

Shared care is a model for patients with stable prostate cancer

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ABSTRACT

INTRODUCTION: Patients with prostate cancer (PC) have so far been followed in specialised hospital departments after diagnosis and initiation of treatment. The main obstacles associated with the transfer of this activity to general practice include lack of experience and uncertainty as to whether general practitioners (GPs) can handle follow-up.

MATERIALS AND METHODS: A Steering Committee was established in collaboration with health-care professionals to devise a strategy for a shared care model. An action plan was designed that included 1) the development of a shared care model for follow-up and treatment, 2) implementation of the shared care model in cooperation between the parties involved, 3) design of procedures for re-referral, and 4) evaluation of effect, change processes and contextual factors.

RESULTS: A total of 2,585 patients with PC were included in the study: 1,172 had disseminated disease, 754 had no recurrence after curative treatment, 244 who had been treated with a curative intent were being treated for relapse, 186 underwent watchful waiting, 135 underwent active surveillance, while other scenarios applied in the remaining 94 cases. A total of 530 patients were transferred to follow-up with a GP and 2,055 were not transferred to their GP. The main reason why patients were considered not suitable for transfer to primary health care was the patients' own desire (33%), followed by clinical or biochemical disease progression (33%). The evaluation found that 96% of the patients were very comfortable with the permanent or temporary closure of the hospital course.

CONCLUSION: The project focused on factors that are essential for the successful transfer of responsibility for long-term follow-up of patients with prostate cancer. Patient transfer succeeded with high initial patient satisfaction.

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The incidence of prostate cancer (PC) is increasing. In Denmark, 4,200 new cases are diagnosed annually and approximately 1,000 underwent surgery (radical prostatectomy) in 2011 [1, 2]. Patients with PC are often followed at hospitals once diagnosis and initial treatment have been initiated. No evidence is available to guide decisions as to where, when or how PC patients with stable disease should be followed. Besides having PC,

several of these patients will suffer from co-morbidities which are treated by their general practitioner (GP). If the necessary prerequisites were present, the cancer follow-up could therefore take place at the GP. However, there is a need for improved exchange of experience and knowledge sharing between primary and secondary sectors [3, 4].

If GPs are to be more actively involved in cancer follow-up, it is important to have clinical guidelines and an agreement among practitioners regarding the purposes and contents of the check-up and their consequences and possible outcomes for the patient. Such agreements have the potential to increase patient cure rates and facilitate the implementation of shared care, i.e. treatment across therapist groups and geographical localizations. The preconditions for establishing shared care are therefore: 1) common cross-sectoral instructions based on national clinical guidelines 2) a clear division of tasks and 3) good communication between GPs. It is very important to involve the patients in the process and in the decision on transferring follow-up to their own GPs, and to provide systematic support in order to achieve shared decision making [5, 6].

The purpose of this project was to describe the development of a shared care model for patients with stable PC or having undergone treatment for PC with a curative intent, and to describe how the model was implemented and the effects it had.

MATERIAL AND METHODS

Setting

The project was carried out in cooperation between GPs and the three departments of urology in the Region of Central Jutland, which covers 1.2 mill inhabitants. The common shared care model was developed through first half of 2011 and its implementation started on 1 September, 2011. All outpatients with PC followed at the urologic outpatient clinics during a six-month period were included in the study.

Development and implementation of the shared care model

The strategy of the shared care model was designed by the Steering Group which counted general practitioners, urologists and nurses from Central Jutland's three de-

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TABLE 1

Number of patients with prostate cancer from three different departments of urology enrolled in shared care programme.

	Holstebro		Skejby		Viborg		Total	
	patients in the out-patient clinic, n	patients referred to the GP for shared care, n (%)	patients in the out-patient clinic, n	patients referred to the GP for shared care, n (%)	patients in the out-patient clinic, n	patients referred to the GP for shared care, n (%)	patients in the out-patient clinic, n	patients referred to the GP for shared care, n (%)
Active surveillance	17	1 (6)	105	5 (5)	13	1 (8)	135	7 (5)
Watchful waiting	89	38 (43)	60	18 (30)	37	4 (11)	186	60 (32)
Curative treatment without relapse	235	26 (11)	314	83 (26)	205	97 (47)	754	206 (27)
Curative treatment with relapse	82	8 (10)	140	12 (9)	22	3 (14)	244	23 (9)
Metastatic disease	337	66 (20)	529	66 (12)	306	88 (29)	1,172	220 (19)
Other	9	1 (11)	62	6 (10)	23	8 (35)	94	15 (16)
Total	769	140 (18)	1,210	190 (16)	606	201 (33)	2,585	531 (21)

GP = general practitioner.

departments of urology along with patient representatives and project coordinators from the Regional Quality Unit "Cancer in Practice".

