**INTRODUCTION**

In localized prostate cancer, individual treatment decisions cannot be made on medical grounds alone [1,2] and, because of this, a lot of our patients carry a heavy burden [3]. Compared with other oncological entities, there are a lot of treatment choices with curative intent, ranging from active surveillance to various types of radiation therapy and different surgical approaches. Additionally, very private and delicate questions arise and these information needs can only partly be met by urologists and other healthcare professionals [4,5]. Discussion in social networks and with other peer groups becomes very important in this setting. Therefore, social support plays a major role for most patients with prostate cancer [6].

Little is known about communication among laypeople unrelated to conventional support groups [7] as it is neither institutionalized nor publicly available for scientific investigation. Thus, online support groups are a unique means for investigating patient-to-patient communication in medical decision-making. Most of the work already done in the field concentrates on formal and stylistic aspects, e.g. by comparing online support groups for breast and prostate cancer [8–10]. However, until now no evaluation of the content itself has been undertaken and the importance and

**OBJECTIVE**

- To investigate patient-to-patient communication with regard to decision-making in localized prostate cancer; as most of it is done in private, online support groups are a unique means for this task.

**PATIENTS AND METHODS**

- Over a 32-month period, we screened 501 threads in the largest German online support group for prostate cancer.
- Threads started by questioners newly diagnosed with localized prostate cancer and stating decision-making as the key topic were included; in all, 82 (16.4%) threads met these criteria.
- Two independent investigators characterized every thread following a standardized protocol.
- Fisher’s exact test and Mann–Whitney U-test were applied for group analyses. A complementary qualitative linguistic approach was chosen.

**RESULTS**

- Threads were most commonly started to ask for therapy recommendations (66%), information on the course of treatment (46%) and emotional support (46%).
- Answers consisted of treatment recommendations (40%), emotional support (37%) and personal experiences (28%).
- A second opinion on the biopsy cores (51%) and additional imaging (40%) were common suggestions.
- The rate of advice for radical prostatectomy (RP) vs radiotherapy was 67 vs 82%. Thus, surgery was less recommended in our sample ($P=0.01$); 75% of the men with an initial therapeutic preference were finally confirmed herein.

**CONCLUSIONS**

- Patients readily receive information, advice and emotional support as part of an online support group.
- The scientific evaluation of an online support group is a complementary way of getting to know our patients’ needs and worries.
- Patient–physician contact can benefit from this knowledge.

**KEYWORDS**

online support group, prostate cancer, decision-making, peer-to-peer support, patient education
impact of peer-to-peer counselling is not sufficiently understood.

In the present study, we present an explorative quantitative investigation for hypothesis-building enhanced by a qualitative linguistic analysis. The resulting picture could contribute to a better understanding of our patients’ needs and worries.

PATIENTS AND METHODS

The largest German online support group on prostate cancer (http://forum.prostatakrebs-bps.de; 1479 registered users and 33 073 postings at the time of data collection) is maintained by the umbrella organization of regional prostate cancer support groups (Bundesverband Prostatakrebs Selbsthilfe e.V.). This freely accessible forum was used as a data source for the present study. As the forum software had been migrated from a previous platform, data were available from May 2006 onwards. Inclusion criteria were as follows: threads started between May 2006 and December 2008 in the forum subdomain ‘First aid and advice’; terminated discussions, defined as threads that had been closed by the moderators or that had not received postings during the last 30 days; threads started by questioners newly diagnosed with localized prostate cancer and with decision-making as the key topic. Exclusion criteria were as follows: off-topic threads, i.e. with content not pertaining to decision-making; threads started by proxy.

In all, 501 threads were screened. Of these, 48.1% (241/501) were excluded as being off-topic and 35.5% (178/501) as being written by proxy; 16.4% (82/501) of threads, with a total number of 1630 postings, were included in the study. A total of 24.5% (399/1630) of the postings had been written by men seeking advice. These men had a mean age of 58.3 ± 7.6 years and were diagnosed with a Gleason score of 6.4 ± 1.1 and an initial PSA level of 9.2 ± 9.3 µg/L. Duration of a thread was 21.4 ± 31.4 days with a mean number of 18.8 ± 17.9 postings per thread. Questions were discussed by 8.1 ± 5.0 different consultants per thread.

