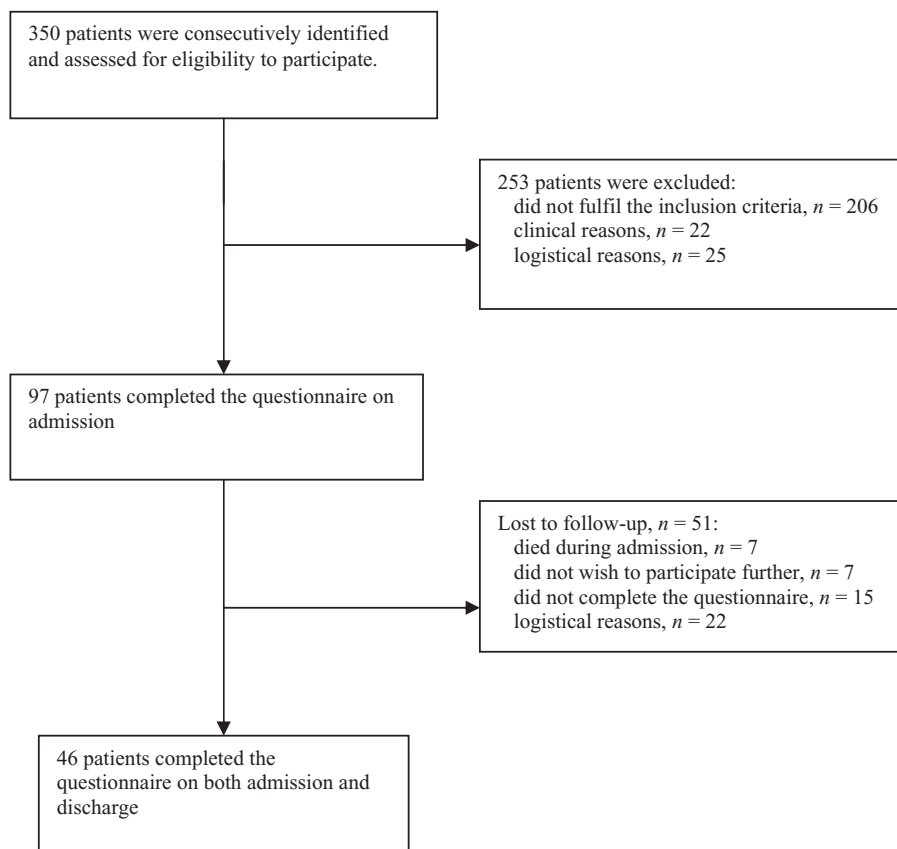
## RESULTS

### Study population and dropout

In the period June 2009–August 2010 350 consecutive adult patients admitted to hospital with an advanced cancer

illness were screened for inclusion in the study (Fig. 1). In all 253 patients were excluded. A total of 206 did not meet the inclusion criteria because the patient: was in the terminal phase ( $n = 5$ ), was in receipt of treatment by a palliative specialist ward ( $n = 48$ ), was not Danish speaking ( $n = 8$ ), was not in a position to give informed consent ( $n = 45$ ), was admitted for  $\leq 2$  days ( $n = 69$ ), did not wish to participate ( $n = 31$ ). A further 22 patients were excluded due to acute, critical conditions (unstable circulation, high fever) and 25 patients were excluded for logistical reasons (e.g. the patient was receiving treatment at another hospital, data collectors' vacation and attendance on course days). Thus, 97 patients participated in the study, all of whom completed questionnaire QLQ-C15-PAL on admission. On discharge the questionnaire completed by 46 patients, either on the discharge day or on average within 1–2 days after discharge. Seven patients had died during their stay, 22 declined further participation and the researcher lost contact with 22 patients as 10 were transferred to another hospital for treatment, 12 unplanned discharge, discharge while on leave at home or during an outpatient visit at another hospital (logistical reasons).

