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## Social support for patients with penile cancer: A mixed-method study

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## Conflict of interests

The authors declare that there are no conflicts of interest.


#### Abstract

Research question: The research questions were as follows: How much social support do patients with penile cancer $(P C)$ receive after surgical treatment for the condition; which factors are associated with the social support received; and how do patients with PC describe the social support they receive in terms of emotional support, affirmation and concrete aid?

Research problem: The purpose of this study is to describe the amount and type of social support (that is, emotional support, affirmation or concrete aid) received by patients with PC. In addition, it describes the associations between patients' background variables and their perceived social support.

Literature review: Men affected by PC experience a range of unmet support care needs, of which social support has not previously been thoroughly studied. Emotional support consists of caring for another person, respecting and creating a safe atmosphere for them and providing spiritual support. Affirmation is the reinforcement of knowledge and is especially evident in decision-making processes through advising or counselling. Concrete aid means the provision of assistance in the form of an activity or service that causes the donor to use time or money for the benefit of another person. Methodology: A partially mixed concurrent dominant status design was used and included semistructured interviews with, or letter responses from, 15 patients and a self-reported social support score survey of 42 patients with PC. The data were analysed using descriptive statistics, a nonparametric test and a deductive content analysis.

Results: Regarding the self-reported social support score survey, 42 patients reported the social support as good (mean [SD]; range 4.34 [1.06]; 1-6). The most frequent form of social support was affirmation (mean [SD] 4.65 [1.07]), and the least frequent was emotional support (mean [SD] 4.14 [1.16]). Employment status and primary operation were significantly associated with the social support received. Qualitative data imply that family members are the most important emotional supporters. Emotional support from healthcare professionals was felt to be insufficient. Despite their affirmation, patients felt they received incomplete information about the disease. Patients received


concrete aid from family members but felt there was a lack of professional help. Although patients deemed the overall social support received to be good, they received insufficient support from healthcare professionals (emotional support) and had unmet informational needs (affirmation) as well as uncertainties regarding income support (concrete aid).

Conclusions: Our results can help nurses provide more holistic care to patients with PC. This information can be utilised in the development of nursing interventions for such patients and their family members. In the future, nurses' and other healthcare professionals' counselling skills should be taken into account in their training. They also need to be supported through consultation and referral resources when they reach the limits of their expertise.

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## What is known about the subject?

Nurses are best placed to provide and coordinate social support resources for patients with penile cancer. Therefore, physical, mental, sexual and social factors must be considered in the nursing of patients with penile cancer.

## What does this paper contribute?

The overall social support received was deemed good; however, the patients had unmet informational needs regarding their illness and uncertainties regarding the amount and type of social and income support they would receive during the course of their illness.

Keywords: patient with penile cancer, penile cancer, penile surgery, social support

## BACKGROUND TO THE STUDY

In serious diseases, such as cancer, there is an emphasis on the importance of social support for patients. This need, and the forms it takes, depends on the individual. Penile cancer (PC) is a rare malignancy with an incidence of approximately 1 per 10000, and 40 new cases are diagnosed annually in Finland (1, 2). PC has an embarrassing and powerful effect on a patient's personality and therefore poses a special challenge to nursing (3, 4, 5). PC and its treatment can seriously impact sexuality, intimacy, urinary function, mental health, body image and health-related quality of life (5, $6,7)$. The need for social support is especially important for patients with cancer and their relatives (8). A prerequisite for high-quality care is that healthcare professionals consider and listen to patients $(8,9)$. According to a systematic review of the international literature, men affected by PC experience a range of unmet supportive care needs (10). Therefore, it is especially important to consider and support patients with PC, and, in particular, to start designing a social support network that provides them with better support $(7,11)$.