ANALYSES

Three members of our interdisciplinary team (JH, AL and AK) coded different random samples of 15 selected threads each. These results were discussed in several joint sessions to work out the protocol for thread analysis according to grounded theory [11]. Subsequently two independent investigators (JH and AK) characterized every thread following this standardized protocol. The content of the question, current treatment preference, answers, feedback by the questioner, final decision and number of hits were noted for every conversation. Divergent judgments were discussed and solved consensually. For balancing different conversation lengths, relative frequencies of advisors’ answers and questioner’s feedback were calculated: the absolute count of events was divided by the number of corresponding postings within the given thread and presented as a percentage. For example, five events of emotional support by advisors result in a value of 50% in a thread with 10 answers and 25% in a thread with 20 answers. Distribution of categorical data was given by absolute and relative frequencies and compared using Fisher’s exact test between groups. Continuous variables are presented as mean ± SD. We applied the Mann–Whitney U-test for explorative univariate statistics. In all tests, P < 0.05 was considered to indicate statistical significance. All calculations were performed using SPSS 16.0 (Chicago, IL, USA). The statistical analysis was approved by the institutional consulting programme. As a complementary approach, a qualitative linguistic analysis was performed: conversation analysis involved ethnographic methods and methods from discourse analysis to generate hypotheses based on grounded theory [11,12].

TRIAL REGISTRATION AND ETHICS COMMITTEE APPROVAL

The present study was part of the project ‘Experienced involvement in counselling for prostate cancer’ (German Clinical Trials Register; DRKS00000296), which was approved by the Institutional Review Board of the University of Heidelberg [Vote S-333/2009].

RESULTS

Specific questions were posed in 79% (65/82) of the threads, while the remaining 21% (17/82) covered more general areas. Most commonly requested were therapy recommendations 66% (54/82), information on the course of treatment 46% (38/82) and emotional support 46% (38/82). The content of the question influenced readers’ interest, resulting in more hits for threads on emotional support (P = 0.04), treatment-related side-effects (P = 0.031) and further diagnostics (P = 0.013). Topics and the corresponding number of hits are given in Table 1. A total of 30% (25/82) of the conversations were completed, whereas the remaining 70% (57/82) were not. This feature did not depend on the type of question posed (P = 0.375).

ANSWERS AND FEEDBACK

The 10 most active advisors account for 34% (419/1231) of all the answers in our sample. With respect to the whole online support group this proportion is confirmed: the top 10 advisors wrote 36% (11 921/33 073) and the most active 5% of all users (74/1479) wrote 70% (23 015/33 073) of the postings.

Answers and questioners’ feedback are given in Table 2. Matching the requested content, answers provided treatment recommendations (40 ± 35%), emotional support (37 ± 24%) and personal experiences (28 ± 21%) were more commonly requested via e-mail (4 ± 7%) and telephone (2 ± 7%), and never in person. The advice to keep calm (14 ± 21%) was more common than the
recommendation to hurry up in a given situation (6 ± 15%).

Additionally, we compared the answers for two statistically independent ($P = 0.171$) pairs of dichotomous subgroups of questioners (undecided vs therapeutic preference; request for emotional support vs none). This comparison is also shown in Table 2.

There were several differences between undecided questioners (54/82) and men expressing a certain therapeutic preference (28/82). The latter received increased emotional support ($P = 0.031$) and were told to gather further information ($P = 0.013$) more often. Likewise, questioners who stated a therapeutic preference were more active in giving feedback: they expressed their gratitude ($P = 0.007$), substantiated their treatment decision ($P = 0.002$) and provided emotional support ($P = 0.034$) more frequently. In all, 75% (21/28) of the men initially expressing a therapeutic preference were finally confirmed herein.

By contrast, the explicit request for emotional support (38/82) vs no such wish (44/82) did not influence the spectrum of answers. In particular, the frequency of providing emotional support was equal for both groups ($P = 0.978$). Nevertheless, those who have asked for emotional support were more thankful ($P = 0.005$) and explained their personal treatment decision ($P = 0.041$) to a greater extent.

The number of positive and negative judgments regarding different treatment options is shown in Table 3. While, in terms of total numbers, positive advice on radical prostatectomy (RP; $n = 92$) was more common than that for radiotherapy ($n = 84$), the rate of advice vs dissuasion was significantly lower for RP (67%, 92/138) than for radiotherapy (82%, 84/102; $P = 0.010$). Thus, surgery was regarded as more controversial in our sample.

Figure 1 shows initial statements regarding these two alternatives ($n = 114$) and final decisions ($n = 45$) disclosed by a subgroup of these men. When comparing initial positive (preferred or decided) and negative (definitely not or rather not) attitudes of the questioners towards these treatment options, the attitude towards RP (16 vs nine) was more positive.