Socio-demographic and clinical characteristics in the 97 patients who were included are shown in Table 1. The average age was 72 (SD 11) and 60% were men. The



**Figure 1.** Flow diagram for inclusion and follow-up.

**Table 1.** Socio-demographic and clinical characteristics of patients (*n* = 97)

Variable		<i>n</i>	%
Age, mean (SD)	72 (11)	97	
Gender	Male	58	60
Civil status	Married/cohabiting	44	45
	Widow/widower	22	23
	Single, divorced, separated	31	32
Employment	Full/self-employed, part-time	14	14
	Sick pay/flex-job, sick pension	10	10
	Old-age pension, early retirement	73	75
Formal education	None	18	19
	Shorter education <3 years	53	54
	Longer education >3 years	27	28
Primary sector	Home nurse	32	33
	Home visit general practitioner, within last 3 months	21	24
Primary cancer diagnosis	Colorectal	26	27
	Prostate	23	24
	Lung	13	13
	Pancreas/gall bladder/liver	12	12
	Bladder/kidney	7	7
	Head and neck	6	6
	Breast	4	4
	Brain	4	4
	Gynaecological	2	2
Cancer stage	Metastases, disseminated	72	74
	Local advanced	25	26
Within palliative oncology	Chemotherapy	23	24
	Radiotherapy	11	11
	Hormone	8	8
Co-morbidity	None	43	44
	Cardiological	32	33
	Diabetes	9	9
	Rheumatism	3	3
	Chronic obstructive pulmonary disease	5	5
	Alcoholic	3	3
	Parkinson's	2	2
	Osteoporosis	1	1
	Epilepsy or other metabolic disease	3	3
Palliative Performance Scale	Full ambulation no evidence of disease	5	5
	Full ambulation, some evidence of disease	12	12
	Reduced ambulation, some evidence of disease	17	18
	Reduced ambulation and significant disease	31	32
	Mainly sit or lie down	29	30
	Mainly or totally bed bound	3	3
Hospitalisation days, mean (SD)	9.2 (11)		
Department	Surgical	61	63
	Medical	36	37
Reason for admission	Bad general condition	46	47
	Pain	25	26
	Infection	21	22
	Constipation	12	12
	Diarrhoea	10	10
	Dyspnoea	9	9
	Fall	8	8
	Operation	5	5
	Volvulus	5	5
	Bleeding	3	3
	Stent	4	4
	Spinal compression	3	3

number of patients with no or a lower level of post-secondary education (during 1 year) was 56, while 53 patients lived alone. Of the 44 patients who lived with a partner, three had an ill partner at home. Furthermore, 32 patients had contact with a home visiting nurse and 21 patients had had home visits by their general practitioner within the previous 3 months. The most common cancer diagnoses were colorectal 27% ( $n = 26$ ), prostate 24% ( $n = 23$ ) and lung cancer 13% ( $n = 13$ ). On admission (Table 1) 42 patients were currently receiving oncological treatment, of which number 23 were having chemo treatment. A third of the patients had a PPS of  $\leq 50\%$ , which means that the patients had severe signs of illness and primarily sit or lie down. The average duration of hospital stay was 9 days (SD 11). The most common reason for admission was generally poor condition (47%), pain (26%), infection (22%) and constipation (12%).

The patients who did not complete the QLQ-C15-PAL on discharge differed significantly, statistically speaking, from the 46 patients who completed the questionnaire, by having a lower PPS ( $P = 0.01$ ) together with poorer physical ( $P = 0.01$ ) and emotional ( $P = 0.03$ ) function. Besides, in the dropout group there were 43% more widowers, 60% more patients with a lower level of education, 62% more patients were currently receiving palliative oncological treatment and 100% more patients had several chronic illnesses when compared with the patients who took part in the final analysis.

### Incidence and intensity of patient-reported issues on admission and discharge

For the 97 patients who completed QLQ-C15-PAL on admission (Table 2) the four most commonly reported problems judged to be clinically relevant ( $\geq 34$  in the total score) related to: fatigue 86%, physical function 81%, pain 67% and loss of appetite 59%. The four most commonly reported problems with a score  $\geq 34$  for the 46 patients who completed the questionnaire on discharge (Table 2) related to: fatigue 74%, physical function 73%, pain 48% and emotional function 58%. For the 46 patients who completed the questionnaire both on admission and discharge (Table 3) there was a significant change for the total score in the category  $< 34$  in relation to pain ( $P = 0.03$ ) and sleeplessness ( $P = 0.01$ ). For the total score in the category  $> 34$  a significant change in intensity can be seen in six out of the nine problem areas (pain, sleep, fatigue, appetite loss, constipation and nausea).

