Chapter 8

Participation in supportive care groups for men with prostate cancer: Unraveling the relationship between needs and evaluation

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Ja, het heeft me verrijkt, wat ik net al zei. En dat komt door het proces als geheel. Ik kan dat moeilijk benoemen op een onderdeel van: de tweede bijeenkomst ofzo. Dat kan ik niet zo benoemen. Het proces als geheel, dat heeft me verrijkt, door de uitwisseling... door mensen die in dezelfde situatie en onder professionele begeleiding.
(Respondent 694)
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Abstract

Objective: To assess the interest of men diagnosed with prostate cancer in participating in supportive care groups and to evaluate whether participation in their group format of choice fulfilled their supportive care needs.

Methods: The study consisted of seven group sessions of 2.5 hours each, every other week. Three different group formats (a social support group for men only, a social support group for couples and a support group for men only, focused on existential issues) were studied. The supportive care needs were assessed using patient interviews conducted before the start of a group session series. The interviews were processed using qualitative methods. Satisfaction was measured at the end of the program by open-ended questions and by quantitative measurement instruments.

Results: Of the men with prostate cancer approached, 6% (n = 48) were interested in supportive care and enrolled in the study. The supportive care needs found most often were contact with fellow patients, and a need to learn about practical issues related to prostate cancer and its treatment. Men also wanted to learn how to cope better with the disease. The majority of the men were satisfied with the supportive care they received and it appears that most needs were fulfilled.

Conclusion: A minority of men with prostate cancer actually used supportive care; however, the care provided is highly valued and met most participant needs.
Participation in supportive care groups

Introduction

Prostate cancer has a high incidence in Western countries (Ferlay et al. 2010; Jemal et al. 2010). Over 11,000 new prostate cancer patients were diagnosed in 2012 in the Netherlands, accounting for about 21% of the total cancer incidence in men (Dutch Cancer Registry 2014). Men with prostate cancer often experience psychosocial problems. More specifically, fear, anger, worries and sleep disturbance were found in about 50 percent of prostate cancer patients after treatment for localized prostate cancer (Walsh & Hegarty 2010; Hinz et al. 2010; Schag et al. 1994). Other studies have shown clinically significant levels of depression and anxiety in 16% and 12% percent of patients respectively (Sharpley & Christie 2007). Many patients report feelings of social isolation (Helgason et al. 2001; Hedestig et al. 2003; Sharpley et al. 2009). Moreover, urinary incontinence and erectile dysfunction were found to be major concerns for many prostate cancer patients (Butler et al. 2001; Walsh & Hegarty 2010). The many challenges men with prostate cancer have to face give rise to the need for supportive care. These needs are reported in several studies (Steinga et al. 2001a; Lintz et al. 2003; Ream et al. 2008).

Despite the problems and needs expressed by prostate cancer patients, studies indicate that men make limited use of supportive care interventions (Gray et al. 2000; Weber et al. 2000; Manii & Ammerman 2008). Similarly, while a Dutch pilot study revealed that 33% of men with prostate cancer indicate a need for psychosocial support, including support groups (Voogt et al. 2001), their actual participation is very low, despite the availability of psychosocial support in psycho-oncological care centers (Pet et al. 2010). At a psycho-oncological care centre in a densely populated area in the Netherlands, only 57 men (a few with prostate cancer) were treated over a period of seven years, compared to 310 women (mainly with breast cancer) (Wildenbeest & Visser 2011). This reflects the lower utilization rate of mental health services in men in general (Ang et al. 2004; Husaini et al. 1994).

Several explanations have been proposed for this low participation rate. Weber et al. stated in their study on the efficacy of support groups that this is due to male socialization: men are supposed to be tough, in control, displaying strength and stamina (Weber et al. 2000). Other studies showed that men with prostate cancer prefer to confide in a few selected persons, sometimes only to their spouses (Gray et al. 2000). Kiss et al. stated that men want to share information whereas women want to share emotion (Kiss & Meryn 2001). Moreover, studies of men in general have shown that men have negative attitudes towards seeking mental healthcare (Mackenzie et al. 2006; Wahto & Swift 2014).

