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A new model of early, integrated palliative care: palliative rehabilitation for newly diagnosed patients with non-resectable cancer

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Abstract

Purpose: The aim of this paper is to describe a model of palliative rehabilitation for newly diagnosed advanced cancer patients and present data on how it was utilized during a randomized controlled trial (RCT).

Methods: We designed a highly flexible, multidisciplinary model of palliative rehabilitation consisting of a "basic offer" and tailored elements. The model was evaluated in the setting on an RCT investigating the effect of systematic referral to a palliative rehabilitation clinic concurrently with standard oncology treatment or standard treatment alone. The "basic offer" of palliative rehabilitation was two consultations and a 12-week possibility of contacting a palliative rehabilitation team, if needed. In addition, patients and family caregivers could be offered participation in a 12-week patient/caregiver school combined with individually tailored physical exercise in groups, individual consultations, or both. Contacts with the palliative rehabilitation team and participant evaluation were registered prospectively.

Results: Between December 2014 and December 2017, 132 adults with newly diagnosed advanced cancer were seen in the palliative rehabilitation outpatient clinic. Twenty percent of the participants received the "basic offer" only (n=26), 45% additionally participated in the group program (n=59), and 35% received supplementary individual consultations without participating in the group program (n=47). The intervention was primarily led by nurses and the main themes of the individual consultations were coping, pain, and nutrition. When asked if they would recommend the intervention to others in the same situation, 93% of the respondents agreed, 7% partly agreed, and no one disagreed.

Conclusion: The new model of palliative rehabilitation presented here had a flexibility to meet the needs of the participants and led to a very high degree of patient satisfaction. It could serve as an inspiration to other cancer centers wanting to integrate palliative care into standard oncology services.

Keywords (4-6): Palliative Care, Rehabilitation, Quality of Life, Neoplasms, Models of Care, Patient SatisfactionTrial registration: Clinicaltrials.gov Identifier: NCT02332317

Introduction

A new clinic offering palliative rehabilitation was opened as a branch under the existing specialized palliative care (SPC) team at Vejle Hospital, Denmark, in 2013. The goal was to offer early palliative care in an outpatient setting to patients with advanced cancer undergoing active anticancer treatment and include elements of rehabilitation. It was decided to test the new service in a randomized clinical trial (RCT).

Early palliative care

Palliative care is often misconstrued as end-of-life care only [1].

In 2012 the American Society of Clinical Oncology published the first provisional clinical opinion (PCO) [1] about the integration of palliative care services into standard oncology practice at the time a person is diagnosed with metastatic or advanced cancer. Seven published randomized, controlled trials formed the evidence base, three of which were in the outpatient setting [2–4]. The PCO stated that early palliative care leads to better patient and caregiver outcomes including but not limited to improvement in symptoms, quality of life, patient satisfaction, and a reduced caregiver burden. Although integration of palliative care early in the cancer care continuum is now supported by health and cancer organisations worldwide [5–7], it has still not been widely implemented [8].

Palliative rehabilitation

Palliative care and rehabilitation professionals are trained to diagnose and treat complex problems through multidisciplinary interventions with the goal of improving quality of life. Rehabilitation services are underutilized among people with advanced cancer [9] even though maintenance of functional independence is central to quality of life and rehabilitation services tend to be most effective when initiated before the cancer related functional loss is too severe [10].

In 2017 Cheville et al. described the integration of function-directed treatments into palliative care and suggested the following definition of palliative rehabilitation; "A function-directed care delivered in partnership with other disciplines and aligned with the values of patients who have serious and often incurable illnesses in context marked by intense and dynamic symptoms, psychological stress, and medical morbidity, to realize potentially time-limited goals" [10].

Only few studies have investigated multidisciplinary, individually tailored and quality of life-directed interventions integrated in standard oncology care for advanced cancer patients and to the best of our knowledge no models of

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palliative rehabilitation for patients with newly diagnosed advanced cancers have yet been published. One of the reasons behind the underutilization of early palliative care and rehabilitation in these patients could be the lack of well described and tested models of delivery.