## Social support

Social support has been highly relevant concept to nursing and social science research since in the 1970s (12). Cobb (13) defines social support as information leading the subject to believe that the person is cared for, loved, esteemed and a member of a network of mutual obligations. Supportive interactions among people protect against the health consequences of life stress (13), while psychosocial support has a generally positive effect on health and longevity and acts as a buffer in stressful life situations (14). Social support is helpful in dealing with anger and depression (15), and it has a positive association with subjective experiences of good health (12), while lack of support has been suggested to predict mortality $(16,17)$. The key elements in supportive transactions are affection, aid and affirmation (18). Social support is given and received within a social network, which has been defined as the vehicle through which social support is provided $(18,19)$.

The definition of social support can be further divided into three areas: emotional support, affirmation and concrete aid (18). According to Kahn (18), emotional support consists of caring for another person, respecting and creating a safe atmosphere for them, and providing spiritual support related to, for example, religion or philosophy. Affirmation is the reinforcement of knowledge and is especially evident in decision-making processes through advising or counselling. Concrete aid is a somewhat ambiguous term. It is easily misunderstood as interactive action or acting on behalf of another person, in which case it is no longer support (13, 18). According to Kahn (18), concrete aid is the provision of assistance in the form of an activity or service that causes the donor to use time or money for the benefit of another person.

In the authors' opinion, nursing staff are best placed to provide and coordinate social support resources for patients with PC. Therefore, physical, mental, sexual and social factors must be considered in the nursing of patients with PC $(11,20)$. More qualitative and quantitative studies are needed to investigate the psychosocial aspects of a rare disease $(7,21)$. According to Dräger et al (22), psychosocial care needs were higher in younger patients or patients with cancer recurrence in a German study carried out in 2010. Additionally, patients' need for psychosocial care depends on their partnership status. For instance, patients who live in marital relationships receive support from their partners (23). A systematic review (10) underscores the need for clinical service reconfiguration internationally to develop new approaches and standardised ways of identifying and addressing the profound unmet support care needs of men and their partners affected by PC.

Quantitative methods do not necessarily tell us enough about the need for social support; therefore, we decided to use a multimethod approach in this study (24). By offering patients with PC the opportunity to share their experiences of social support, we aimed to achieve a more comprehensive understanding of the social support received and the factors associated with it. We used a partially mixed concurrent dominant status design (25) to investigate the support needs of PC patients.

## RESEARCH QUESTIONS

The present study aims to provide a better understanding of the perspectives of patients with PC on the social support they receive. The research questions were as follows:

1) How much social support do patients receive after surgical treatment for PC?
2) Which factors are associated with the social support received?
3) How do patients with PC describe the social support they receive in terms of emotional support, affirmation and concrete aid?

The information provided by both the quantitative and qualitative methods through this study can be used to optimise social support services and provide holistic care to patients with PC.

## SAMPLE

## Participants

To achieve a more comprehensive understanding of the social support received by patients with PC, a partially mixed concurrent dominant status design (25) was used, in which both quantitative and qualitative data were collected (24). The sample of patients with PC was collected using patientreported outcome (PRO) questionnaires in a university hospital in southern Finland between May and August 2020. All patients with diagnostic codes (C60, C60.0, C60.1, C60.2, D07.4) in the International Statistical Classification of Diseases and Related Health Problems, $10^{\text {th }}$ Revision, were included, and a further cross search was undertaken with operation codes (KGB00, KGD00, KGD05, KGC10, KGD96) according to the Nordic Medico-Statistical Committee (NOMESCO) Classification of Surgical Procedures (NCSP). Only participants living independently in their homes and whose native language was either Finnish or Swedish were eligible under inclusion criteria for the quantitative element of this study. To give patients with PC the change to give their personal experiences of social support that could not be quantified, we also invited these patients with PC to participate in the qualitative part of this study, which was conducted in the form of an interview or a letter response.

## Data collection methods

Questionnaires were mailed to 65 patients with PC who met the inclusion criteria and had undergone operation for PC between 2009 and 2019. The questionnaires were re-posted once to those who did not return the questionnaire in the first round. Fifteen men agreed to participate in the qualitative part of the study (telephone interview or letter response) of whom five participated in the telephone interview and 10 answered the questions in writing.

