

The task 'Permanent Point of Contact' in the care pathway of breast cancer patients

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Introduction

In 2010, 13.257 patients were diagnosed with breast cancer in the Netherlands, a number that has grown with 8% since 2000 (1). Breast cancer treatment is complex as various professionals are involved in diagnosis, treatment, and follow-up (2). This complexity risks many gaps between professionals, stages and processes and thereby increases the risk of discontinuity and fragmentation of care (3,4). Cooperation between different health care disciplines can improve diagnosis, staging of care, treatment, follow-up, supportive care, and quality of life (5). The Dutch Inspection of Health Care (IGZ) reported the importance of cancer care coordination (6). For improving the coordination and care continuity the UMC-Utrecht developed care pathways for oncological patients. A care pathway is a complex intervention for the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period (7). For breast cancer patients, a care pathway was developed that states at what moment, which action should be performed by which professional from which department. Despite the care pathways, there are gaps in the progress of the care process (8). Since the pathway procedure was not guarded, gaps were not recognized and solved. This threatened the care continuity, and impaired patient outcome (9). These difficulties made the hospital realize that only working with pathways was not enough and that something had to be changed.

In 2009 the IGZ stated that oncological care had to be improved on the following four points: 1) patients should have one single contact, who is clearly identifiable from the patient's medical record; 2) there should be one person in the care process with an overall view over the treatment process and the authority to adjust that process; 3) there should be a single plan for each patient; 4) one single comprehensive patient file should be maintained, available for all health care workers (HCWs) involved (6). Van Walraven and colleagues (2010) stated that one direct contact may contribute to improvement of cancer care (9). Patients, their partners, and family also express a preference for one contact (2), as patients feel more supported during their disease process (10).

In view of their own experience with gaps in the care pathway, the recommendations of the IGZ and previous research, the Cancer Center of the UMC-Utrecht started a pilot study to introduce the task 'Permanent Point of Contact' (PPC) for breast cancer patients in May 2011. For this pilot each breast cancer patient was assigned to a PPC with two subtasks: 1) guard the care

pathway progress and realizing continuity across departments by intervening when necessary; 2) provide a clear point of contact for the patient (11). The new task is directed to nurse practitioners (NPs) who are already involved in the care pathway of breast cancer patients. This is in line with the vision of the the Dutch organization for oncology nurses that indicated PPC as a task instead of a function, as a new function in cancer care was not desired (12). This study evaluates the pilot project of the PPC task on professional adherence, time spent per patient and experiences of the PPCs themselves and HCWs involved in the care pathway for breast cancer patients.

Problem statement

Improving care pathway coordination is an important mission. To improve coordination and care continuity, a PPC for breast cancer patients is introduced in the study hospital. Yet, the professional adherence with respect to performing the task and the effectiveness of the task are unclear.

Research questions

Research question

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

Secondary research questions

What is the time spent per patient to perform the task PPC in the care pathway for breast cancer patients?

How do the PPCs and HCWs involved in the care pathway for breast cancer patients experience the PPC task?

Aim of this study

The aim of this study is to evaluate the PPC task in the care pathway for breast cancer patients. This study thereby provides recommendations to improve the task. Ultimately, working with a PPC aims to reduce care discontinuity for cancer patients and to thereby improve cancer care.

Method

Design

Formative evaluation, a form of process analysis, is undertaken to obtain descriptive information about the PPC implementation process in order to optimize quality and effectiveness of the PPC task. Because of the complexity of the evaluation a mixed method design based on the concept of “triangulation” is most suitable. With triangulation the confidence of findings increases when observations of one type are confirmed by other types of evidence (13). The quantitative, cross sectional part of this study consisted of analyzing data files registered by the PPCs, containing the patient contacts and their care pathway progress guarding activities. The qualitative part consisted of semi-structured interviews according to the principles of phenomenology. Phenomenology studies the lived experiences to seek essence and meaning of a new phenomenon, especially when a phenomenon is not completely clear (13,14). Semi-structured interviews with the PPCs and HCWs involved in the relevant care pathway for breast cancer patients were conducted to evaluate the task PPC.