The principles of the model were (1) a clear assignment outline (which patient categories were suitable for shared care including follow-up elements), (2) a fixed structure for communication with GPs and (3) systematic patient involvement. Standards for disease stability were established which defined the criteria for transfer to shared care in which the GP served as the coordinator of future follow-up. Patient information material including a treatment plan and description of follow-up was created. Furthermore, a standard discharge summary template was made with two compulsory elements: 1) the diagnosis with a short summary of the patient's case history 2) the criteria for re-referral (for instance a rise in prostate-specific antigen (PSA) or the creatinine level exceeding an individually determined threshold value).

Patient registration, study monitoring and evaluation

All patients attending follow-up visits after treatment had been terminated or who attended follow-up as part of on-going treatment for PC were registered ahead of their planned outpatient clinic visit. For each patient, it was indicated where the patient was in the course of his disease, if disease was stable or if the patient was considered to have been cured of PC. If so, the patient could be transferred to the care of the GP according to the above-mentioned common criteria. After the consultation, it was registered if the patient had, in effect, been transferred. Any reasons for non-transfer (which in some cases were several) were stated as well. The pre-clinic evaluation in the three departments of urology was conducted in different ways: in one department, a urologist revised the entire programme of the following week and filled-in the documents before the outpatient

clinic visits started; in the second department, a specially trained nurse filled in forms in the morning ahead of the patient's visit; and in the third department registration was made both by doctors and nurses. At the end of the consultation, an evaluation questionnaire postcard was handed out to all patients who had been transferred to shared care.

For audit, ten discharge summaries were randomly chosen from each month. They were evaluated for information standards to the GPs regarding plan of treatment, individual control interval and which PSA value should lead to the patient being re-referred to the urologic department.

Trial registration: not relevant.

RESULTS

Table 1 shows the patients' stage of disease in the three departments along with the percentage of patients who were transferred to shared GP-coordinated care. Data are presented by disease stage.

Table 2 presents the pre-consultation estimated rate at which patient were expected to be included into

TABLE 2

Number of patients with prostate cancer considered suitable for shared care and the number of patients actually enrolled in the shared care programme.

Department	Suitable for shared care, n (%)	Actually enrolled in shared care, n (%)
Holstebro (N = 769)	225 (29)	140 (18)
Skejby (N = 1,210)	227 (19)	190 (16)
Viborg (N = 606)	306 (50)	201 (33)
Total (N = 2,585)	758 (29)	531 (21)

the shared care programme. It was estimated that a total of 758 (29%) patients would be transferred to their GP, and 531 patients (21%) were, in fact, transferred. The departments' evaluations of their patients' capability for programme participation showed only small differences. In Viborg, it was estimated that it was possible to include up to 306 (50%) of the patients, while only 201 (33%) were actually included. This number was almost twice as high as the percentage in the two other outpatient clinics. At the two other clinics, both the estimated and the actual percentage of included cases were significantly smaller. A total of 227 patients were initially believed to be eligible for transfer, but turned out not to be. **Table 3** shows that the "patient wish" was the most frequent reason for not entering the shared care programme. This reason was followed by either "unstable PSA" or "clinically unstable disease". These reasons accounted for a total of two thirds of all reasons why patients were not transferred to shared care.

A total of 375 (71%) of 531 transferred patients responded to the postcard study of patients' experience with the care transfer. A total of 99% of these respondents stated that the information they had received from doctors and nurses in the outpatient clinics regarding the future follow-up was "good" or "really good". In all, 69% stated that they felt safe "to a great extent" and 27% "to some degree". Only 4% answered "to a lesser extent/not at all". Almost all patients (95%) knew that they had to contact their own GP if they had any future questions related to their PC.

DISCUSSION

We found that one in every five patients regularly seen for follow-up in the outpatient clinics for stable disseminated or possibly cured PC could be transferred to a shared care programme in which their GP served as coordinator while working in close cooperation with the department in question. The patients were mainly satisfied with the programme and almost all of them followed the scheduled follow-up as recommended.

A total of 227 patients who were believed to be eligible for the programme ahead of the consultation turned out not to be. The most frequent reason was a "patient wish", followed by either "unstable PSA" or "clinically unstable disease".

The shared care model compared with previous experience

Different shared care programmes have been introduced for follow-up in cancer patients. Studies comparing follow-up in the hospital and at the GP have demonstrated that hospitals focus more on disease-related circumstances and less on other medical circumstances, while the opposite applies to treatment at GPs [5-7]. A

TABLE 3

Reasons for not enrolling patients into shared care programme.