However, a small proportion of men actually do attend supportive care facilities or involve themselves in social support groups (either peer support or professionally led), and others express the need to do so. It does, however, remain unclear what supportive care format is most appealing and helpful to these men.

One way of getting directions concerning the supportive care format is to look at the supportive care needs in more detail. Different forms of supportive care needs can be distinguished. The need for information is reported most frequently. Patients most often need information about the recurrence of the disease, the long-term expectations and the side effects of the various treatment options (Visser et al. 1997; Steinga et al. 2001a; Echlin & Rees 2002; Boberg et al. 2003; Lintz et al. 2003; Ruesch et al. 2014). Often, this need is barely satisfied by the healthcare professionals (Wong et al. 2000; Echlin & Rees 2002; Walsh & Hegarty 2010; O’Brien et al. 2011).
Another frequently reported need for support is related to sexual issues. This need involves the desire to obtain the tools needed to be able to become sexually active again, or support on how to deal with the loss of manliness and libido problems (Visser et al. 1996; Steginga et al. 2001a; Boberg et al. 2003; Lintz et al. 2003; Smith et al. 2007; Carter et al. 2011).

Another need topic is the fear of recurrence or spreading of the cancer, often raised by a routine check on the blood PSA level. The need for support on how to deal with this anxiety and the emotions of loved ones is frequently expressed (Hart et al. 2008; Lintz et al. 2003; Steginga et al. 2001b).

Further, patients express the need for support in learning how to cope with practical daily life issues such as problems with micturation or fatigue (Carter et al. 2011; Ream et al. 2008; Lintz et al. 2003; Steginga et al. 2001a; Visser et al. 1996; Voogt et al. 2001).

The supportive care need can be influenced by disease stage. During diagnosis and at the onset of the treatment, there are more informational and practical needs and issues around communication with physicians (Oh et al. 2007; Steginga et al. 2001a; Voogt et al. 2001), whereas some men with prostate cancer in advanced stages need more social support and existential reflection on the meaning of their experience of the disease (Ketelaar 1998; Steginga et al. 2001a; Carter et al. 2011).

The need for supportive care combined with a lack of participation in supportive care interventions underlines the importance of tailoring interventions to the specific needs of men with prostate cancer. Therefore, it is first of all important to assess interest in supportive care groups. Moreover, different intervention formats have been studied, yielding contradictory results (Berglund et al. 2007; Helgeson et al. 2006; Templeton & Coates 2004; Weber et al. 2004). Our study approach was first to assess the supportive care needs and then to give the participants a choice between different group formats, to choose the format most appropriate to their needs. The research questions of this study are summarized below.

1. What proportion of the men with prostate cancer approached are interested in participating in a supportive care group, and what kind of group do they choose?

2. Which care needs do prostate cancer patients intending to participate in supportive care groups express?

3. To what extent did the offered support fulfill the needs expressed before the start of the groups and what is the level of satisfaction with the support received?

4. Are the different supportive care needs expressed related to satisfaction and the fulfillment of the needs?
Methods

Participants
This study is part of a larger research project. Potential participants received a leaflet providing information about the study, including the offer to attend professionally led support groups for free. These leaflets were handed out by urologists in five hospitals and at educational meetings organized by two other hospitals. They were also sent to all members of the Dutch prostate cancer patients’ association (PCF). We distributed a total of 784 leaflets and received 303 (39%) affirmative response cards. Of these prostate cancer patients, 66 indicated the desire to participate in one of our support groups. Intake interviews were scheduled to assess whether a patient was eligible to join a support group. Eighteen men dropped out during this process following a change of mind about participation or as a result of becoming unable to participate in the study for practical reasons. This left 48 men in our participant group sample. Before starting the seven group sessions and after completing all of them, a questionnaire was distributed with questions on sociodemographic and medical factors, as well as an open-ended question on supportive care needs. Moreover, before the start of the group sessions, men were asked in interviews to indicate what their supportive care needs were and what they expected from supportive care. The participants’ experiences were evaluated after all seven sessions were complete.