Figure 2 shows the number of patients for whom there was a change in intensity category as a result of the change in mean score. The problem areas where most patients

**Table 2.** Dichotomised patient-reported problem intensity on admission and discharge

QLQ-C15-PAL	Score 00–33.9*		Score 34–100†	
	Admission $n = 97$	Discharge $n = 46$	Admission $n = 97$	Discharge $n = 46$
Physical function	18 (19)	12 (27)	79 (81)	33 (73)
Dyspnoea	71 (73)	38 (83)	26 (27)	8 (17)
Pain	32 (33)	24 (52)	65 (67)	22 (48)
Sleeplessness	61 (63)	37 (80)	36 (37)	9 (20)
Fatigue	14 (14)	12 (26)	83 (86)	34 (74)
Appetite loss	40 (41)	30 (65)	57 (59)	16 (35)
Nausea	73 (75)	40 (87)	24 (25)	6 (13)
Constipation	57 (59)	34 (74)	40 (41)	12 (26)
Emotional function	52 (54)	19 (42)	45 (46)	26 (58)
Mean‡ (SD)			5 (2)	4 (2)

\*Problem reported as 'not at all' or 'a little'.

†'Clinically relevant problem'; problem reported as 'quite a bit' or 'very much'.

‡Mean number (SD) of 'clinically relevant' problem.

**Table 3.** Mean differences in intensity score, between admission and discharge ( $n = 46$ )

QLQ-C15-PAL	Score 00–33.9		Score 34–100	
	Mean	$P$ -value	Mean	$P$ -value
Physical function	-13.33	0.121	4.4444	0.672
Dyspnoea	0	1.000	-15.1515	0.187
Pain	8.7719	0.034*	-24.0740	0.000*
Sleeplessness	12.1212	0.016*	-30.7692	0.007*
Fatigue	19.7530	0.093	-16.5165	0.000*
Appetite loss	5.5555	0.494	-37.8787	0.000*
Nausea	0.9523	0.818	-31.8181	0.050*
Constipation	3.8461	0.562	-36.6666	0.001*
Emotional function	-1.960	0.554	6.5476	0.205

Wilcoxon signed rank test, \* $P$ -value  $< 0.05$ .

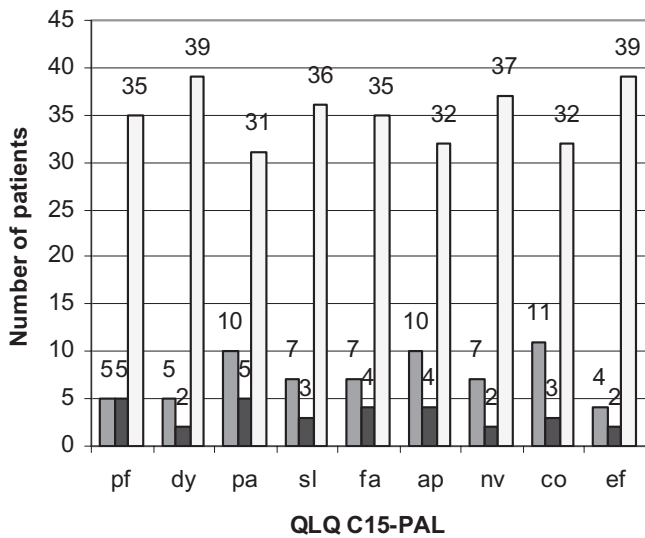
Negative number = improvement, positive number = aggravation.

move to lower categories are: pain (10 patients), appetite loss (10 patients) and constipation (11 patients). For the same problem areas there are five, four, and three patients respectively, who have moved from the low to the high categories. Generally 67–70% of the patients remained in the intensity category that was applied on admission.