## Quantitative phase

Quantitative data were obtained on demographic variables, and the participants completed the social support score (26). Sociodemographic data included patients' age, partner status, children,
education and employment status. Patients' clinical information was collected from the hospital register.

Social support for patients with PC from healthcare professionals was measured using the social support score, which is a dimension of The Family Functioning, Health and Social Support (FAFHES) scale (26). Permission was obtained from the developers of the instrument. The FAFHES instrument was initially developed to assess families of cardiac patients $(27,28)$. Since then, it has been further developed and used in a variety of settings as well as among different populations, including patients with prostate cancer and their family members and families with children or older people living at home (29, 30, 31, 32). The social support score, which consists of 18 items, includes three subscales: emotional support (six items), affirmation (seven items) and concrete aid (five items). Each item is answered on a 6-point scale ranging from 1 (strongly disagree) to 6 (strongly agree). Cronbach's alpha coefficients for the social support score ranged from $0.889-0.963$ in the sample of patients with PC (Table 3).

## Qualitative phase

The interviews were conducted using an interview guide with an open question (What kind of social support did you receive concerning your care from diagnosis to survivorship?). The question was clarified as follows: social support refers to all the supportive activities that a patient needs after and during a serious illness from healthcare professionals, family members, relatives and peers. Support can be emotional support, affirmation or concrete aid (18). If required, these three areas of social support were clarified (e.g., emotional support means discussing and listening). The interview guide was not piloted. In total, five telephone interviews were conducted during November 2020 by the first author. The 10 men who chose the letter response option received questions with clarifications by mail in November 2020.

## Data analysis

Quantitative data were described using frequencies, percentages, means, standard deviations, medians and quartiles. The associations between sociodemographic characteristics and the social support received were analysed using the Mann-Whitney and Kruskal-Wallis tests because the social support score did not meet the assumption of normality. Spearman's correlation coefficient was used to analyse the relationship between the social support received and age. The internal consistency of the summated variables was examined using Cronbach's alpha coefficients (33). Analyses were performed using IBM SPSS statistics Version 27 (IBM Corp., Armonk, New York). The level of statistical significance was set at $p<0.05$.

Qualitative data were analysed by the first author in consensus with the research team using deductive-inductive content analysis (34). The analysis was guided by a categorisation matrix consisting of the concept of social support categorised as emotional support, affirmation and concrete aid (18). The data were first organised according to these three categories, and the meaning units were condensed if they were not already in a condensed form. The condensed meaning units ( $n=86$ ), which were words, expressions or sentences related to the context, were grouped according to the content in each of the three categories. The meaning units were grouped into sub-categories ( $\mathrm{n}=15$ ) according to content similarity. Substantially similar sub-categories were formed into three categories (emotional support, affirmation and concrete aid) $(34,35)$. The description of the perceived social support is presented in Figure 1.

## Ethical considerations

This study followed the ethical directions of the Helsinki Declaration (36). Permission (R19026H) to carry out the research was sought and obtained from the relevant director of the department. Participants received information both orally and in writing about the purpose of the study, the voluntary nature of their participation, the confidentiality of their data and how their data would be
kept anonymous. Participants provided their informed consent prior to the interviews (37). The interviews were recorded with the consent of the study participants, and only the research team used the interview material (37).

## RESULTS

## Quantitative phase

A total of 42 of 65 men (64\%) returned the completed questionnaire. The mean age of the patients was 70 (SD = 11; range 45-91). Twenty patients had undergone penile resection or penectomy (48\%), twenty (48\%) had undergone glansectomy, and two (4\%) had undergone minor surgery. The background variables of patients are presented in Table 1.

