The Task Permanent Point of Contact in a Care Pathway for Patients with Oesophagus and Pancreas Cancer

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Status: final Date: July 2012

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Journal intended: Lancet Oncology

Reference style: Vancouver

Number of words: 3479

Number of words Dutch summary: 307 Number of words English summary: 278

BACKGROUND

In the Netherlands the combined incidence of oesophagus and pancreas cancer is over 4500. This number has grown since 2000 with over 40%.(1)

The treatment of oesophagus and pancreas cancer is known as a complex process. Due to the involvement of several professionals (physicians, nurses) of different departments (oncology, surgery) the tuning of care and care transition is not always faultless, causing a risk for the continuity of care. (2) Therefore the University Medical Centre Utrecht (UMC Utrecht) designed care pathways for the treatment of both types of cancer. A care pathway is a complex intervention for the mutual decision making and organizing of care processes for a well-defined group of patients during a well-defined period (3). In a care pathway of oesophagus and pancreas cancer several professionals with different specialities from several departments work together providing care and treatment to one patient. (4) Complex processes have a risk on discontinuity of care or gaps (4), which have been proven to have a negative influence on patient outcomes (5).

In 2009 the Dutch Inspection of Healthcare (IGZ) stated that there is a lack of coordination in the cancer care process and recommended cancer care to be improved on the following points: 1) patients should have a single point of contact, who is clearly identifiable from the patient file; 2) there should be one person in the pathway with an overall view over the treatment process and the authority to adjust that process (6). Despite the care pathways, there are gaps in the care for patient with cancer in the UMC Utrecht, and patient transfers between professionals and/or departments of the organisation are not yet guarded structurally (7). To improve continuity of care and to meet the improvement points of the IGZ, the hospital introduced the task permanent point of contact (PPC) in the cancer care pathway as a pilot in May 2011. Each cancer patient was assigned to one PPC, which has two sub tasks. Firstly, for the patients and their families the PPC is the first person to address their questions to about the process of care (8). Research has shown that patients and health care workers (HCW's) see several benefits of having such a person (9,10). Patients feel more supported throughout their illness, and patients and HCW's are confident knowing that there is someone to contact in case of any concern. Secondly, the PPC guards the progress of the multi-disciplinary treatment and care by monitoring the patient (8). Earlier study showed that identifying gaps makes it possible to provide solutions for closing the gaps. (4).

The task is added to functions of nurses who are already involved in the care pathway (11). This is supported by the Dutch Nursing Association (V&VN) who state that it is not desirable to add another official. (11) These specialized nurses see the patients in the outpatient surgical clinic and help them preparing for surgery. Nurses do have the competence to organize care and to communicate with patients and other HCW's (12). This study evaluates the pilot of the task PPC on professional adherence, time spent on the task and experiences of the

July 2012 2 of 14

PPC and other HCW's involved in the care for patients with oesophagus and pancreas cancer.

Problem Statement

Despite care pathways in cancer care, there are discontinuities in this care. By introducing a PPC continuities in care are monitored and patients have a single point of contact. Yet it is unknown what the feasibility and effect of this task are.

Research questions

What is the professional adherence with respect to the task PPC?

Secondary questions

How much time is spent on the task PPC by the PPC's in the care pathway for oesophagus and pancreas cancer?

What are the experiences of the PPC and other health care workers in the care pathway for oesophagus and pancreas cancer?

Aim

To evaluate the task PPC in the care pathway for patient with oesophagus and pancreas cancer and thereby providing suggestions for refining and improving the task. Ultimately, working with a PPC aims to reduce care discontinuity for cancer patients and improve cancer care.

METHOD

Design

This study was a formative evaluation. Formative evaluation is a process analysis which aims to improve the studied process, in this case the task PPC (13). It is done in the early stages of implementation (14). A mixed method design is suitable for this study, because the process is complex (13,15). Mixed method is built on the idea of "triangulation", what increases the reliability of the findings (13,16). The quantitative part is cross sectional and descriptive, and describes the activities belonging to being a single point of contact and guarding the care process. The information was obtained from a data file filled in by the PPC's in the pilot period May – November 2011.