Aim

The aim of this paper is to describe a model of palliative rehabilitation for newly diagnosed, advanced cancer patients and present data on how it was utilized during an RCT.

Methods

Preparation and test phase

The development and testing of the model were based on the British Medical Research Council Guidance for the Development and Evaluation of Complex Interventions [11] (Figure 1).

[Insert Figure 1]

We identified the evidence base by reviewing the literature on early palliative care, palliative day-care services, and rehabilitation services for advanced cancer patients in November of 2013. The literature and the clinical experience in the specialised palliative care team from working with advanced cancer patients and their families formed the basis of the new outpatient service to be tested in the setting of an RCT. The aim of the RCT was to investigate the effect of systematic referral to a palliative rehabilitation clinic concurrently with standard oncology treatment versus standard care alone for newly diagnosed advanced cancer patients. During the first year of service, while the RCT was under preparation, procedures in the palliative rehabilitation outpatient clinic were tested with patients receiving chemotherapy who were referred to the specialised palliative care team. They were offered palliative rehabilitation in the outpatient clinic and the model was subject to ongoing adjustments based on feedback by patients, caregivers, and staff before enrolment in the study began. The main element of the new offer was designed as a group program based on two components; a patient/caregiver school and individually tailored physical exercise in groups. Feedback from patients and caregivers was collected through semi-structured interviews performed approximately 12 weeks after the initial consultation or when the patient was discharged from the palliative rehabilitation clinic, whichever came first (data not presented). A topic guide for the semi-structured interviews included the patients' and caregivers' thoughts on being referred to and participating in a palliative rehabilitation program and their suggestions for future alterations to

the offer. If they had participated in the group program they were further asked about the frequency and duration of the group program, the relevance of the topics in the school sessions and the elements of the exercise program, and the strengths and limitations of a group setting. The contents and organisation of the offer were discussed at monthly staff meetings. The study protocol was thoroughly discussed with the hospital's Patient and Relatives Council.

The palliative rehabilitation outpatient model

The final and highly flexible model consisted of a "basic offer" and tailored elements (Figure 2).

[insert Figure 2]

The "basic offer" was two mandatory consultations and the option of contacting a palliative rehabilitation team directly during the participation period of 12 weeks, if needed. The two consultations were an initial one-hour consultation with a physician and nurse specialised in palliative care and a 40 minute follow-up consultation with a nurse after 6-7 weeks. In addition, patients and family caregivers could be offered participation in a 12-week patient/caregiver school combined with individually tailored physical exercise in groups, individual consultations with members of the palliative rehabilitation team, or both. At the end of the first consultation the patient and family caregivers were given the team's contact information and the name of a contact nurse and physician.

The palliative rehabilitation team

The usual specialised palliative care team counting physicians, nurses, physiotherapists, and psychologists was enhanced by engaging a part time social worker, dietician, occupational therapist, and chaplain from other clinical departments at the hospital, all experienced in dealing with cancer patients. Except for the chaplain all team members offered individual consultations to patients and family caregivers in the palliative rehabilitation clinic or over the telephone. The team assembled for weekly multidisciplinary conferences discussing each patient at least once.

The initial consultation

A template was developed for the initial consultation with a specialised palliative care physician and nurse drawing on inspiration from the template used during an earlier trial on the early integration of palliative care by Temel et al. [4]. The consultation would address symptoms, mood, barriers to activities of daily living (ADL), illness and prognostic understanding, thoughts and goals for the future, a map of the patient's family and network, coping mechanisms, and individual needs of the family caregiver(s). If found relevant based on specific symptoms, a focused physical

examination was performed. A plan was made for the next approximately 12 weeks in collaboration with the patient and family caregivers, documented in the electronic patient record, and a copy sent to the patient's general practitioner.

The group program

If patients and family caregivers were eligible for the group intervention, they were offered participation in a 12-week group program with weekly meetings. Groups were formed by consecutive patients and family caregivers. Main exclusion criteria were statements of discomfort from the patients about participating in a group setting or indications of personal crisis, where an individually tailored intervention was deemed more appropriate. The program consisted of a patient/caregiver school with educational sessions followed by individually tailored physical exercise in groups for patients only. The educational sessions lasted approximately one hour initiating with a 20-minute lecture and 40 minutes for questions, debate, and exchange of personal experience. The topics of the educational program can be seen in Table 1.