Patients were eligible for the study if they had prostate cancer without having another disabling disease. They also had to comprehend the Dutch language sufficiently to understand the questionnaires. Exclusion criteria were having another type of cancer or another serious chronic disease which impaired health-related quality of life. Information on these criteria was obtained from medical files and from the patients’ self-reports. The Medical Ethical Committee of the Onze Lieve Vrouwe Gasthuis in Amsterdam, the Netherlands, approved the study. Respondents signed a letter of informed consent and gave permission for the retrieval of their medical information. The urologist associated with the research project contacted the various hospitals to ensure access to all relevant medical information.

The offered support groups
Three kinds of support groups were offered for participants to choose from: a social support group for men only, a social support group for couples only, and an existentially oriented group for men only. The couples group was created at the request of several patients who wanted to involve their spouse in the process. All groups received seven sessions of 2.5 hours each at intervals of 14 days, with the last session taking place one month after the sixth session, covering a period of 12 weeks in total. All groups were facilitated by a male and a female counselor. During the intake interview, the patients were informed about the different group formats and were asked to choose one. After the sessions began, no new participants were allowed to join the groups. The topics for each session were described to all groups in a session manual. However, the counselors were free to depart from the order of the topics if appropriate. The goal of all groups was to increase knowledge about the topics targeted, to reduce distress and to increase the participants’ sense of wellbeing by facilitating (further) adjustment to the prostate cancer. The material covered at each session was recorded by the counselor.
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- **In the social support group** for men only, the session themes were 1) introduction and getting to know each other; 2) presentation by a urologist about the disease and treatment, and answers to questions; 3) support experiences at hospital and contact with medical staff; 4) coping with physical complaints; 5) social relationships, intimacy and sexuality; 6) self-image and dealing with emotions; and 7) a follow-up session about any theme which emerged in the group.

- **In the social support group for couples** the session themes were 1) introduction and getting to know each other; 2) coping with physical complaints; 3) continuation of coping with physical complaints; 4) social relationships, intimacy and sexuality; 5) self-image and dealing with emotions; 6) continuation of self-image and dealing with emotions; and 7) follow-up session, back to daily life, looking ahead.

- **The existentially oriented group** had a looser format: a set of topics were scheduled and introduced, but the subject could change based on group dynamics and the protocol allowed the counsellors to follow the group’s wishes. The topics scheduled for each session were 1) introduction and getting to know each other; 2) the experienced body; 3) dealing with emotions; 4) sexuality; 5) self-worth and emotional autonomy; 6) farewell ritual for the participants; 7) follow-up, looking back and looking ahead.

**Design**

We used a mixed method design in this study. Information on the supportive care needs was obtained from intake interviews conducted before the group sessions started. These interviews were held with the prostate cancer patients who had indicated the intention to participate in one of our support groups. The interview included in-depth questions about their problems, their reasons for participating in a support group, their desires and preferences for this group, and their expectations about participating in a support group with fellow patients. The interviews were audio taped and typed out verbatim.

**Measurements**

After the whole series of seven group sessions was complete, a questionnaire was handed out, including the Dutch version of the Client Satisfaction Questionnaire (CSQ) (Brey & Peereboom 1986; Larssen et al. 1992). This questionnaire was used to measure the extent to which the participants’ supportive care needs were met as well as the level of patient satisfaction with the supportive care. The questionnaire consisted of eight questions about satisfaction with the support, rated on a four-point Likert scale from not at all to very much. The CSQ total scale range is 8 to 32, however, in the analysis, the total scores were divided by eight to create a range from 1 to 4. The scale has a reliability of $\alpha = 0.88$. Three questions were added, also rated on a four-point Likert scale. These questions concerned the perceived value of support group participation. The questions were 1) do you feel more at ease to talk about prostate cancer after your participation in the support group; 2) do you have fewer disease-related problems after your participation in the support group; and 3) did the support contribute to greater acceptance of your disease? Finally, participants were asked to provide a general rating of the support received, ranging from 0 (very poor) to 10 (very good).
Data analysis – qualitative part
The qualitative data were analyzed using the open-coding system (Boeije, 2005). In addition to the interviews, the answers to an open-ended question in the questionnaire were used in the open-coding system. Qualitative analysis was performed to identify the needs of the men with prostate cancer participating in the support groups (research question 2). The needs formulated by the patients in the interview and in the open question were classified to represent their content as closely as possible (open coding). Since respondents could indicate more than one need, the open coding system did not lead to mutually exclusive categories for further quantitative analyses. Therefore, we created nominal variables indicating whether the respondent did or did not indicate a specific need. The whole analysis was checked by another researcher (MvdB) and discrepancies were resolved by deliberation.