The qualitative part was supportive to the quantitative part, consisted of semi structured interviews according to the principals of phenomenology. Phenomenology concerns the experiences of people and seeks for the essence and the meaning of a phenomenon, especially when a phenomenon is not completely clear (13,17). By conducting interviews, first with the

July 2012 3 of 14

PPC's and later with HCW's, both their experiences with the task PPC were explored to gain more understanding.

Population and recruitment

Information in the data file is about patients who received care from the PPC's in the pilot period. Interviews with the PPC's working with patients with oesophagus and pancreas cancer in UMC Utrecht were conducted by the first author (CNEB). Other health care workers (HCW's) were asked to participate by two of the PPC's. The criterion for being interviewed was working with patients with oesophagus or pancreas cancer in UMC Utrecht and being contacted by the PPC in the pilot period. The interviewer asked these HCW's to participate in this study by mail or phone.

Setting

The interviews took place in the workplace of the participants in the period January till May 2012. UMC Utrecht is one of the 30 hospitals in the Netherlands allowed to perform surgery for these type of diseases (18). The hospital treats yearly 150 patients with oesophagus and pancreas cancer (19). Only the participant and the interviewer were present during the interview.

Ethics

The study was conducted in accordance with the Helsinki Declaration. Since it was not an intervention testing investigation and no test subjects were necessary, approval of the Institutional Review Board was not necessary. For the privacy of the patients the study was conducted according the Personal Data Protection Act (Wpb). The data about patients from the files of the PPC's were coded, unknown to the investigator. The names of the HCW's were not used in any report. Permission for this study was obtained from the management.

The task PPC

Each patient is assigned to one PPC during a multi-disciplinary meeting. The task PPC has two sub tasks. Firstly, the PPC's are the single point of contact for the patients to address all questions to about the process of care. Therefore, the PPC's initiated a first contact with the patient at the start of the treatment to explain their role, and when a patient has a transfer from one department to another or a treatment has ended. Furthermore they have to be reachable for patients. During contacts they ask the patient if there are any problems. The PPC's act on problems or questions indicated by the patient. Secondly, the PPC's guard the process of the multidisciplinary treatment and care. Therefore, they monitor the progress in

July 2012 4 of 14

the medical file. When they detect a problem they take action to solve the problem (8). The PPC has seven hours available to perform the task for every patient.

Variables

The professional adherence of the task is measured by the adherence with respect to being single point of contact and by the adherence to guarding the process. The adherence with respect to being single point of contact was measured by 1) the proportion of patients a) who have been contacted by the PPC before the patient contacted the PPC; b) who contacted the PPC; c) contacted by the PPC; d) the PPC had to perform an action for; 2) the number of a) contacts per patient; b) actions per patient. The adherence with respect to guarding the progress in the care is measured by the proportion of patients a) monitored by the PPC; b) for who the PPC had to take action for after monitoring.

The amount of time spent is measured by the average time per patient and the average time per week on contacts, actions and monitoring.

Data collection

Two types of data were obtained. First the data files of the patients were collected. The PPC's registered their activities in a data file in the period May-November 2011. They noted the duration of the contact; the phase of treatment; problems experienced by the patient; whether there are any gaps in the care process; if and what questions the patient had; what actions were performed; the duration of the actions. This was done immediately after the contact. Every time they checked up on the patient in the computer, they noted the spent time.

Secondly interviews with the PPC's and other HCW's in the care pathway were conducted. To explore their experiences a topic list was used. The list was made by the research team and consisted of questions about benefits of the PPC, problems with working with a PPC and promoting and limiting factors. The participants were interviewed once. The interviews were audio recorded and transcribed verbatim.