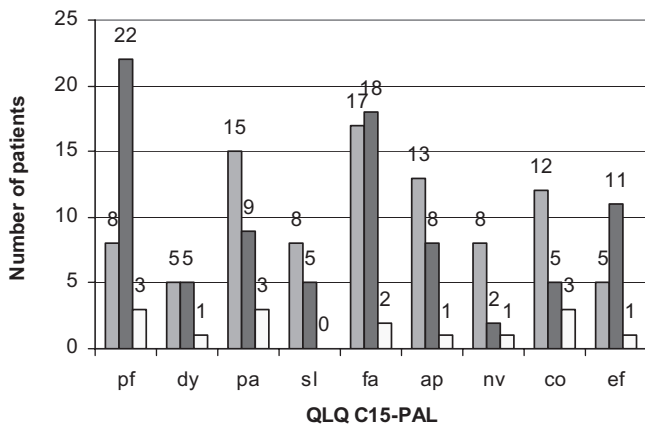
Figure 3 shows the changes of  $\geq 1$  point for patient-reported scores 3 and 4, measured by the original measurement scale. Here it can be seen that, for pain, 15 patients have reported an improvement, for appetite loss 13 patients and for constipation 12 patients reported an improvement.

### Concordance between patient-reported issues and health staff's intervention

Figure 4 illustrates the degree to which there was concordance between the problem areas that the patients



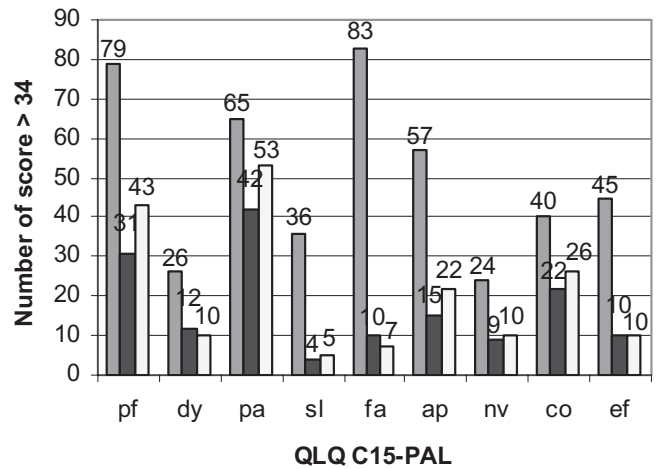
**Figure 2.** Rates of change in intensity category ( $n = 46$ ). ■, moved to <34; ■, moved to >34; □, unchanged. pf, physical functioning; dy, dyspnea; pa, pain; sl, sleeplessness; fa, fatigue; ap, appetite loss; nv, nausea/vomiting; co, constipation; ef, emotional function.



**Figure 3.** More than or equal to one point change in patient-reported score 3 or 4 ( $n = 46$ ). ■, improvement; ■, unchanged; □, aggravation. pf, physical functioning; dy, dyspnea; pa, pain; sl, sleeplessness; fa, fatigue; ap, appetite loss; nv, nausea/vomiting; co, constipation; ef, emotional function.

regarded as significant (scores  $\geq 34-100$ ) and which were the subject of intervention by the health staff (doctors and nurses). For both groups the intervention was most commonly taken in relation to physical function, pain, constipation and appetite loss and the fewest interventions took place in relation to fatigue, sleeplessness, nausea and stress and depression.

During the hospital stay other problems areas encountered by patients were addressed, which are not withheld in QLQ-C15-PAL, as 28 patients were treated for infection



**Figure 4.** Agreement between problem score 34-100 and doctors' and nurses' intervention ( $n = 97$ ). ■, Np; ■, DPI; □, NPI. Np, number of problem; DPI, doctor's problem intervention; NPI, nurse's problem intervention; pf, physical functioning; dy, dyspnea; pa, pain; sl, sleeplessness; fa, fatigue; ap, appetite loss; nv, nausea/vomiting; co, constipation; ef, emotional function.

during hospital stay, most often for pneumonia (11 patients) and infection of unknown source (8 patients).