Population and setting

The pilot study was conducted from January till May 2012 in the UMC-Utrecht, starting with two breast cancer patient PPCs. All new patients that were diagnosed with, or suspected of breast cancer were assigned to one of these PPCs, who registered their activities in data files. After finishing the pilot two more breast cancer patient PPCs were appointed. Based on interviews with all four PPCs, HCWs involved in the breast cancer care pathway were contacted for inclusion if the PPCs contacted them more than once.

Ethical considerations

All PPCs and HCWs were contacted by mail to ask cooperation for an interview. Since there was no need for approval of the Institutional Review Board, an oral informed consent of the participants was sufficient. This consent was obtained from the PPCs and HCWs before every interview. All data were coded. The names of the HCWs were not used in any report. For patients' privacy the study was conducted according the Personal Data Protection Act (Wpb). The data about patients in the log files of the PPCs were coded, unknown to the investigator. Permission for this study was obtained from the Cancer Center of the UMC-Utrecht.

The PPC process

All patients diagnosed with or suspected of breast cancer were assigned to a PPC who have two tasks. First, to guard and intervene in case of a gap in the in the care pathway progress across departments. Secondly, to provide a clear point of contact for the patient. According to the protocol the PPC introduces himself to the patient at the start of treatment and contacts the patient after every transfer between hospital departments. Furthermore, the PPC is a first contact for logistical questions and, if required, the PPC can solve a logistical problem. In case of a care related question patients have to contact their own doctor. In the pilot the PPC has five hours per patient to perform the tasks.

Variables

Professional task adherence is measured with respect to the two subtasks: being single point of contact and guarding the care pathway process. The adherence with respect to being single point of contact was measured by: 1) percentage of patients that had at least one contact with the PPC; 2) percentage of patients that have had a contact initiated by the PPC; 3) percentage of patients that initiated a contact; 4) number of contacts per patient; 5) number of actions performed after a contact, and 6) type of actions (logistical or care related) performed after a contact. Professional adherence when guarding the care pathway progress is measured by: 1) percentage of patients that is monitored; 2) the percentage of patients of which the PPC noticed a gap in the care pathway, and 3) number of actions directed to solving logistic problems.

A contact or action was done when the PPC registered a date or a duration.

Time involved is measured by: 1) duration of patient contacts; 2) duration of performed actions after patient contact; 3) duration of monitoring and 4) duration of performed actions after monitoring a gap in the care pathway.

Based on the interviews, the PPCs and HCWs experiences with the PPC task were catalogued.

Data collection

During the pilot (May – November 2011) the PPCs kept a log file to register the activities performed related to their PPC task. This included noting information about the patient contacts, such as date, questions and problems, and actions taken based on the patient contact.

Furthermore, was recorded how often a patients' medical record was accessed for monitoring the care pathway progress and which actions were undertaken to solve a logistic problem. The total time investment in patient contacts, performing actions and monitoring the care process

was also registered. The log file is developed by the Cancer Center of the UMC-Utrecht. PPCs were trained to use the log files and data collection was frequently evaluated during the pilot. The PPCs and HCWs were interviewed in a semi-structured way to investigate how the PPCs and HCWs experienced the PPC task. The themes of the topic list that were addressed during the interviews with the PPCs and HCWs were: 1) the benefits of the task; 2) problems with working with a PPC, and 3) promoting and limiting factors to perform the task. The topic lists are developed by the research team and are inspired on the information in the data files.

Analysis

The data log files are converted to IBM SPSS statistics 19.0 format for an exclusively descriptive analysis. Frequencies and percentages for contact moments, guarding of the care pathway progress and the performed actions are generated for all patients. The time investment is depicted with means and sums. In case of missing durations of contacts or actions, the mean duration of the other contacts or actions were extrapolated to calculate the total time investment. All interviews are audio-taped and transcribed verbatim. The interpretation of the data of the interviews took place in close collaboration with the second author CNEB. First, the transcribed interviews are interpreted to identify and reduce codes, relate categories, and create a viewpoint in an analytical framework. With the software program NVivo9 notes were taken during the entire analysis process. These data were compared constantly to extract the essential data and develop a clear overview. Internal validity was realised by constant comparison, triangulation, and peer debriefing.

Results

The log files contained information from 88 patients that were assigned to a PPC during the pilot study. All patients were woman and suspected of, or diagnosed with, breast cancer.