Analysis

All data extracted from the data files were analyzed using SPSS version 19 for descriptive statistics. The information about the actions in the data files was coded in categories of types of actions. A sample of the cases was also coded by the second author (LAL), to check for differences.

The interviews were coded using NVivo 7. All codes were compared and similar codes were grouped in themes to extract the most important experiences. (17), (20). Coding was peer-reviewed by the second author (LAL) to enhance validity and reliability.

July 2012 5 of 14

RESULTS

The data files contained information on 88 patients. The patients were mostly men (64%), and were diagnosed with oesophagus cancer (57%), pancreas cancer (33%), other types of cancer (7%) or unknown (3%). A contact was indicated either by date or duration of the contact. For 112 (71%) of 157 contacts initiated by the PPC the duration is known and for 65 out of 75 (87%) contacts on patients initiative the duration is known. Actions were indicated either by describing the action or by a time indicating the duration of the action. It was possible to perform more than one action at the same time. Of the 174 actions after patient contact 132 (76%) and of 51 out of 58 (88%) actions performed after monitoring the duration is known.

Interviews were conducted with all two PPC's. Seven HCW's were asked to participate, one refused because of maternity leave. A variety of disciplines were involved: nurses, nurse specialists, dieticians, surgeons, oncologists. (Table 1) Two of the HCW's and one PPC had a role in developing the task before the pilot. The duration of the interviews was between 15 and 45 minutes. Sometimes people asking the participant questions disturbed the interview.

Adherence regarding being single point of contact

The PPC's contacted 81 (92%) of the patients in the period May-November 2011. Thirty-five patients (40%) contacted the PPC, all but three were contacted by the PPC first. Reasons for not having contact were: patient was not curable (n=2), patient died (n=1), patient started treatment shortly before the pilot period ended (n=1), or unknown (n=3). In total, 232 contacts were made (157 on PPC's initiative (68%)), with an average of 2.9 contacts per patient (range 1-9). For 72 patients (89% of 81) 106 actions were performed after the PPC contacted the patient, meaning 1.5 per patient (range 1-4). For 33 patients (41%) 68 actions were taken after the patient contacted the PPC, meaning 2 per patient (range 1-5) (Table 2).

For 128 of in the total 174 actions, the type of actions is known, being logistic actions (46 times, 36%), meaning making an appointment with a HCW, for treatment or for an medical examination was scheduled; give information to the patient (55, 43%) about the task PPC, the treatment, the disease, or who to consult; or nursing actions (15, 12%) for instance removing drains, starting tube feeding or having a talk to comfort the patient (Table 3).

Adherence regarding guarding the care process

Nearly all patients (98%) were monitored by the PPC's in the period May – November 2012. The PPC's monitored 430 times, with a median of 4 per patient. For 36 patients (42% of monitored patients) 58 gaps were detected, for what the PPC had taken actions, such as contacting a HCW or making an appointment for the patient.

July 2012 6 of 14

Time

The average time spent per patient is 2.5 hours. This is calculated with the average time per contact, actions and monitoring, based on complete cases (Table 2). The average duration of a contact is 22 minutes, of an action after the PPC contacted the patient is 20 minutes, after the patient contacting the PPC is 11 minutes. An action after monitoring takes approximately 12 minutes. Multiplied with the average amount of contacts and actions this gives the following durations per patient: in case of contacts, the average duration is 64 minutes per patient; in case of an action when a PPC contacted a patient is 30 minutes per patient, when a patient contacted the PPC is 20 minutes, after monitoring is per patient is 18 minutes; in case of monitoring the average duration is 54 minutes per patient. Based on the percentage of patients who had contact, for whom an actions was performed the total time spent per patient is 2.5 hours.

The average time spent per week is 7.5 hours in the 30 weeks pilot period.