[insert Table 1]

Written material on the weekly topic was handed out after each session in a personal folder for the patient to take home. After the educational session a 30-minute break gave the participants the possibility to relate more informally to each other before the one-hour exercise program led by a physiotherapist. The exercise program would combine aerobic exercises on treadmills, steppers, and cross trainers with dynamic muscle strengthening exercises using weight-lifting machines, elastic bands, or the patients' own weight, as applicable. Two parallel groups were established, each with a maximum of 10 participants. A facilitating nurse attended the group each time and offered individual consultations immediately after the group session or arranged consultations with other members of the palliative rehabilitation team, if needed.

Before entering the group program the patient met with a physiotherapist who introduced the program, tested the patient's performance level, set a shared and realistic goal for the 12-week intervention, and, if relevant, made instructions for supplementary home exercises. The performance tests applied were; six-minute walk, hand grip strength measurement, and sit-to-stand ability [12–14]. At the end of the 12-week program a final, individual evaluation with the facilitating nurse and physiotherapist was offered. The physical performance tests were repeated and the patients advised individually on how to maintain the obtained results. A summary of the intervention and future directions was documented in the electronic patient record and sent to the patient's general practitioner.

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Setting

The specialised palliative care team is organised under the Department of Oncology, Vejle Hospital. The team has 15 years of experience in treating patients with life threatening illnesses and their caregivers, predominately as home based specialised palliative care and in the late phases of the disease.

In connection with the establishment of the palliative rehabilitation outpatient clinic the team moved to new facilities adjacent to the hospital with outpatient consultation rooms, group rooms, lounge areas and physical exercise facilities. All members of the team received three days of formal training before the new clinic was established; a one day course by a Danish PhD in Health Education teaching about group dynamics and the facilitator role in health services and a two day visit from researchers and palliative rehabilitation clinicians Gail Eva and Cathy Payne from the British and Irish Health Systems, respectively. Two nurses were appointed to have a facilitating role in the group program.

Patients

Patients diagnosed with non-resectable solid cancer for the first time within eight weeks of randomization who were receiving standard oncology treatment were eligible for participation in the RCT. Details on study design and eligibility criteria have previously been reported [15].

Data collection

Before randomization baseline characteristics were registered and patients were asked to select the "primary problem" they needed help with from a list of 12 possible problems corresponding to scales in the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30). EORTC QLQ-C30 consists of 15 scales and is an extensively validated and widely used questionnaire for assessing symptoms and quality of life in cancer patients [16]. A 13th option on the list was "none of the above". Diarrhoea, financial difficulties and global health status/ quality of life were not included as possible "primary problems".

All contacts with the palliative rehabilitation team, including individual consultations with family caregivers, were registered prospectively. The themes of the individual supplementary contacts were categorized by means of a retrospective review of the patient records. One main theme was chosen to represent each contact. Twelve weeks after enrolment patients were given an evaluation form asking if they agreed, partly agreed or disagreed with the statements "The intervention made a positive difference to me" and "I would recommend the intervention to others in a situation

like mine". The evaluation form for participants in the group program also included the following statements; "It was a positive experience to spend time with others in the same situation" and "The physical exercise program improved my wellbeing".

Data analyses

Descriptive statistics were applied and included median and range of continuous variables, and number and percentage of categorical ones. All data analyses were performed using the statistical package, STATA, version 14 (StataCorp 2015, Texas, USA).

Results

Between December 2014 and December 2017, 132 adults with newly diagnosed advanced cancer were seen in the palliative rehabilitation outpatient clinic after enrolment in the RCT. Baseline characteristics and "primary problems" selected by the participants appear from Table 2.

[insert Table 2]

After the initial consultation participants were distributed as follows: 20% received the two mandatory consultations only (n=26), 45% additionally participated in the group program (n=59), and 35% received supplementary individual consultations without participating in the group program (n=47).