### DISCUSSION

The aim of this study was to describe the incidence and intensity of advanced cancer patients' self-reported physical and mental problems on admission and discharge after more than 2 days' stay, and the concordance between these problems and health staffs intervention to address them. No other studies have been found that investigate patients' self-reported problems on admission and discharge from hospital wards that do not provide palliative specialist treatment.

The results show that the patients experience on average five and four problem areas on admission and discharge respectively, which are reported with an intensity score of 3 (quite a lot) or 4 (very much). The limited difference in relation to the number of problems and their intensity can relate to several factors, which must therefore be taken into account. The study population's average age was 72 and 66% of the patients also had a second chronic illness, which together with side effects of opioid and chemo treatment could mean that older cancer patients report more problem areas than younger patients, as is indicated in a national study (Johnsen *et al.* 2009). Furthermore, stress and depression can be natural consequences of the insecurity and lack of control, which for many patients is linked with having a progressive, life-threatening illness (Penrod 2007). Apart from the



individual illness and treatment-related conditions the patients were also affected by social conditions, such as insecurity about their housing situation or a seriously ill partner at home. Since physical and emotional problems interact, these factors can be significant to the patients' subjective assessment that the problem intensity is not or only to a small degree affected by an intervention during their hospital stay (Osoba 2007).

The altered average difference in the total score from admission to discharge in the intensity category <34 showed a significant aggravation of problems related to pain and sleep. However, there was a small change in patient reporting from score 1 (not at all) to 2 (a little). Sleeplessness can be linked to change of environment, which is of course a condition of admission, and the result is therefore not as surprising as when pain is reported as aggravated during a hospital stay. For the intensity category >34, a significant improvement can be seen for pain, sleep, fatigue, appetite loss, nausea and constipation of >20, which can be evaluated to be of moderate clinical relevance, cf. the interpretation scale in the score manual (Groenvold & Petersen 2006). This result does not reflect on the number of patients who reported an improvement. In the intensity category >34 the number of patients who reported (change of at least one point) improvement/unchanged or aggravation for pain was proportional 15/12, sleep 8/5, fatigue 17/20, appetite loss 13/9, nausea 8/3 and for constipation 12/8.

The level of achievement in terms of health staff's intervention in relation to the patients' problems was greatest for pain and constipation; nevertheless, 48% and 26% of the patients reported 'quite a bit' or 'very much' for these two problems on discharge. It is important to point out the patients' reduced physical functioning level as a risk factor in relation to constipation apart from morphine treatment. Furthermore, pain and constipation were indicated as reasons for admission in 26% and 12% respectively, of the patients in our study. Previous studies have shown that constipation is a common and important issue for both admitted and outpatient, palliative cancer patients, and only a third of patients are adequately treated for it (Potter *et al.* 2003; Droney *et al.* 2008). In Denmark constipation is one of the most common reasons for re-admission in non-cancer patients older than 67 years of age (Sundhedsstyrelsen 2009). A recent, broad European study has investigated the adequacy of treatment for constipation, nausea, depression and sleeplessness on oncology wards (including general wards) and the study's results indicate that 60% of the patients receive insufficient treatment for constipation, depression and sleeplessness (Laugsand *et al.* 2011). Insufficiency was judged on whether the patient had

received an intervention or whether, despite treatment, the patient still reported the problem as being moderate or very bad (Laugsand *et al.* 2011). An assessment of our results of the same three problem areas (depression in our study is one of two items in emotional function), based on the same interpretation shows that our results can carefully indicate the same tendency. We consider, however, that this is a simplified way of assessing sufficiency, since the method does not say anything about the decision-making process and the collaboration with the patient, nor to what extent the patient him/herself considers that the problem requires treatment. Our descriptions of the patients' problem profile support results from other studies that show that it should be possible to improve palliative services at home as well as in hospital (Stiel *et al.* 2009; Becker *et al.* 2011). The divergence in regard to pain and constipation can indicate a preventive potential that has not yet been fully exploited in basic palliative care (Schneider & Walter 2007).