All four PPCs and five HCWs were approached to participate. One HCW refused because of maternity leave, all others were included. The PPCs were all women working at the outpatient clinic of surgery (1,5 - 10 years) as NP. Two of them had been fulfilling the task PPC from the beginning of the pilot study (for nine months), the other two for two months. The interviewed HCWs were an oncologist, a radiotherapist, a surgeon and a mamma care nurse. The length of the interviews with the PPCs varied from 30 to 45 minutes, with the HCWs 10 to 20 minutes.

Clear point of contact

Sixty two of the patients (70%) had at least one contact with the PPC (table 1). The PPCs initiated at least one contact (mean 1.7, range 0-4) with 59 (67%) of the 88 patients. Thirty-two of the 88 patients (36%) initiated one or more contacts (mean 1.7, range 0-4). Twenty-six patients (30%) had no contact with the PPC. Three patients were palliative and thereby taken over by their general practitioner, two patients were treated in another hospital and one patient died. For the other 20 patients the reason of having no contact with the PPC is unknown. In total, there were 154 contacts (table 1). Following a PPC initiated contact, these contacts resulted in one or more actions on 33 occasions (56%). When the patient was the initiator of the contact this resulted in one or more actions in 86%. Overall, the PPCs performed 98 actions after patient contact. Sixty-two of the 98 actions (63%) had a logistical character (table 2).

Guarding the care pathway progress

The PPCs guard the care pathway progress of 87 patients (99%). The number of times they monitored individual patients varied from 1 to 10. For 35 patients (40%) one or more omissions in the care pathway were identified (table 1), this always resulted in an action taken by the PPCs. In general, the action consisted of contacting a HCW or making an appointment.

Time involved

The average time spent per patient is 76 minutes. This is calculated with the average time per contact, actions and monitoring, based on complete cases (table 1). The average duration of a contact is 16 minutes and of an action following after the contact 9 minutes. An action after monitoring takes approximately 10 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 54 minutes per patient; in case of action after a contact 14 minutes per patient, when a patient contacted the PPC is 14 minutes, after monitoring is per patient is 13 minutes; in case of monitoring the average duration is 32 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 76 minutes.

Experiences with the PPC task

The PPCs have positive experiences with the task. They see several benefits for the patients: they can give them support, answer questions and they noticed patients are feeling more save and guarded. The PPCs indicated it is hard to distinguish the task of their other responsibilities,

for they already had a function in contacting patients and answering questions. Often patients contacted the PPCs for care related questions too. Although this was not described in the tasks of a PPC it did meet the tasks of the NP. Besides that, the PPCs said it is an added value they can answer logistic questions and care related questions as well. At this way they can support the patient the best possible way.

PPC 2: The task PPC and my function as NP are difficult to distinguish. Although I am not directly involved in the care process as patients NP it is impossible to answer only logistical question and pass the care related question through.

The main limiting factor they mentioned is the time investment. During the pilot the number of patients that are assigned to a PPC grew and there were no more man-hours available. The two PPCs who started with the task since the start of the pilot indicated they need several hours extra a week to perform their task in a good way but it is hard making time available to perform the task.

The HCWs were positive about the new task too, they were all aware of the introduction of the task PPC.

HCW 1 "Now we are working with a PPC I cannot imagine how we could have worked without a PPC all that time".

HCW 4 "Since the introducing of the PPC I get more information about struggles the patients are dealing with. During a consult I can react directly at these things.

They indicated patients feel glad having a key contact person and see benefits for themselves as well.

HCW 2: "When a patient heard we were working with a PPC she said literally: 'I looks like I come home in a warm bath.' She felt really protected".

The HCWs suggest somebody that monitors the care pathway progress across department could improve care continuity. However they did not encounter it in practice, they only expect it.

Investigator: Has the care improved after the introduction of the PPC?

HCW 3: Yes, it can improve, that seems logical. Gaps can be detected more earlier.

HCW 2: I can imagine working with a PPC improved care continuity, however I did not noticed that already.