The contents of the offer divided by "primary problem" as selected by the patient at baseline can be seen in Table 3.

[insert Table 3]

Of the 59 patients who entered the group program 83% (n=49) had one or more supplementary individual consultations. Patients in the group program participated in an average of 10 of the 12 planned weekly sessions (median=10, range 1-13) and had an average of five individual non-mandatory supplementary contacts (median=5, range 0-21). Patients receiving supplementary individual consultations without participating in the group program had an average of 3 non-mandatory contacts (median=2, range 1-18).

Apart from the planned individual elements (i.e. the two mandatory consultations in the "basic offer" and the introduction and test by a physiotherapist for participants in the group program) patients received 411 individual consultations. The distribution and themes of these consultations can be seen in Figure 3.

[insert Figure 3]

Family caregivers

Half of the participants brought one or more family caregivers to the initial consultation (n=67) and half of the participants in the group program brought a family caregiver to the weekly sessions (n=29).

Individual consultations with family caregivers consisted of ambulatory solo consultations with a psychologist (n=18), ambulatory consultations (n=3) and telephone consultations (n=9) with a nurse about coping, and telephone consultations with a social worker (n=9).

Coordination of care

Part of the intervention was the coordination of care with other healthcare professionals and institutions. The specialised palliative care physicians referred a patient to another hospital department or to the general practitioner due to unmanaged co-morbidity 16 times during the study. Other types of coordinated care were the establishment of community based occupational therapy (n=8), community based home nursing (n=7), community based physiotherapy (n=5), and social worker contact to the patient's municipal authorities (n=4).

Participant evaluation

Twelve weeks after enrolment, 122 of the 132 participants were eligible for evaluation (four died before 12 weeks, one withdrew consent, and five were not given the evaluation form, because the staff considered it inappropriate in the situation). The evaluation form was completed by 80% of the eligible participants (n=97) of which 80% (n=78) agreed that the intervention had made a positive difference, 15% (n=15) partly agreed, and 4% (n=4) disagreed. When asked, if they would recommend the intervention to others in the same situation 93% (n=90) agreed, 7% (n=7) partly agreed, and no one disagreed.

For participants in the group program 82% (n=46) of the respondents agreed that it had been positive to spend time with others in the same situation, 17% (n=9) partly agreed, and 1% (n=1) disagreed. When asked if the physical exercise program had improved their well-being 88% (n=49) agreed, 9% (n=5) partly agreed, no one disagreed, and two did not answer the question.

Termination or continuation of care

The intervention was designed to be time-limited and ultimately 84% of the participants (n=111) were discharged from the palliative rehabilitation clinic after having received the planned intervention. The average time from first to last contact with the team was 76 days (median 70, range 3-196).

On the other hand, 17 participants (13%) were evaluated to still need specialised palliative care and were either referred to the team's home based palliative care function (n=11), their local specialised palliative care team (n=4), or admitted to a hospice (n=2).

Discussion

This paper presents a flexible model of multidisciplinary, integrated palliative rehabilitation to patients and their family caregivers early in the course of advanced cancer treatment combining a group program and individual consultations. The model was designed to match the needs of individual patients and caregivers and is presented in detail together with an analysis of its utilization during an RCT and how it was received by the patients.

In this cohort of newly diagnosed advanced cancer patients 20% did not need palliative rehabilitation in excess of the basic offer of two mandatory consultations. The largest group of 45% additionally entered the group program with the majority receiving one or more supplementary individual consultations (83%). Finally, 35% of the participants received supplementary individual consultations without entering the group program.

The patients were expected to have conflicting schedules due to anticancer treatment, comorbidity, and possible deterioration potentially making weekly attendance in a group program difficult. At the same time a group offer had obvious administrative benefits in addition to the possibility for the participants to form relationships with the staff and other people in a situation like their own. This was high-lighted as the main outcome of a 2005 review of British specialist palliative day-care offers [17]. In the present study the participants also found it beneficial to spend time with others in the same situation. During the test and preparation phase it was a focal point of the participants that the educational session would not last too long allowing sufficient time for questions, debate and the exchange of personal experiences. Thus, the initial 45 minutes of lecture was ultimately cut down by more than half to 20 minutes, leaving 40 minutes for the less formal part of the one-hour session. Ground rules for the debates were secured by information to all participants about discretion and absolute confidentiality.