The study's limitations are primarily related to dropout at the recruitment stage and after inclusion. Limitations in relation to sample size and 'lost to follow up' are not unusual, since the course of the illness in cancer patients in the palliative phase is progressive and unstable, which restricts the patients' ability and resources to participate and remain in the study (Fielding *et al.* 2006; Addington-Hall *et al.* 2007). On recruitment of patients the most commonly applied exclusion criteria related to length of stay <2 days ( $n = 69$ ), which was a necessary criterion due to the need for 'time to respond' to the questionnaire (a minimum of 24 h between the first and second completion of the questionnaire after the intervention was begun). We did not gather information about patient characteristics and problem profile for those on short hospital stays. It could involve patients who are not yet so progressed in their illness and who have a lighter problem profile, but it can also involve patients who have good support and help at home. Furthermore, 45 patients were not in a position to give informed consent and 31 with not wish to participate. One must therefore be very careful in generalising the results of the patient-reported problem profile on admission to a larger population. Dropout after inclusion was 52% ( $n = 51$ ) and these patients had a significantly worse physical and emotional function than those who completed the questionnaire on discharge. The reduction in the study population to  $n = 46$  patients weakens the statistical significance and the force of the result statements. The results of the patient-reported problem profile on discharge are probably under-reported, because the most ill patients did not complete the questionnaire on discharge.

A study based on data from patient questionnaires gives a subjective and momentary assessment of the patients' condition in relation to standardised questions, and the study does not say anything about the patient experience of continuity and the effect of the hospital stay for the individual patient. There is therefore a need for qualitative studies to describe the patient perspective of these issues. The patient's medical notes are a communication tool during hospital stay and give information on the professional treatments undertaken. In order to ensure valid and reliable results of a factual intervention, two variables were collected from the medical records and nursing records with a yes/no answer choice: (1) was the problem described only, or (2) was the problem described along with a prescription or treatment. We also chose to observe all the days of the stay, since a single day's monitoring gives only a random picture. The study does not offer knowledge about the content of the interventions nor their quality, nor

does it list all the professional health services that the patients received. Therefore, there is a need for descriptive studies that would take these factors into account.

There was significant improvement in the group of 'clinically relevant problems', but there is a need for further focus on potential improvements to palliative services on general wards, especially for pain and constipation which can prevent some hospital admissions.