### Table 2: Advisors' answers and questioner's feedback: total values and explorative comparison of subgroups

<table>
<thead>
<tr>
<th>Event</th>
<th>Total sample (82)</th>
<th>Undecided (54) vs therapeutic preference (28)</th>
<th>Requesting emotional support: no (44) vs yes (38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advisors' answers</td>
<td>$\bar{x}_{total} \pm \sigma$, %</td>
<td>$\bar{x}_{undecided} \pm \sigma$, %</td>
<td>$\bar{x}_{preference} \pm \sigma$, %</td>
</tr>
<tr>
<td>Specific answer to posed problem</td>
<td>20 ± 19</td>
<td>19 ± 19</td>
<td>22 ± 20</td>
</tr>
<tr>
<td>Emphasis on individuality</td>
<td>6 ± 13</td>
<td>6 ± 15</td>
<td>5 ± 9</td>
</tr>
<tr>
<td>Report of first-hand experience</td>
<td>28 ± 21</td>
<td>27 ± 23</td>
<td>31 ± 17</td>
</tr>
<tr>
<td>Providing emotional support</td>
<td>37 ± 24</td>
<td>33 ± 23</td>
<td>45 ± 24</td>
</tr>
<tr>
<td>Offer contact via e-mail</td>
<td>4 ± 7</td>
<td>4 ± 7</td>
<td>4 ± 8</td>
</tr>
<tr>
<td>Offer contact via telephone</td>
<td>2 ± 7</td>
<td>3 ± 8</td>
<td>1 ± 4</td>
</tr>
<tr>
<td>Advice to keep calm</td>
<td>14 ± 21</td>
<td>15 ± 22</td>
<td>13 ± 18</td>
</tr>
<tr>
<td>Urging to hurry</td>
<td>6 ± 15</td>
<td>7 ± 17</td>
<td>4 ± 11</td>
</tr>
<tr>
<td>Advice to gather more information</td>
<td>6 ± 11</td>
<td>5 ± 12</td>
<td>9 ± 11</td>
</tr>
<tr>
<td>Advice for further diagnostics</td>
<td>19 ± 22</td>
<td>21 ± 22</td>
<td>14 ± 22</td>
</tr>
<tr>
<td>Recommendation for a second opinion</td>
<td>9 ± 13</td>
<td>9 ± 13</td>
<td>7 ± 13</td>
</tr>
<tr>
<td>Recommendation for specific address</td>
<td>25 ± 28</td>
<td>23 ± 26</td>
<td>30 ± 33</td>
</tr>
<tr>
<td>Recommendation for specific treatment option (advice or dissuasion)</td>
<td>40 ± 35</td>
<td>41 ± 35</td>
<td>37 ± 36</td>
</tr>
</tbody>
</table>

### Table 3: Dissuasion and advice concerning different treatment options for localized prostate cancer

<table>
<thead>
<tr>
<th>Treatment option</th>
<th>Dissuasion, $n$ (%)</th>
<th>Advice, $n$ (%)</th>
<th>Total number of mentions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watchful waiting</td>
<td>18 (35)</td>
<td>33 (65)</td>
<td>51</td>
</tr>
<tr>
<td>RP</td>
<td>46 (33)</td>
<td>92 (67)</td>
<td>138</td>
</tr>
<tr>
<td>Complementary medicine</td>
<td>5 (23)</td>
<td>17 (77)</td>
<td>22</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>18 (18)</td>
<td>84 (82)</td>
<td>102</td>
</tr>
</tbody>
</table>

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than that towards radiotherapy (four vs 15). This difference is statistically significant ($P = 0.006$).

LINGUISTIC FEATURES: TENTATIVE STYLE AND SOCIAL TABOO

The nomenclature used varied considerably, thus indicating a wide range in the levels of knowledge among people contributing to the site [13]. A typical strategy used by participants to avoid humiliation due to content-related mistakes was the use of the tentative style. Most of the non-professionals deliberately presented their contributions as being in need of correction: they used subjunctives ('If I were in your place, I would . . .') and corresponding grammatical particles ('maybe', 'actually'). Moreover they quoted external experts ('I have read about several cases . . .', 'It was explained to me . . .', 'My urologist told me . . .') or simply stated their level of knowledge right from the start ('I do not belong to the medical experts here . . .').

The use of professional phrases such as 'prostate carcinoma' or 'positive biopsy findings' was extraordinarily common. Contrary to our expectations that the word 'cancer' would be very common among laypeople, this expression was rarely used. The term 'prostate cancer' was avoided by using acronyms ('PC'), colloquial synonyms and surrogate constructions ('urological problems', 'the described problem'). Sometimes the disease was not mentioned at all and elusive phrases concerning the participant's personal situation were used instead ('now it caught me, too', 'my situation').

DISCUSSION

For more than a decade, the importance of online resources for decision-making has become increasingly recognized [14]. However, until now researchers have mainly evaluated professional information and sites of healthcare providers [4,14,15]. In the present study, using an approach that combined quantitative and qualitative methods, we analysed form, content and language used in peer-to-peer communication between patients with localized prostate cancer in an online support group. Furthermore, we explored the course and possible impact on individual decision-making.