The groups were mixed in terms of diagnoses, "primary problems" and other potentially predictive variables. The first group program tested during the preparation phase assigned the patients to different groups depending on their main

problem (e.g. fatigue group, cognitive impairment group, dyspnea group etc.) However, the participants and staff found this division to be artificial and noted that the problems, symptoms, and worries presented by the patients and caregivers were more universal than first assumed. Also, the participants did not mind that not all subjects in the group educational program were of equal relevance in their present situation. On the contrary it was evaluated as one of the strengths of the program that participants were given pieces of information that provided them with more knowledge of potential future complications and where to seek more information and help at a later stage in their disease trajectory, if relevant, - thereby enhancing the self-efficacy of patients and family caregivers. The attendance in the group program was high with a median of 10 out of the 12 planned weekly meetings.

Patients participating in the group program had more individual contacts than participants receiving supplementary consultations without participating in the group program. This finding does not necessarily reflect a greater need for individual consultations among the group program participants but maybe rather that the relationship building of patients and caregivers with healthcare professionals is an important mechanism in palliative care [18]. Hence, participation in the group program itself may have led to a higher identification of needs.

When patients were asked before randomization what they needed help with the most, the largest group did not choose any of the 12 possible "primary problems" but instead the 13th option "none of the above" (25%) (Table 2). Other large groups were participants selecting emotional function (12%) and pain (11%) as their primary problem. However, 64% of the patients who indicated at baseline that they did not need help with any of the possible "primary problems" ultimately received more than the "basic offer" - either as part of the group program or as supplementary individual consultations (Table 3). Of the patients who selected a specific "primary problem" 12% had no need for palliative rehabilitation other than the two mandatory consultations. This suggests that if the initiation of an intervention is based solely on a patient's perception of needs, an important point may be missed; namely that the true establishment of a need may occur in the meeting of patient values and preferences with health care professionals' assessments and knowledge of potentially beneficial and accessible interventions. Also, irrespective of the patient's perceived needs, many family caregivers have unmet needs and would like more information, preparation, and support to assist them in the caregiving role [19]. This supports the design of the study with highly individualized interventions only fully determined after the patient and caregivers had met the palliative rehabilitation team.

Unfortunately, in this cohort only around half of the participants brought a family caregiver to the palliative rehabilitation clinic, which means that the full potential of the support offer to the caregivers was probably not met.

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Nurses were the responsible health care professionals in the majority of individual consultations (55%) and 70% of the consultations were either conducted over the telephone or in connection with participation in the group program keeping the use of resources low (Figure 3).

No individual consultations with an occupational therapist (OT) took place during the study. This is probably due to the fact that the team's physiotherapists manage many of the tasks that could be provided by OTs, e.g. guiding in ADL and instructing in the use of assistive devices. Additionally, the specialised palliative care physiotherapists refer the patients to community based occupational therapy if a need for ongoing support is identified. This happened eight times during the study.

In this cohort 13% of the patients were re-directed to hospice or home based specialised palliative care. Early palliative care is not generally implemented in healthcare [8] and this is also true in a Danish context with the median survival time after referral to specialised palliative care in 2016 being 39 days [20]. The model presented here efficiently identified the patients in need of ongoing specialised palliative care already at the onset of their disease.

Some limitations of the investigation must be noted. The study population was based on participants of an RCT and generalization of the results should be considered in that light. The participants were relatively well-educated, not living alone, and in good performance status, which may lead to "healthy volunteer bias", a well-known challenge in palliative care trials [21].

Themes of the individual contacts were established retrospectively by reviewing patient records. It might have been more accurate to give team members a checklist for registration immediately after the contact as was done in a newly published evaluation of the elements of an American early palliative care intervention by Hoerger et al. [22]. However, the finding in our study that pain management and coping (22% and 18%, respectively) were the main themes of the individual consultations is consistent with the findings of Hoerger et al.