Experiences of the PPC's

Both PPC's have positive experiences with the task. They value the responses of the patients, which are mostly positive and grateful. They see benefits for the patient, because they can give them support and answer questions, and they feel the patients are feeling more save and guarded. Both PPC's confirmed that they have done other actions than only logistic actions, because they don't want to withhold care from the patient.

PPC: (about a patient calling complaining about stomach acid) I go to the Nurse Practitioner, who may prescribes this kind of things, saying: mister Z. suffers from stomach acid. Will you... He writes a recipe. I fax it directly to the Pharmacy, call the patient, say it lies with your pharmacy ready you can retrieve. Of course, it is too much for PPC that I go all the way. On the other hand I think it is all very quickly arranged for him, within an hour he stands at the Pharmacy and then he has it.

The task PPC is additional to their normal job. The PPC's say it takes a lot of time, which was in the beginning hard to claim. The activities for the pilot cost a lot of time. The PPC working as nurse specialist indicates that he did the PPC task as a nurse specialist as well. Together they have 12 hours per week for the task.

Experiences of the HCW's

The experiences of the other HCW's with the PPC differ. Three HCW's were not fully aware of the existence of and the tasks of the PPC. They were surprised to hear about the starting date of the PPC and/or the possibilities. Nobody has opposed to be approached.

July 2012 7 of 14

C1:.....not actually knew that P. was PPC and D as well...

C2: But for example, I know not whether they work crossing the department borders...

The HCW's have only little experience with the task PPC, but have positive feelings about the task PPC, which they say is confirmed by patients. They theoretically see several benefits for the patients, themselves and the care pathway. All see a role for the PPC in signaling flaws in the care pathway and act upon it to secure continuity of care. The PPC is considered to have a helicopter view over the total treatment process of the patient group, which makes them feel save to know there is someone that has that responsibility.

All interviewees (PPC and HCW) see benefits in the PPC being able to answer all kinds of questions, other than logistics, because that takes burden away from them. Two participants state that an administrative employee can do the monitoring and then inform another one to take action on signaled problems. Five prefer to not separate that assignment.

C3:the idea that you can give them a phone number, where they can reach someone. That is a good feeling. The fact that the process is being watched.....

Investigator: makes you feel save?

C3: yes....

C4: I really consider them as the guardians of the logistics at micro level, at the individual patient level. And if you but enough patients at the individual level, you can also see a pattern emerge. And then you say, therefore, this change is fantastic, but I saw 15 times it went wrong, what are we going to do about it?

DISCUSSION

A new task PPC was introduced in the care pathway for patients with oesophagus and pancreas cancer in the UMC Utrecht. This study investigated the feasibility of the task. The adherence of the executing nurses regarding the two elements of the task was good. Both sub tasks were executed, there was contact between almost all patients and PPC's, nearly all patients were guarded by the PPC and actions to solve discontinuity have been performed. The PPC's have a positive feeling by executing the task, as well as the HCW's involved. HCW did not find it objectionable to be approached by a PPC. This contributes to the willingness of the PPC's and HCW's to work with the task, what is important to feasibility and gives room for refinement.

This study showed that it is possible to perform the task within the available time of the PPC's. Yet the PPC's indicated that it was time consuming and they needed all available time. But since only activities for individual patients are noted in the data file and not the time

July 2012 8 of 14

spent on multi-disciplinary meetings, it is possible the PPC uses more time per patient than can be retrieved from the data file.

The PPC performed different kind of actions after contact with patients. Most of the known type of actions were giving information. This information was about organisational, as well as care related matters. Giving care related information was not included in the task. The PPC's do wish to be able to answer care related questions, because they are able to answer the questions and the patient is helped immediately. The desirability is confirmed by the HCW's. Earlier study showed that patients do have a need for informational support (21).