While most of the queries are asking for treatment recommendations, emotional support also plays a major role. It is explicitly sought in 46% (38/82) of the threads and frequently provided (37 ± 24%), making it the most common subject after decision-making itself. The analysis further shows that a lot of information-seeking is answered by emotional support. Therefore, the lay advisors cover the support-needs of patients with cancer [16] very well and regardless of their specific request. The data in the present study adjust former findings concerning patients facing prostate cancer [9], as emotional support is readily welcome and a substantial part of nearly every conversation. Moreover, social interaction via online support groups might have therapeutic importance with regards to the coping of affected people and counsellors likewise [17].

Although an open access online discussion board is one of the most democratic forms of social interaction, we found evidence of inhomogeneous participation (50% of all users contributed 70% of the postings). Therefore, only a few people influence the range of opinions largely and are opinion-forming. This oligarchic structure becomes especially noticeable in the high frequency of recommendations for a second opinion on biopsy cores. This advice was commonly proposed and mirrors the belief of only a few users. At the same time, two pathologists are named in most cases. There is also a trend towards additional imaging that is not medically necessary [2]. These potentially negative effects of medical advice given by laypeople are a well-known source of criticism towards traditional support groups [5].

Treatment recommendations appear to be more balanced (Table 3). Surgical therapy received less support in our sample than radiotherapy ($P = 0.01$), but all three guideline-conform options are adequately represented [2,18]. Additionally, complementary medicine did not play a significant role, as it only accounted for 7% (22/313) of all treatment advice. Initially, most of the questioners tended to prefer a surgical approach, as they entered the online support group after counselling their urologist [19,20]. Whether advice from the online support group actually affects final treatment decisions cannot be judged, as too few were documented in feedback postings and additional influences were not controlled.

The effect of an initially expressed therapeutic preference is interesting. Besides receiving more emotional support, these patients were told to become better informed and to undergo additional diagnostics. Thus, their preference was actively questioned. Finally, most of the men (75%) stuck with their initial preference and gave feedback on the grounds for their decision. The sample in the present study depicts a well-founded process of decision-making triggered by social interaction where balancing reasons is actively demanded. Therefore, online support groups are a very strong tool for involving patients with cancer in their own care [17].

Tentative use of language was very common, showing that the participants originate from quite diverse backgrounds with most of them being non-professionals. As similar strategies are used in verbal communication between patients and physicians, these linguistic features imply that written communication within an online support group is conceptually verbal [21].

Although widely used, tentative phrases are rather vague and leave the weighting of opinions and statements to the reader. This is problematic as it can cause unease at the worst. Uncertainty in the informational domain could be further amplified by the dominant use of medical terms. Lay understanding of medical terminology is often poor, yet, at the same time, non-professionals tend to overestimate this understanding [22]. Also, medical expressions appear more serious [23] and hamper a genuine conversation about personal issues [24]. Common words such as ‘cancer’ are

FIG. 1. Initial preference ($n = 114$) and final treatment decision ($n = 45$) for RP and radiotherapy.
avoided and the disease becomes a taboo with the use of acronyms or paraphrases. It therefore seems that not even the anonymity of nicknames can counterbalance the public nature of the internet and thus reserved language characteristics prevail.

The main weaknesses of the present study are its descriptive nature and a sample consisting only of postings by men, due to our focus on prostate cancer. This sample selection could mean our results are not representative of online support groups in general and limit their generalizability. Furthermore, the large standard deviations in the percentages of answers and feedback can be interpreted as evidence that the communication characteristics are not uniform, and could be further explained by factors not addressed in the present study.

Another important aspect that is hardly touched upon in the present study is the large number of passive observers, the so-called ‘lurkers’. The threads of the chosen online support group are easily found by web search engines and readers benefit to a similar extent even without making an active contribution [25].

In conclusion, virtual peer-to-peer interaction could provide similar positive benefits to those known to be offered by conventional support groups [26]. Without the necessity of direct personal contact, patients readily receive information, advice and emotional support. Emotional issues are covered whether or not they are requested. Focusing on facts and figures does not rule patient-to-patient counselling in patients with prostate cancer. Instead, social interaction via the internet is successful and appears to be a regular part of coping with the disease as well as the decision-making process. Scientific evaluation of peer-to-peer counselling is a complementary way for clinicians to get to know their patients’ needs and worries. Moreover, the possible negative effects of support groups [5,27] can be discussed during patient–physician contact.

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Abbreviation: RP, radical prostatectomy.