## Social support received

The social support received is presented in Table 2. Patients with PC reported moderate social support from healthcare professionals (mean $=4.34, \mathrm{SD}=1.06$ ). Emotional support (mean $=4.14$, SD $=1.16$, range $1-6)$ was the least reported type of social support. Based on the average value, patients with PC reported that healthcare professionals demonstrated a great deal of consideration for the well-being of patients (mean $=4.61, S D=1.16$ ) and were very interested in how the patients were coping with aftercare ( mean $=4.68, S D=1.21$ ). Correspondingly, showing interest in family affairs (mean $=3.55, S D=1.52$ ) and appreciation of family involvement in care (mean $=3.75, S D 1.37$ ) were the least commonly reported dimensions of emotional support. On average, patients with PC reported high levels of affirmation (mean $=4.65, S D=1.07$ ), this being the most reported type of social support. Healthcare professionals' discussion was mainly related to progress of care (mean $=$ $4.88, \mathrm{SD}=1.13$ ). Concrete aid (mean 4.16, SD 1.20 ) was the second most reported type of social support. Explanation related to the prognosis of PC (mean = 4.79, SD = 1.22) was, on average, the most commonly experienced dimension of concrete aid. Congruently, family involvement in patient care (mean = 3.80, SD = 1.64) was the least commonly reported dimension of concrete aid (Table 2.)

## Background variables and social support received from healthcare professionals

The associations between the background variables of patients with PC and social support received are presented in Table 3. The patients' employment status ( $p=0.006$ ) was associated with emotional
support. Patients who were retired or unemployed $(\mathrm{Md}=4.67, \mathrm{Q} 1=3.50, \mathrm{Q} 3=5.00)$ reported receiving higher emotional support than those who were employed $(\mathrm{Md}=3.50, \mathrm{Q} 1=2.25, \mathrm{Q} 3=$ 4.17). Patients who had undergone glansectomy ( $M d=4.83, \mathrm{Q} 1=4.44, \mathrm{Q} 3=5.14$ ) reported receiving higher social support ( $\mathrm{p}=0.039$ ) than those who had undergone minor surgery $(\mathrm{MD}=2.56, \mathrm{Q} 1=$ $2.39, \mathrm{Q} 3=2.72$ ) or penile resection/penectomy $(\mathrm{Md}=4.11, \mathrm{Q} 1=3.10, \mathrm{Q} 3=5.06)$. Age, partner status, children, education level and place of residence were not associated with the social support received by patients.

## Qualitative phase

One of our primary aims was to examine how patients with PC described the social support they received in terms of emotional support, affirmation and concrete aid. The perceived social support, as related to emotional support, affirmation and concrete aid, is presented in Figure 1.

## Emotional support

Patients reported that their partners were the most important supporters. Emotional support from partners was pivotal because they could discuss intimate topics together (Figure 1):

Well, yes, I prefer to talk to my wife. She is a familiar person and so on. Obviously, I'm not going to talk about it with the neighbours. This is so close to sexuality... (Man, aged 80)

Other family members also had important roles. For instance, children were an important support to the patients; indeed, emotional support from children was primary, especially if the patient was not in a marital relationship:

Yes, the young man [son] has had to experience the worst at his young age. But at the same time, he has grown mentally, at least. He has learned [to deal with] whatever life brings him. Yes, it is so. Let's say that if it wasn't for my son, I wouldn't be on this call here... (Man, aged 61)


#### Abstract

Patients received emotional support from their friends and were able to discuss the disease with a trusted friend:


If, during the recovery process, I hadn't found an understanding relationship where I eventually dared to open up, and if this person had not 'forced' me further than the psychologist, I would have been really alone with the issue. I really had the best luck in this regard, which might not be the case for everyone. At the least, a person returning from hospital/recovering from an illness should not be left alone, at the least ensuring that the person recovering has someone close to them to turn to. (Man, aged 57)

Patients felt that open discussion about PC with other people gave them support and said that conversation with other people helped them understand that their own situation was not as bad as it seemed. In contrast, peer support was perceived as suspicious: the patients did not know any other men with the same illness and did not believe they could receive emotional support from a peer support group:
... I have this kind of experience/feeling that most of the patients with PC end up committing suicide. I guess so. Just a bet. I have not seen any statistics or anything else, but it is said that if you have a slightly weaker psyche, that's what will happen... Well maybe, you could exchange a word (with peers) and so on, but I am not in support of this modern nonsense that there is always peer support for everything and
everything has this and this and that. I'm so old-fashioned that I bite my lip as much as I can ... (Man, aged 71)