Data analysis – quantitative part
The differences between participants with respect to demographic variables, need fulfillment and satisfaction with the support received were analyzed using Chi-square tests on the nominal variables, and ANOVA tests on interval level variables. Non-parametric tests on ordinal variables were applied, because several variables were not normally distributed and the compared groups were smaller than N = 30. To answer research questions 3, 4 and 5, the Mann-Whitney U test was used to compare the CSQ and satisfaction scores of men indicating a need with men not indicating that need. The Kruskal-Wallis test was used to compare the fulfillment of the needs and the satisfaction across the different group formats.
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Results

Background characteristics

The demographic and medical variables of the men are presented in Table 1.

Table 1. Background characteristics (N = 48)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>66 (7.8)</td>
</tr>
<tr>
<td>Range</td>
<td>51–81</td>
</tr>
<tr>
<td><strong>Socio-economic Status</strong></td>
<td></td>
</tr>
<tr>
<td>Lower</td>
<td>19% (n = 9)</td>
</tr>
<tr>
<td>Medium</td>
<td>25% (n = 12)</td>
</tr>
<tr>
<td>Higher</td>
<td>56% (n = 27)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>85% (n = 41)</td>
</tr>
<tr>
<td>Single</td>
<td>15% (n = 7)</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Less than two years</td>
<td>40% (n = 19)</td>
</tr>
<tr>
<td>More than two years</td>
<td>60% (n = 29)</td>
</tr>
<tr>
<td><strong>Stage of disease</strong></td>
<td></td>
</tr>
<tr>
<td>Local</td>
<td>60% (n = 29)</td>
</tr>
<tr>
<td>Advanced</td>
<td>29% (n = 14)</td>
</tr>
<tr>
<td>Unknown</td>
<td>10% (n = 5)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
</tr>
<tr>
<td>Radical Prostatectomy (RP)</td>
<td>25% (n = 12)</td>
</tr>
<tr>
<td>Radiation therapy (RT)</td>
<td>15% (n = 7)</td>
</tr>
<tr>
<td>Hormone therapy (HT)</td>
<td>23% (n = 11)</td>
</tr>
<tr>
<td>Intentionally curative (RP, RT &amp; HT)</td>
<td>31% (n = 15)</td>
</tr>
<tr>
<td>RP &amp; RT</td>
<td>2% (n = 1)</td>
</tr>
<tr>
<td>No treatment/watchful waiting</td>
<td>4% (n = 2)</td>
</tr>
</tbody>
</table>

The participants’ age ranged from 51 to 81 years with an average of 66 years (SD = 7.8 years). Most men were married (85%) and more than half the men had received education at least to secondary school level. The mean time since diagnosis was 3.7 years (SD = 2.5) with a range of 0 to 10 years. Most of the men had local prostate cancer. Radical prostatectomy and an intentionally curative combination of treatments were mostly found.
Participation in supportive care groups

Data on supportive care needs were missing for five patients: one participant was allowed to join a group without an interview, two participants did not mention any needs, and data from two other participants were lost due to tape recorder malfunction. This left 43 participants with complete data on supportive care needs.