Discussion

Concerning professional adherence, the results of this study show that the PPCs largely performed their task as predetermined. There has been contact with most of the patients, for 98% of the patients the care pathway progress is guarded and actions are performed to solve care discontinuity. Thus the PPCs and HCWs both have positive experiences with the new task. Furthermore 70% of the patients have had at least one contact with the PPC, although in general the reasons for the lack of contact in the other 30% are unclear. Possibly the PPCs saw the patients without registered contact in their role as nurse practitioner (NP) on the outpatient clinic and did not register these contacts in the log file. Because the PPCs are NPs who play an important role in the care pathway, it is hard to distinguish between these two functions. The PPCs frequently gave care related information, which was viewed by both the PPCs and HCWs as an improvement of the old situation. Previously all care related questions were passed through, which led to patients waiting and feeling uncomfortable.

Studies about functions similar to the task PPC show that giving medical support next to logistic support stimulates patient wellbeing and improves the coordination of care (10,15,16). Therefore the UMC-Utrecht should consider extending the PPC task to include answering care related questions. This extension fits well with adding the PPC task to an NP based on their medical knowledge. The function description of an NP as described by the V&VN also confirms the combination of coordination and medical skills (17).

It is difficult to determine the average time necessary to perform the PPC task. Time spent per patient is calculated to be 76 minutes, which is less than anticipated. The PPCs mention limited time as a constraint to perform the task in an adequate manner. It is questionable whether all time spent on the task is registered in the log files. Besides patient contact and guarding the care pathway progress the PPC also spends a substantial amount of time updating the log files and attending meetings. This was not taken into consideration in the calculation of total time spent per patient. Furthermore, some of the patients are assigned to a PPC only a few weeks before the end of the pilot. This may give a biased presentation of total time spent.

In the current study PPCs and HCWs feel positive about the task and see several benefits for the patients and themselves. It did not examine patient satisfaction, but HCWs and PPCs heard that they felt supported by having a PPC. Several other studies confirm patients and HCWs positive feelings towards PPCs (2,10,18).

Robinson (2000) noticed navigation in breast cancer care is necessary to coordinate the multidisciplinary providers and complexity of care across disease trajectory inherent in breast cancer treatment (16). The current study does not prove whether working with a PPC leads to an improvement of the care coordination and continuity. Nevertheless, care continuity is expected to improve as nobody guarded the care process progress before. In 40% of all cases the PPC had to perform an action because one or more omissions occurred in the care pathway. Most likely these omissions would not have been revealed without a PPC and hence the PPC contributes on the care continuity. To make a clear statement, more research is required to investigate whether the task PPC really contributes to the cancer care continuity.

Strength and limitations

A strength of this study is the triangulation. The qualitative interviews confirm the findings of the quantitative log files. Another strength is the internal validity by peer debriefing and constant comparison, but some limitations need to be addressed. Firstly, the missing data, especially regarding actions performed after patient contact, are addressed by extrapolating the mean durations of a contact or performed action. This must be kept in mind, in relation to the reliability of the log files. Secondly, it is not possible to retrieve the exact moment patients were assigned to a PPC. Some of the patients are guarded only for a few weeks and were in the middle of the treatment process. This may bias the number of contacts and the overall time investment. Finally, when interviewing the HCWs, the task PPC was introduced nine months before, so the HCWs had little experience with the PPCs.

Conclusion and recommendations

In conclusion, it is possible to perform the task PPC as predetermined. PPCs and HCWs are satisfied with the results. Furthermore it shows that there is a need to extend the task with the possibility to answer care related questions. The possibilities for this extension need further investigation. Further research on the effect of the task on care continuity is recommended.

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Table 1 Number and time investment of contacts, monitoring patients' medical record and performed actions

	Total numbers ¹	Number known duration ¹	Number of patients ²	Complete cases ³	Average duration per contact/action ⁴	Average number of contact/actions per patient ⁴	Average duration per patient ⁵	Total durations based on full cases ⁶
Contacts								
PPC initiative	100	88 (88%)	59 (67%)	49 (83%)	16	1,7	27	1593
Patient initiative	54	46 (85%)	32 (36%)	28 (88%)	16	1,7	27	864
No contact			26 (30%)					
Monitoring	458	458 (100%)	87 (99%)	87 (100%)	6	5,3	32	2784
Actions								
After PPC initiated contact	51	34 (67%)	33 (56%)	19 (58%)	9	1,5	14	462
After pat initiated contact	47	29 (62%)	31 (86%)	16 (52%)	9	1,5	14	406
After monitoring	47	46 (98%)	35 (40%)	33 (94%)	10	1,3	13	598
Total			88				767	6707