Support from healthcare professionals was recognised as part of emotional support, but it felt insufficient. Patients would have liked to discuss the illness more, and they described situations where the discussion had been stopped by a professional:

> More discussion is needed at the doctor's office, other than just take your pants off and get on your back! (Man, aged 71)

However, and somewhat inconsistently, while patients with PC reported insufficient emotional support, they also maintained that such support was not required and that everything was fine.

## Affirmation

Some patients found information about the disease through the Internet even though they received enough information about the care process from healthcare professionals. On the other hand, some of the patients were satisfied with the brief and concise information received from healthcare professionals. The information from healthcare professionals focused on counselling related to physical changes such as urination (Figure 1).
...Yes, I thought it went just OK. I mean the nurse appointment was (before surgery, and) the nurse was saying things and so on. I don't see that there was anything to complain about... And there is not much to say here. It is [laughs] quite briefly and succinctly explained that the penis is amputated and that's it ... (Man, aged 56)

Despite the positive affirmation mentioned above, patients felt that information about the disease was incomplete. They not only expected more spoken counselling and information on the prognosis but found it difficult to ask for more information about the disease, and topics such as sexuality were ignored (Figure 1):


#### Abstract

...I was going to have the operation done there XXX (to the hospital), so I went, and when I had already put on these surgical clothes this urologist announces that a penis amputation is now being done ... And I was so depressed that I wondered why this cancer happened to me? (Man, aged 61)


Patients were told that affirmation was unnecessary and that they did not need more information or counselling: "sexual therapists are not needed when the whole penis is cut off" (man, aged 56).

## Concrete aid

Patients received concrete aid from partners and loved ones, including assistance with housework, such as cleaning and grocery shopping. Patients did not want help from anyone outside their own family or circle of friends. Rather, patients wanted to survive on their own and rejected concrete aid from other people (Figure 1):

> ...I don't really need any help because I'm used to handling things on my own and given I didn't have a penis, I didn't have any pain in it. That disadvantage was in itself very small after all, if you compare what has happened during your life, there have been all kinds of disadvantages, now, this is just a little thing. (Man, aged 62)

Healthcare professionals supported patients with income support, but the help was not sufficient. There were problems with income support for entrepreneurs/freelancers. After a long period of sick
leave, one patient was not given the opportunity to take up lighter work offered and was forced, against his will, to retire on a disability pension (Figure 1):

The mind was willing to go to work, but hopes do not always go hand in hand with reality in life. There would have been enthusiasm but no ability, and no alternative was ever offered by the employer that would have given me a lighter job or something like that. Not even offered. The most I got was that, a day or two after the surgery, the boss called me from work and asked when I was coming back... (Man, aged 61)

## CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The purpose of this study was to describe perceived social support received by patients with PC. On average, the patients reported adequate perceived social support. The most reported form of social support was affirmation, and the least reported was emotional support. Employment status and primary operation are patient-related factors that have a significant association with social support received. The patients experienced a disparity in the quality of perceived social support. Patients with PC would have liked to discuss illness and income support further.

Our findings regarding statistically reported social support are in line with studies of other patient groups. Previous studies have shown that most heart patients (28), patients with prostate cancer (30) and aged people (31) are satisfied with the social support they have received from healthcare professionals. According to statistical findings, they generally receive sufficient information and counselling about the disease, but these primarily focus on physical changes such as urination. According to respondents, employment status is a factor that has a significant association with the need for emotional support. Patients who were retired or unemployed reported receiving higher levels of emotional support than those who were employed. It is possible that patients may think that nurses assume that regaining the ability to work after surgery is a more important topic for the patient to discuss than intimate matters. Studies of lower back patients have found that talking about intimate matters is difficult for patients, because they assume that it is an irrelevant topic in comparison to other rehabilitation-related issues (38).