Reason	n
Patient's wish	80
Disease not stable	41
PSA not stable	37
Not reported	37
Complications to treatment	11
Need for adjustment of treatment	10
No doctors available	8
Other reasons ^a	23
Total	247

PSA = prostate-specific antigen.

a) Co-morbidity, lack of test answer, postponed to next visit.

systematic review demonstrated no difference in the clinical outcomes of different follow-up strategies [4]. Clinical guidelines for the treatment of cancer-related diseases can help ensure a better survival of cancer patients while reducing national health-care costs [8-10]. Clinical guidelines are also an important prerequisite for a shared care programme in which responsibilities and tasks are clearly divided [11-13]. Immediately after diagnosis and possible active treatment, patients are in close contact with the hospital. However, once the condition has stabilised, the number of visits is supposed to be reduced, and patients are to be transferred to their GP for follow-up [14, 15]. However, at present there are no official clinical instructions or official guidelines for the organisation of shared care.

In this study, we aimed at developing and introducing a shared care model for the follow-up of PC patients with stable stage disease based on existing evidence regarding the implementation of complex interventions [16].

Involvement of patients

Shared decision making is key in the shared care mind set, which is an approach in which clinicians and patients communicate on the basis of the best available evidence when faced with the task of making decisions. This approach has been ignored in the somatic health-care system for a long time [17]. In this shared care programme, patient information material was developed in cooperation with patient representatives in the Steering Group after common analysis of the patient perspective. Moreover, the implementation integrated a systematic involvement of patients in the decision concerning transfer to shared care. In consequence, not all patients initially judged to be suitable candidates for shared care were eventually transferred; this came as no surprise as a similar experience was gained in other shared care



Aligning expectations to treatment for prostate cancer.

programmes involving patients in the decision-making process. When asked about their preferences, patients will often choose to stay with the specialist [18]. However, this study shows that when given appropriate information, the vast majority chose to be transferred to shared care and that they felt comfortable about the way they were transferred.

Role of the practice sector/general practice

A successful implementation of a shared care model depends on various factors, but shared care is totally dependent on the GP, who play a new and more active role and receives the necessary support from the secondary sector, i.e. relevant information regarding tasks and specialized support, including the opportunity to receive guidance. A previous study from Canada with 189 GPs showed that 7 % of the GPs would undertake the task of monitoring breast cancer patients [19]. In line herewith, this study has demonstrated that GPs would like to participate in check-up and treatment of stable PC patients; however, it is important that the preliminary work is thorough and it is important to maintain a high level of information exchange. During the development and implementation of the present shared care programme, we aimed at integrating the practice sector in the development work and to fulfil the need for patient-specific information. The final evaluation showed that we had achieved this objective.

Development and implementation of the shared care model

The core elements in the present model included a systematic evaluation of whether the patient was suitable for the shared care regime, shared decision-making and structured communication with general practice. With

these core elements in place present local adaptation was possible. Such an approach to complex interventions is fully in line with present recommendations of having a “hard” core in the interventions combined with a “soft” periphery that allows flexibility in the intervention [20]. The intervention is not as standardised as we know it from drug trials, but it is more realistic and enhances the possibility of generalizing the results so that they may subsequently be applied to other settings. Similarly, there was a range of “hard” and “soft” elements in the implementation process that should bring the model into the daily clinical life. The “hard” components consisted in an established structure with a Steering Group where learning occurred cross-departmentally, while local project groups managed the implementation. Other “hard” elements in the implementation process were continuous monitoring of patients transferred to shared care and feedback to the local project teams from project coordinators. However, it was decided locally how the different elements of the shared care model should be introduced and how the organisational changes were to be implemented.

On the basis of present knowledge and recommendations, it was easy to achieve agreement in the Steering Group regarding which patient categories were suited for follow-up in general practice and concerning what a check-up should include and when re-referral was indicated. At the same time, the variation in the percentage of each patient category transferred to shared care among departments and hence also the total percentage indicate variations in local conditions and evaluations which may be important for the interpretation of whether a patient is suited for shared care or not. Such a variation is well-known in relation to clinical evaluations.

Perspectives

Currently, PC patients have visits scheduled at outpatient clinics. However, these follow-up visits have no documented advantages for patients and it therefore seems reasonable to consider transferring them to general practice. The increased resource pressure on departments of urology can result in unplanned and often inappropriate transfer. Based on existing knowledge of how changes happen in complex organisations, our study shows that it is possible to develop and implement an efficient and safe shared care programme with a high level of patient satisfaction. Furthermore, we demonstrated that a shared care programme made it possible to reduce visits at the outpatient clinics of each of the three participating departments to an extent that equals four weeks of visits in the annual calendar of the outpatient clinic.

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