What proportion of the men with prostate cancer approached are interested in participating in a supportive care group, and what kind of group do they choose? (Research question 1)

Of the 784 men with prostate cancer approached, initially 8% (n = 66) were interested in participation in one of our groups. Ultimately, 6% (n = 48) of those approached actually participated in a support group. Of these 48 men, 18 (37%) participated in the social support groups for men only (divided across two groups). Three social support groups for couples were formed for 21 (44%) patients and their partners. The existential support group consisted of 9 men (19%). The men who participated in one of the groups were better educated (\( \chi^2 = 7.6, df = 2, p = 0.02 \)) than the men who did not wish to participate. No other differences on background characteristics were found between participants and non-participants.

Which care needs do prostate cancer patients intending to participate in supportive care groups express? (Research question 2)

Nine need categories were derived from the open coding process. These categories could be further aggregated into three main categories of need:

A. A need for contact with fellow patients was expressed by 91%. Within this need category, ‘giving’ refers to participatory desires such as wanting to educate others or offer support to others, ‘receiving’ refers to the opposite, the need for information and support. ‘Interaction’ refers to the need to be in touch with fellow patients and exchange experiences.

B. Learning about treatment-related issues was expressed by 58% of participants. This category refers to the more ‘technical’ information on the side-effects of treatment, practical issues around sexuality, while others wished to learn how others deal with metastasis.

C. Coping with the disease was expressed by 53% of the participants. This involved the emotional reactions to the prostate cancer.

More than one need could be expressed, with 21% expressing needs in only one main category, 47% expressing needs in two main categories and 32% expressed needs in all three main categories.

When forming mutually exclusive categories of expressed needs as variables to enable further quantitative analysis, the results show that only four men did not express the need for contact with fellow patients. This means that this need could not be used in further analysis as a discriminating factor or variable. Table 2 presents the results of the qualitative analysis.
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Table 2. Number and percentage of participants who indicated a supportive care need in the intake interview and in the questionnaire (N = 44)*

<table>
<thead>
<tr>
<th>Need Category</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Contact with fellow patients</td>
<td>39</td>
<td>(91)</td>
</tr>
<tr>
<td>Giving</td>
<td>20</td>
<td>(47)</td>
</tr>
<tr>
<td>Receiving</td>
<td>27</td>
<td>(63)</td>
</tr>
<tr>
<td>Interaction</td>
<td>16</td>
<td>(37)</td>
</tr>
<tr>
<td>2. Learning about treatment related issues</td>
<td>25</td>
<td>(58)</td>
</tr>
<tr>
<td>Treatment-related issues</td>
<td>14</td>
<td>(33)</td>
</tr>
<tr>
<td>Sexuality</td>
<td>5</td>
<td>(12)</td>
</tr>
<tr>
<td>Other issues</td>
<td>12</td>
<td>(28)</td>
</tr>
<tr>
<td>3. Coping with the disease</td>
<td>23</td>
<td>(53)</td>
</tr>
<tr>
<td>Coming to terms and acceptance</td>
<td>11</td>
<td>(25)</td>
</tr>
<tr>
<td>Coping with psychosocial consequences</td>
<td>12</td>
<td>(28)</td>
</tr>
<tr>
<td>Other issues</td>
<td>3</td>
<td>(7 )</td>
</tr>
</tbody>
</table>

* Percentages add up to over 100% since men could indicate multiple care needs

To what extent did the offered support fulfill the needs expressed before the start of the groups and what was the level of satisfaction with the support received? (Research question 3).

The results on the fulfillment of needs and satisfaction are displayed in Table 3. Nearly three quarters of all participants (72%) indicated that most or nearly all their needs were fulfilled after participating in the support group. Men who expressed only one need found the support more in accordance with their wishes compared to the men who expressed all three main needs (U = 48.0, p =.044).

The satisfaction rating overall was 7.5. The mean rating in the social support group for men only was 8.2, in the couples group 7.1 and in the existential group 7.3. The lowest rating was 5 (n = 2) and the highest was 10 (n = 1). 94.5% of the participants would recommend this kind of support to other men with prostate cancer. The mean fulfillment level (range 1-4) was 3.3 in the social support group for men only, 2.7 in the couples group and 2.6 in the existential group.