A third major theme in this study was nutrition, which accounted for 17% of the individual consultations. This finding emphasizes the relevance of including the expertise of dieticians in quality of life-directed interventions for newly diagnosed, advanced cancer patients.

Conclusion

In conclusion, the flexibility of the palliative rehabilitation model presented here allowed for consideration of the needs of individual patients and caregivers. In this cohort of newly diagnosed, advanced cancer patients the use of resources was relatively low and the patient satisfaction was very high. The main themes of the individual consultations were pain management, coping, and nutrition. Patients who entered the group program had a high degree of adherence.

Long term follow-up, comparison of clinical outcomes between patients enrolled in this model and patients in standard care as well as an economic evaluation will be reported later when mature data from the RCT are available.

This new model of palliative rehabilitation could serve as an inspiration to other cancer centers wanting to integrate palliative care into standard oncology services early in the disease trajectory of advanced cancer.

Compliance with Ethical Standards

The authors declare no conflicts of interest.

All procedures performed in this study were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki declaration and its later amendments. Informed consent was obtained from all individual participants included in the study.

The study protocol, including all written material intended for study participants, was approved by The Regional Committees on Health Research Ethics for Southern Denmark on April 2nd, 2014 (Project ID S-20140038).

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Table 1. Contents of the group education	ational program for pa	tients and family caregivers.
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Торіс	Responsible healthcare professionals		
•	x x		
Body and movement	Physiotherapist and facilitating nurse		
Sleep and tiredness	Two nurses (one being the facilitating nurse)		
Breathlessness	Physiotherapist and facilitating nurse		
Fatigue	Occupational therapist and facilitating nurse		
Nutrition	Dietician and facilitating nurse		
Coping with the patient role	Psychologist and facilitating nurse		
Open session	Physician and facilitating nurse		
Coping with the caregiver role	Psychologist and facilitating nurse		
When life hurts	Hospital chaplain and facilitating nurse		
Financial and social issues	Social worker and facilitating nurse		
Open session	Psychologist and facilitating nurse		
Rest and relaxation	Physiotherapist and facilitating nurse		

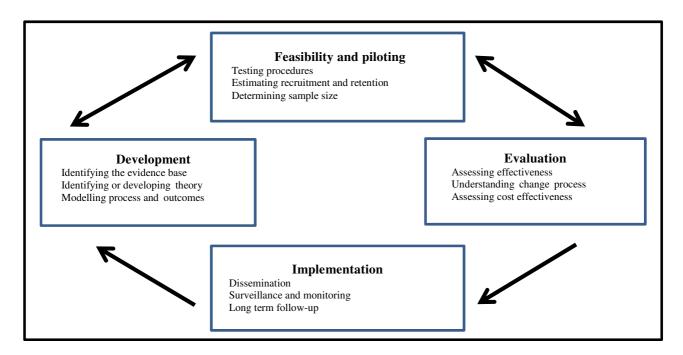
Characteristics	Patient (N=132
Mean age, years (SD)	66 (9)
Age group, N (%)	
18-59	27 (20)
60+	105 (80
Sex, male, N (%)	77 (58
Education, \leq 13 years, N (%)	84 (65)
Married or partnered, N (%)	93 (70
Cancer type, N (%)	
NSCLC	36 (27
SCLC	16 (12
Breast cancer	11 (8)
Colorectal cancer	35 (27
Prostate cancer	24 (18
Gynaecological cancer	4 (3)
Other	6 (5)
Intention of oncology treatment, N (%)	
Potentially curative	23 (17
Non-curative	109 (83
ECOG performance status, N (%)	
0	52 (39
1	65 (49
2	15 (11
Primary problem chosen by patient, N (%)	
Physical function	10 (8)
Role function	11 (8)
Emotional function	15 (12
Cognitive function	4 (3)
Social function	1 (1)
Fatigue	11 (8)
Nausea and vomiting	4 (3)
Pain	14 (11)
Dyspnoea	10 (8)
Insomnia	11 (8)
Appetite loss	5 (4)
Constipation	1 (1)
None of the above	33 (25)
Missing value	2 (-)
The sum of percentages may not reach 100 becaus NSCLC, Non-small cell lung cancer; SCLC, Small Eastern Cooperative Oncology Group; SD, standar	e of rounding. Abbreviations: l cell lung cancer; ECOG,