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## REFERENCES

- Aaronson N.K., Ahmedzai S., Bergman B., Bullinger M., Cull A., Dues N.J., Fiberti A., Flechtner H., Fleishman S.B., de Haes J.C.J.M., Kaasa S., Klee M., Osoba D., Razavi D., Rofe P.B., Schraub S., Sneeuw K., Sullivan M. & Takeda F. (1993) The European Organization for Research and Treatment of Cancer QLO-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute* **85**, 365–376.
- Addington-Hall J.M., Bruera E., Higginson I.J. & Payne S., eds (2007) *Research Methods in Palliative Care*. Oxford University Press, New York, USA.
- Ahmedzai S.H., Costa A., Blengini C., Bosch A., Sanz-Ortiz J., Ventafridda V., Verhagen S.C. & International working group convened by the European School of Oncology (2004) A new international framework for palliative care. *European Journal of Cancer* **40**, 2192–2200.
- Anderson F.G., Downing M., Hill J., Casorso L. & Lerch N. (1996) Palliative Performance Scale (PPS): a new tool. *Journal of Palliative Care* **12**, 5–11.
- Becker G., Hatami I., Xander C., Dwarschak-Flach B., Olschewski M., Momm F., Dreibert P., Higginson I.J. & Blum H.E. (2011) Palliative cancer care: an epidemiologic study. *Journal of Clinical Oncology* **29**, 646–650.
- Centeno C., Clark D., Lynch T., Rocafort J., Praille D., Lima L.D., Greenwood A., Flores L.A., Brasch S. & Giordan A. (2007) Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC Task Force. *Palliative Medicine* **21**, 463–471.
- Doorenbos A.Z., Given C.W., Given B. & Verbitsky N. (2006) Symptom experience in the last year of life among individuals with cancer. *Journal of Pain and Symptom Management* **32**, 403–412.
- Dronney J., Ross J., Gretton S., Welsh K., Sato H. & Riley J. (2008) Constipation in cancer patients on morphine. *Supportive Care in Cancer* **16**, 453–459.
- European Organisation for Research and Treatment of Cancer (EORTC) *Translation*. Available at: <http://groups.eortc.be/qol/translations.htm> [accessed 28 April 2011].
- Fielding S., Fayers P.M., Loge J.H., Jordhøy M.S. & Kaasa S. (2006) Methods for handling missing data in palliative care research. *Palliative Medicine* **20**, 791–798.
- Groenvold M. & Petersen M.A. (2006) Addendum to the EORTC QLQ-C30 Scoring Manual: Scoring of the EORTC QLQ-C15-PAL. EORTC Quality of Life Group.
- Groenvold M., Klee M.C., Sprangers M.A.G. & Aaronson N.K. (1997) Validation of the EORTC QLQ-C30. Quality of life questionnaire through combined qualitative and quantitative assessment of patient-observer agreement. *Journal of Clinical Epidemiology* **50**, 441–450.
- Groenvold M., Petersen M.A., Aaronson N.K., Arraras J.I., Blazeby J.M., Bottomley A., Fayers P.M., de Graeff A., Hammerlid E., Kaasa S., Sprangers M.A.G. & Bjorner J.B. (2006a) EORTC QLQ-C15-PAL: the new standard in the assessment of health-related quality of life in advanced cancer? *Palliative Medicine* **20**, 59–61.
- Groenvold M., Petersen M.A., Aaronson N.K., Arraras J.I., Blazeby J.M., Bottomley A., Fayers P.M., de Graeff A., Hammerlid E., Kaasa S., Sprangers M.A.G. & Bjorner J.B. (2006b) The development of the EORTC QLQ-C15-PAL: a shortened questionnaire for cancer patients in palliative care. *European Journal of Cancer* **42**, 55–64.
- Haggerty J.L., Reid R.J., Freeman G.K., Starfield B.H., Adair C.E. & McKendry R. (2003) Continuity of care: a multidisciplinary review. *British Medical Journal (Clinical Research Ed.)* **327**, 1219–1221.
- Hjermstad M.J., Fossa S.D., Bjordal K. & Kaasa S. (1995) Test/retest study of the European Organisation for Research and Treatment of Cancer Core Quality-of-Life Questionnaire. *Journal of Clinical Oncology* **13**, 1249–1254.
- Horton R. (2002) Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. *Palliative Medicine* **16**, 488–494.
- Johnsen A.T. (2008) *Palliative needs in Danish patients with advanced cancer*. PhD. Thesis. The Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark.
- Johnsen A.T., Petersen M.A., Pedersen L. & Groenvold M. (2009) Symptoms and problems in a nationally representative sample of advanced cancer patients. *Palliative Medicine* **23**, 491–501.