We found differences in the need fulfillment and satisfaction levels between the different group formats. In the groups for men only the support was more in accordance with participant wishes (K-W Chi² = 9.4, p = 0.01, df = 2) and the general satisfaction level scores were higher (F = 4.91, p = 0.01, df = 41) compared to the other two group formats. This difference could not be attributed to any differences in the background characteristics between the groups.
Participation in supportive care groups

Are the different supportive care needs expressed related to satisfaction and the fulfilment of the needs? (Research question 4)

The support provided was less in accordance to the wishes of men who expressed the need to learn how to cope better (U = 98.5, p = .006) and they also had a lower satisfaction score compared to participants who did not express this need (U = 111.0, p = .033), as shown in Table 3. No difference in satisfaction was found between men with and without the need to learn about treatment related issues.

Table 3. Satisfaction outcome measures compared for different supportive care needs (N = 43)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Contact with fellow patients#</th>
<th>Learning about treatment</th>
<th>Coping with the disease</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>Yes (N)</td>
<td>No (N)</td>
<td>Yes (N)</td>
</tr>
<tr>
<td>According to wishes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(range 1–4)</td>
<td></td>
<td>2.9 (0.73)</td>
<td>2.9 (0.67)</td>
<td>2.8 (0.84)</td>
</tr>
<tr>
<td>CSQ total score</td>
<td></td>
<td>3.1 (0.47)</td>
<td>3.1 (0.47)</td>
<td>2.8 (0.47)</td>
</tr>
<tr>
<td>General satisfaction level</td>
<td></td>
<td>7.5 (1.06)</td>
<td>7.73 (0.97)</td>
<td>6.8 (0.84)</td>
</tr>
</tbody>
</table>

# No statistical testing conducted due to the small size of the ‘no’ group
* Mann-Whitney U test, significance p < 0.05
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Discussion and conclusion

This study examined to what extent men with prostate cancer were interested in participating in supportive care groups and what care needs these men express. After completing seven group sessions, we evaluated the degree to which these needs were met and how satisfied the men were with the support received.

Of the men with prostate cancer approached, only a small proportion (6%) participated in the support groups. These men appear to be better educated than the men who did not participate. The main needs expressed were contact with fellow patients, wanting to learn about treatment-related issues such as incontinence and sexuality, and learning how to cope with the disease. Nearly 75% of the participants found that most of their needs were fulfilled by participating in one of the supportive care groups. The participants were also satisfied with the support received and 94.5% would recommend this kind of support to others. Men who initially expressed the need to learn how to cope better with the disease found their needs less well fulfilled and were less satisfied compared to men who did not express this need.

Our result concerning the interest in group participation and actual participation is in accordance with existing literature. One study of 210 prostate cancer patients found that 14% wished to participate in supportive care groups while 9% actually participated in such a group (Lintz et al. 2003). An earlier study by Krizek et al. found a 13% participation rate in men invited for psychosocial support, against 33% participation rate in women (Krizek et al. 1999). These percentages are, however, still higher than what we found in our study. It is possible that differences between healthcare systems account for this difference.

There remains a discrepancy between the finding that many studies on supportive care needs show that 11% to 40% of men with prostate cancer report psychological and/or emotional care needs (Ream et al. 2008; Lintz et al. 2003; Steginga et al. 2001a) on the one hand, while only a small percentage of men enroll in supportive care groups addressing those needs. To complicate things further, if men do participate in supportive care groups, they are usually very content and find the support offered to be beneficial in several ways (Coreil & Behal 1999; Steginga et al. 2005). To explain the low participation rate among men in such groups, the authors point to male socialization, in that men do not typically enjoy talking about feelings and prefer to concentrate on maintaining normal life, not burdening others with problems and using avoidant coping strategies (Weber et al. 2000). This is probably related to the negative attitudes about psychosocial help found in men (Mackenzie et al. 2006).