This study also investigated the effects of the task PPC. Actions taken to maintain the progress of the care process of the patient, provide continuity of care. This indicates that the task is effective for the continuity of care, which has a positive effect of quality of care (9). This is important for the UMC Utrecht wants to improve the quality of cancer care (19). Effect on patient satisfaction is not measured. PPC's and HCW's reported patients reactions indicating patients are satisfied with the task. This is confirmed by a review of Servellen et al, who have found a positive relation between patient satisfaction and continuity of care (22)

There are some limitations in this study. Firstly, there were some missing data in the data file, but cases were complete for at least 70%. It is not to be expected that there will be systematic differences in the time spent on the task. Secondly, during some of the interviews people disturbed the interview by entering the room. This had no negative influence on the conduct of interview. Thirdly, there are indications that the task has a positive effect, yet further research to point out the size of the effect on different end points need to be determined by executing an experimental study with a control group not receiving care from a PPC.

Strengths of this study is the triangulation, making it possible to confirm findings in the database by the interviews. Furthermore, the data file is filled right after every contact, so there is minimum change of recall bias (13).

CONCLUSION AND RECOMMENDATIONS

It is feasible to perform the task PPC. Performing the task takes about 2.5 hours per patient. It is desirable to extend the task with the possibility to answer care related questions. The task is effective, because patients have contact with the PPC and actions to solve discontinuities have been performed. Further investigation on effect is necessary.

July 2012 9 of 14

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July 2012 10 of 14

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July 2012 11 of 14

Table 1 Interviews were conducted with the following persons

	Number	Department	Function/education/degree		
PPC's 1		Outpatient clinic surgery	Nurse Practitioner		
	1	Outpatient clinic surgery	Senior oncology nurse		
	1	Internal medicine	Team leader nursing ward		
	2	Nurse	Oncology nurse		
Other HCW's	2	Surgery	Professor		
	1	Medical oncology	PhD		
	2	Dietetics	Dietician		
	1	Outpatient clinic surgery	Nurse		

Table 2 Activities of the Permanent Point of Contact in numbers and duration in minutes, number of patients, averages and percentages

	Total num- bers ¹	Number known duration ¹	Number of patients ²	Complete cases ³	Average duration per con- tact/action ⁴	Average num- ber of con- tact/actions per patient ⁴	Average duration per patient ⁵	Total durations based on full cases
Contacts								
Total	232	177	81 (92%)	50 (62%)	22	2.9	64	5184
PPC initiative	157	112	81 (92%)					3454
Patient initia- tive	75	65	40 (45%)					1730
Monitoring	430	430	86 (98%)	86 (100%)		4	54	4727
Actions								
After contact	174	132						
After ppc ini- tiated contact	106		72 (89%)	51 (71%)	20	1.5	30	2160
After pat initi- ated contact	68		33 (83%)	24 (73%)	11	2	20	660
After monitor- ing	58	51	36 (42%)	30 (83%)	12	1.5	18	648
TOTAL			88				2.5 hours ⁷	13379 223 hours

¹of contacts, actions or monitoring; ²percentage of contacts and monitoring based on all patients; percentage of actions based on number of patients with contact or being monitored; ³percentage based on number of patients with contact, being monitored or for whom actions were taken; ⁴in minutes based on full cases; ⁵average duration times average number of contact/actions; ⁶ average duration per patient times number of patient with contact/action; ⁷total duration based on full cases divided by total number of patients (n=88).

Table 3 Types of actions taken after contact between PPC and patient in numbers

Type of action	Initiated by the PPC	Initiated by the patient	Total
Giving information ¹	33	22	55
Logistic action ²	16	30	46
Nursing actions ³	13	2	15
Other	7	5	12
Unknown	37	9	46
Total	106	68	174

Answering questions and give info about logistics, disease and treatment;

July 2012 12 of 14

² Arranging appointment for examinations and consults with the physician, or another expert such as a dietician, a pulmonologist, a geriatric specialist.

³ Removing drains, giving socio-psychological support

SAMENVATTING

Titel De taak Vaste Contactpersoon in het zorgpad voor patiënten met slokdarm of alvleesklierkanker.