		Intervention recei	ived	- Total N
-	"Basic offer" only. N	Group program (with or without individual contacts).		
		Ν		
A specific "primary problem" chosen* - total.	12	51	34	97
Physical function	2	5	3	10
Role function	1	6	4	11
Emotional function	3	8	4	15
Fatigue	1	8	2	11
Digestive symptoms** (appetite loss, nausea and vomiting, and constipation)	0	5	5	10
Pain	1	6	7	14
Dyspnoea	2	5	3	10
Insomnia	1	7	3	11
Other ** (social function and cognitive function)	1	1	3	5
"None of the above" chosen as primary problem.	12	8	13	33
Missing value for "primary problem"	2	-	-	2
Total N (%)	26 (20)	59 (45)	47 (35)	132 (100)

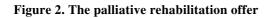
Table 3. The intervention received divided by "primary problems" chosen by patients at baseline.

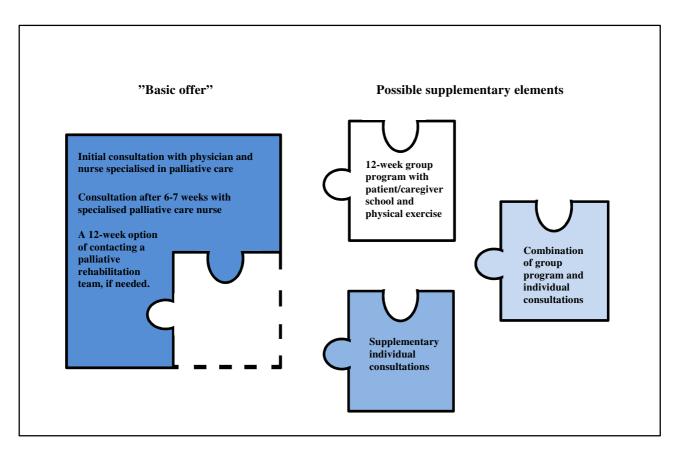
**"primary problems" combined due to few observations

Figure 1. Key elements of the development and evaluation process.

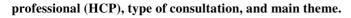


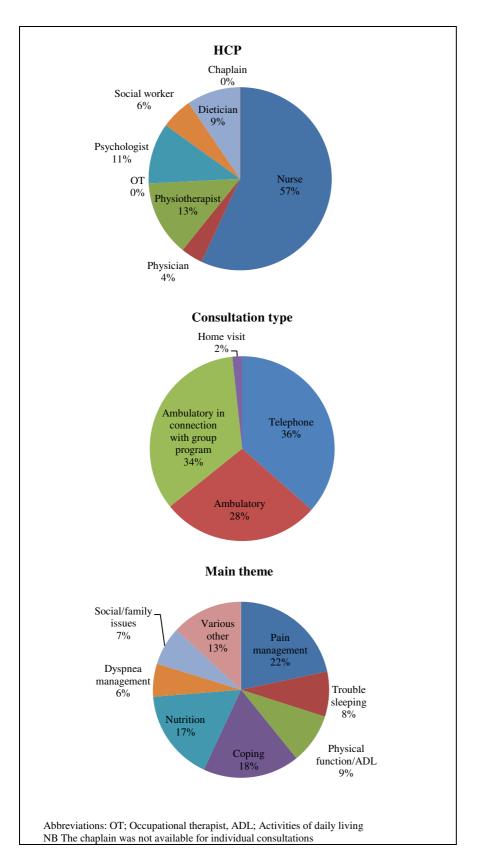
Source: The Medical Research Council 'Developing and evaluating complex interventions: new guidance', 2008. Reprinted with permission.





 $Figure \ 3. \ Supplementary, individual \ patient \ consultations \ (N=411) \ distributed \ by \ responsible \ health care$





Supportive Care in Cancer