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; ⁶average 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 2 Type of actions performed after patient contact

Type of action	Total
Logistical ¹	62
Care related ²	25
Other ³	1
Unknown	1
Total	98

¹ Give info about logistics, arranging appointment for examinations and consults with other professionals

² Give care related information about treatment of disease and giving socio-psychological support

³ Make a note in patients' medical record

Samenvatting

Achtergrond Om de coördinatie en continuïteit van zorg voor borstkankerpatiënten te bevorderen werkt het UMC-Utrecht met zorgpaden. Niemand controleerde echter in hoeverre de zorg, zoals beschreven in het zorgpad, werd nageleefd en logistieke fouten bleven onopgemerkt. Daarom startte in mei 2011 een pilotstudie om de taak Vaste Contact Persoon (VCP) te introduceren. Deze VCP heeft twee taken: vast aanspreekpunt zijn voor de patiënt en het bewaken van de voortgang van het zorgpad.

Doel Het evalueren van de VCP in het zorgpad voor borstkankerpatiënten. Deze studie biedt hiermee kansen om de taak VCP te verfijnen en verbeteren. Uiteindelijk is het werken met een VCP gericht op vermindering van discontinuïteit en daarmee verbetering van zorg.

Methode Een 'formative evaluation' met een mixed method design is uitgevoerd. Het kwantitatieve deel, gebaseerd op een logbestand waarin in de VCPs hun activiteiten bijhielden, beschrijft de professionele naleving van de twee taken van de VCP. Het kwalitatieve deel, gebaseerd op fenomenologie, bestond uit interviews met de VCPs en andere professionals om hun ervaringen met betrekking tot de taak VCP te onderzoeken.

Resultaten De VCP had contact met 70% van alle patiënten. Na een patiëntencontact zijn er 98 acties uitgevoerd, waarvan 74% een logistiek karakter had. De VCPs monitorde van 99% van de patiënten in hoeverre de zorg werd geleverd als beschreven in het zorgpad. Bij 40% zijn een of meer hiaten getraceerd binnen de voortgang van het zorgpad. De gemiddeld besteedde tijd per patiënt is 76 minuten. De VCPs en andere professionals reageerden positief op de invoering van de taak VCP.

Conclusie De taak kan worden uitgevoerd zoals vooraf vastgesteld en de VCPs en andere zorgverleners zijn positief over de nieuwe taak. Er blijkt behoefte te zijn om de taak VCP uit te breiden met de mogelijkheid voor patiënten tot het stellen van zorg gerelateerde vragen. Deze uitbreiding vraagt om verder onderzoek. Tevens wordt verder onderzoek naar het effect van de taak op continuïteit van zorg aanbevolen.

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

Abstract

Background To improve coordination and care continuity the UMC-Utrecht worked with care pathways for breast cancer patients. However, nobody monitored whether this care pathway was followed properly and forestall gaps in the care pathway. Therefore, the hospital started a pilot study in May 2011 introducing the task of Permanent Point of Contact (PPC). This PPC had two subtasks: provide a clear point of contact for the patient and guard the care pathway progress.

Objectives To evaluate the PPC task in the care pathway for breast cancer patients. The study thereby provides opportunities for refining and improving the task. Ultimately, working with a PPC aims to improve care continuity for cancer patients and to thereby improve cancer care.

Method A formative evaluation with a mixed method design has been conducted. The quantitative part, based on a log file where the PPC recorded their activities, explores professional adherence with respect to the two tasks of the PPC. The qualitative part, based on phenomenology, consisted of semi-structured interviews with PPCs and HCWs to examine their experiences regarding the task PPC.

Results The PPCs had contact with 70% of all patients. Following on a contact, the PPCs performed 98 actions. 74% of the actions had a logistical character. The PPCs guarded 99% of patients' individual progress in the care pathway. In 40% of all cases, it turned out that one or more omissions had occurred in the care pathway progress. Average time spent per patient is 76 minutes. The PPCs and HCWs feel positive about the introduction of a PPC.

Conclusions The PPCs performed the task in most parts as predetermined and PPCs and HCWs feel positive about the task. The study shows that there is a need to extend the task with the possibility to answer care related questions. The possibilities for this extension need further investigation. Further research on the effect of the task on care continuity is recommended.

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

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