Men also prefer to discuss their feelings within their families or even only with their partners (Gray et al. 2000; Manii & Ammerman 2008). Other explanations can be found by considering how men deal with prostate cancer. Men typically want information on the disease and a supportive care group might not be the most useful place to get the information desired. In contrast, women want to share emotion (Kiss & Meryn 2001).

The care needs the men expressed in our study are partly different from what is found in the literature. This could be explained by the different methods used. Many studies use the Supportive Care Needs Survey (Bonevski et al. 2000). This results in topics within which the needs are expressed in categories such as information needs, psychological needs and needs in sexual areas (Ream et al. 2008; Lintz et al. 2003; Steginga et al. 2001a). We derived our data from interviews and found partly different needs, especially in the need for contact with fellow patients.
Participation in supportive care groups

However, finding the need for contact with fellow patients so strongly is probably an artifact, since this sample is self-selected and interested in participating in a support group. Comparable results are, however, found in the literature on the experiences of men with prostate cancer with support groups. Meeting fellow patients is found to be a very important reason in most studies, as it offers the possibility of sharing information (Krizek et al. 1999; Gray et al. 1997; Coreil & Behal 1999).

The giving and taking we found is also described in some literature (Gray et al. 1997). This mainly concerns giving and receiving information. The need to learn how to cope better with prostate cancer is not directly described in the literature; however, needs in the psychological domain might reflect a need for better coping. Needs in the psychosocial domain are found in studies on supportive care needs (Steginga et al. 2001a; Lintz et al. 2003; Ream et al. 2008). A study in Scotland found that men in support groups were less satisfied regarding their expectations for learning how to cope better with cancer (Deans et al. 1988).

In our study an explanation for this result is that men set their expectations of what they will learn about coping too high. Alternatively, they might want to talk about the emotional aspects of prostate cancer, but remain hesitant to do so in groups.

Most studies evaluating support groups for men with prostate cancer report high satisfaction levels (Coreil & Behal 1999; Steginga et al. 2005). It should be noted that the average satisfaction score of 7.5 on a scale from 1 to 10 reported in our study seems high, but this kind of measure could be subject to social desirability. Remarkably, the groups including partners had the lowest satisfaction rates for all three group formats, despite the fact that men chose these groups themselves and requested the involvement of their partners. This could be for various reasons.

Firstly, the higher satisfaction scores for the men-only groups can be explained by the presence of an urologist as part of this group format. This was valued very highly by the participants. Secondly, the men might not have been completely free in their choice of participating with their spouses, as their decision may have been the result of pressure from their partner. Thirdly, it has been established that men and women often differ in how they tend to cope with adverse events like cancer, and differ in the kind of support they prefer (Gray et al. 1996; Kiss & Meryn 2001). The women may have been dominant in these groups, imposing their way of sharing. There was no difference in background characteristics that could account for these differences in satisfaction.
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Limitations
This study is unique in the sense that in a single sample it assessed the supportive care needs of men who enrolled in a supportive care program, evaluated the program in terms of need fulfillment and measured program satisfaction. This design provides insight into what needs men with prostate cancer do express, and how these needs could best be addressed. However, some methodological limitations should be noted. Seventy-two percent of the participants were members of the prostate cancer patients association and were therefore specifically different from men who are not, for instance in having a greater wish to talk about prostate cancer and having higher levels of distress (Voerman et al. 2006). Another issue which should be considered is that satisfaction scores could be subject to social desirability and a measure for social desirability was not included in the questionnaire.

General conclusion
In sum, it can be concluded that many men with prostate cancer need support but only a small subset of these men will consider participation in a supportive care group.

The men who do participate in supportive care groups benefit from them in terms of finding most of their needs fulfilled. Participation therefore contributed to their adjustment to the disease. An exception was the fulfillment of needs in the area of coping, learning more or better coping skills, which seemed unfulfilled in all the groups. Future research could aim to develop interventions for men with this specific need.
Participation in supportive care groups

References


Chapter 8


Participation in supportive care groups


Chapter 8

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