- Kaasa S., Bjordal K., Aaronson N., Moun T., Wist E., Hagen S. & Kvikstad A. (1995) The EORTC Core Quality of Life Questionnaire (QLQ-C30): validity and reliability when analysed with patients treated with palliative radiotherapy. *European Journal of Cancer* **31A**, 2260–2263.
- Laugsand E.A., Jakobsen G., Kaasa S. & Klepsta P. (2011) Inadequate symptom control in advanced cancer patients across Europe. *Supportive Care in Cancer* **19**, 2005–2014.
- Murray S.A., Kendall M., Boyd K. & Sheikh A. (2005) Illness trajectories and palliative care. *British Medical Journal* **330**, 1007–1011.
- Nekolaichuk C.L., Bruera E., Spachynski K., MscEachern T., Hanson J. & Maquire T.O. (1999) A comparison of patient and proxy symptom assessments in advanced cancer patients. *Palliative Medicine* **13**, 311–323.
- Osoba D. (2007) Translating the science of patient-reported outcomes assessment into clinical practice. *Journal of the National Cancer Institute. Monographs* **37**, 5–11.
- Osoba D., Zee B., Pater J., Warr D., Kaizer L. & Latreille J. (1994) Psychometric properties and responsiveness of the EORTC Quality of Life Questionnaire (QLQ-C30) in patients with breast, ovarian and lung cancer. *Quality of Life Research* **3**, 353–364.
- Penrod J. (2007) Living with uncertainty: concept advancement. *Journal of Advanced Nursing* **57**, 658–667.
- Petersen M.A., Groenvold M., Aaronson N., Blazeby J., Brandberg Y., de Graeff A., Fayers P., Hammerlid E., Sprangers M., Velikova G. & Bjorner J.B. (2006) Item response was used to shorten EORTC QLQ-C30 scales for use in palliative care. *Journal of Clinical Epidemiology* **59**, 36–44.
- Potter J., Hami F., Bryan T. & Quigley C. (2003) Symptoms in 400 patients referred to palliative care service: prevalence and patterns. *Palliative Medicine* **17**, 310–314.
- Radbruch L., Payne S. & EAPC Board of Directors (2010) White Paper on Standards and norms for hospice and palliative care in Europe: part 2. *European Journal of Palliative Care* **17**, 22–33.
- Rydahl-Hansen S. (2005) Hospitalized patients experienced suffering in life with incurable cancer. *Scandinavian Journal of Caring Sciences* **19**, 213–222.
- Rydahl-Hansen S. (2009) Suffering – as expressed in nursing diagnosis within palliative care [Danish]. *Nordic Journal of Nursing Research and Clinical Studies/Vård i Norden* **29**, 4–8.
- Schneider N. & Walter U. (2007) Where do prevention and palliative care meet? A systematic literature study on the interfaces of two different health care sectors. *The American Journal of Hospice and Palliative Care* **24**, 114–118.
- Schneider N., Dreier M., Amelung V.E. & Buser K. (2007) Hospital stay frequency and duration of patients with advanced cancer diseases – differences between the most frequent tumour diagnosis: a secondary data analysis. *European Journal of Cancer Care* **16**, 172–177.
- Stiel S., Joppich R., Korb K., Hahnen M., Elsner F., Rossaint R. & Radbruch L. (2009) Problems and deficits in the transition from inpatient and outpatient care of cancer patients. A qualitative analysis. *Schmerz (Berlin, Germany)* **23**, 510–517.
- Streiner L.D. & Norman G.R. (2003) *Health Measurement Scales – A Practical Guide to Their Development and Use*. Oxford University Press, New York, USA.
- Stromgren A.S., Groenvold M., Pedersen L., Olsen A.K., Spile M. & Sjogren P. (2001a) Does the medical record cover the symptoms experienced by cancer patients receiving palliative care? A comparison of the record and patient self-rating. *Journal of Pain and Symptom Management* **21**, 189–196.
- Stromgren A.S., Groenvold M., Sorensen A. & Andersen L. (2001b) Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating. *Acta Anaesthesiologica Scandinavica* **45**, 1080–1085.
- Suárez-del-Real Y., Allende-Pérez S., Alférez-Mancera A., Rodríguez R.B., Jiménez-Toxtle S., Mohar A. & Onate-Ocana L.F. (2011) Validation of the Mexican-Spanish version of the EORTC QLQ-C15-PAL questionnaire for the evaluation of health-related quality of life in patients on palliative care. *Psycho-oncology* **20**, 889–896.
- Sundhedsstyrelsen (2009) Genindlæggelser af ældre i Danmark 2008. Nye tal fra Sundhedsstyrelsen. [Readmission of older people in Denmark 2008. The national Board of Health].
- Weaver C., Schiech L., Held-Warmkessel J., Kedziera P., Haney E., DiLullo G., Babb J.S., Ruth K., Dell D. & Barsevick A. (2006) Risk for unplanned hospital readmission of patients with cancer: results of a retrospective medical record review. *Oncology Nursing Forum* **33**, 44–52.
- WHO (2002) *National Cancer Programmes. Policies and Managerial Guidelines*, 2nd edn. World Health Organization, Geneva, Switzerland.
- WHO (2004) *The Solid Facts. Palliative Care*. World Health Organization, Copenhagen Ø, Denmark.
- World Medical Association (1964) *Declaration of Helsinki. Ethical Principles for Medical Research Involving Human Subjects*. WMA General Assembly, Helsinki, Finland.