Achtergrond Ondanks de invoering van zorgpaden in de zorg voor kanker patiënten, bestaan er discontinuïteiten in deze zorg. Het Universitair Medisch Centrum Utrecht introduceerde de taak Vaste Contact Persoon (VCP) in het zorgpad voor patiënten met slokdarm of alvleesklierkanker in mei 2011. Door de invoering van de taak VCP wordt de continuïteit van de zorg en behandeling gecontroleerd door het bewaken van de voortgang van het zorgproces en hebben patiënten een vast aanspreekpunt.

Doel. Het evalueren van de taak VCP in zorgpad voor patiënten met slokdarm of alvleesklierkanker en daarmee de mogelijkheden voor het verfijnen van de taak te bepalen. Uiteindelijk het verbeteren van de kwaliteit van de zorg voor kankerpatiënten door het werken met een VCP.

Methode. Een "formative evaluation" met een mixed method design is uitgevoerd. Het kwantitatieve deel was een analyse van een gegevensbestand waarin de VCP's hun activiteiten met betrekking tot de twee sub taken registreerden in de periode van mei tot november 2011. Het kwalitatieve deel was ondersteunend aan het kwantitatieve en bestond uit semi gestructureerde interviews met zowel de VCP's, als andere zorgverleners om hun ervaringen met de taak VCP te verkennen.

Resultaten. Bijna alle patiënten hebben contact gehad met een VCP en het proces van bijna alle patiënten is bewaakt door de VCP. Voor 72 (89%) patiënten zijn 232 acties uitgevoerd na contact. Voor 42% van de gemonitorde patiënten zijn 58 acties uitgevoerd. Er is per patient 2,5 uur besteed, per week 7,5 uur. De VCP's en de andere zorgverleners vinden de taak zinvol, maar niet alle zorgverleners waren op de hoogte van het bestaan en de mogelijkheden van de VCP.

Conclusie Het is mogelijk om de taak VCP uit te voeren. Het is wenselijk om de taak uit te breiden met de mogelijkheid om ook zorg inhoudelijke vragen te beantwoorden. Om de effectiviteit te bepalen is nader onderzoek nodig.

Steekwoorden: 'vaste contact persoon', bewaken, zorgpad, continuïteit

July 2012 13 of 14

ABSTRACT

Title The Task Permanent Point of Contact in a Care Pathway for Patients with Oesophagus and Pancreas Cancer

Background Despite of care pathways in cancer care, there are discontinuities in this care. The University Medical Centre Utrecht introduced the task PPC in the care pathway for patients with oesophagus and pancreas in May 2011. By introducing the task Permanent Point of Contact (PPC) the progress of the care process is monitored and patients have a single point of contact.

Objectives To evaluate the task PPC in the care pathway for patient with oesophagus and pancreas cancer and thereby providing opportunities for refining and improving the task. In the long run, working with a PPC aims to reduce care discontinuity for cancer patients and improve cancer care.

Method A formative evaluation using mixed methods has been conducted. The quantitative part was an analysis of a data file in which PPC's noted their activities concerning the two element of their task in the period May till November 2011. The qualitative part was supportive to these finding and consisted of interviews with PPC's and with other health care workers (HCW's) to explore their experiences with the task PPC.

Results Almost all patients had contact with the PPC and the care process of almost all patients had been guarded. For 72 (89%) patients 232 actions had been performed after contact. For 42% of the monitored patients 58 actions had been performed. Time spent per patient is 2.5 hours, per week 7.5 hours. PPC's and HCW's find the task useful, not all HCW's were aware of the existence and possibilities of the PPC.

Conclusions The task PPC is feasible to perform. It might be expanded with the possibility to answer care related questions. To determine effectiveness in further research is needed.

Key words: 'key contact person', guarding, care pathway, continuity

July 2012 14 of 14