According to the qualitative findings of this study, the partner was the most important support to the patient because they were able to discuss intimate and personal issues together. If a patient had no partner, a family member or close, trusted friend could also become an important provider of emotional support. In the men's experience, support from healthcare professionals was insufficient. Previous studies $(10,20)$ have demonstrated that nurses and other healthcare professionals may not
have sufficient professional skills and courage to counsel patients and their partners in issues such as sexuality. In addition, it has been found that patients expect healthcare staff to start the conversation about sexuality $(38,39)$. In the future, this should be taken into account in the education of urological nurses. Using communication tools such as PLISSIT or BETTER can help nurses gain confidence in their abilities to address sexuality concerns in an effective and comfortable manner and provide patients with useful information and insights (40). Nurses also need to be supported with consultation and referral resources when they reach the limits of their capacity (41).

In contrast with patients considered in previous studies (21), patients with PC were sceptical of peer support. Due to the rarity of the disease, there are no organised face-to-face peer support groups in Finland. According to Akers et al. (21), support groups are a mode of delivering support to men who have been diagnosed and treated for this rare disease. The preconceptions and experiences of peer support may be country- and culture-specific.

Patients with PC had an expectation of information and guidance related to PC and would have liked a more unhurried and intimate discussion with nurses. A key area for the development of the treatment of PC is ensuring that patients are well-informed about the extent and potential consequences of their treatment (6). According to Witty et al. (6), nurses in urology clinics and wards should play a key role in supporting patients with PC and their family members through treatment and post-discharge aftercare. Overall sexual functioning, the ability to have erections and the changes experienced in sexual capacity are the main factors associated with post-treatment healthrelated quality of life of patients with PC (7). In light of the present study's results, it seems that systematic appointments with nursing staff would be justified

According to this study, patients had a strong desire to cope with situations on their own, without outside help. However, social support should be individualised. Not every patient with PC needs the same kind of support at the same timepoint in the caring process.

## Strengths and limitations

One of the limitations of the study is that it studied a small sample drawn from one university hospital. The scope of the surgical methods and recovery time from surgery were very heterogenous in this study population, leading to limitations in statistical analysis. Also, the questionnaire has not been previously piloted in this patient group. The response rate of the study, albeit acceptable at $64 \%$, may have been affected by the research topic. A main strength of this study is its multimethod approach. Both qualitative and quantitative methods were applied to all participants to collect data. In the quantitative data, the primary operations of the non-responders differed from those of the responders. The majority of non-responders underwent penile resection or penectomy. The weakness of the qualitative part of the study is that the interview theme questions were not pretested with a person who was not part of the study before the actual research interviews were carried out. However, the interviews went as planned, and the same theme questions were used for all interviewees. The strength of the qualitative part of the study is its accurate reporting, from which the reader can assess the transferability of the results to the social support of men with PC $(42,43$, 44).

## Practical implications

The results of the present study suggest that systematic appointments with a nurse would be justified. Such appointments would ensure that nurses have sufficient time to discuss the intimate and personal issues needs of patients with PC and help support them. The results indicate that while the overall social support received was deemed good, the patients had unmet informational needs regarding their illness and uncertainties regarding the amount and type of social and income support
they would receive during its course. The results can help nurses provide more holistic care to patients with PC. This information can be utilised in the development of nursing interventions for patients with PC and their family members.

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Table 1. Background variables of patients with PC ( $n=42$ )

|  | n (\%) |
| :---: | :---: |
| Sociodemographic characteristics |  |
| Age (Mean 70, SD 11, Min 45, Max 91) |  |
| Partner status |  |
| Partner | 37 (88) |
| No partner | 5 (12) |
| Children |  |
| Yes | 38 (90) |
| No | 4 (10) |
| Educational level |  |
| High (Polytechnic/University degree) | 23 (55) |
| Middle (Vocational degree) | 7 (17) |
| Low (None/short qualification) | 11 (26) |
| Missing | 1 (2) |
| Employment status |  |
| Employed | 11 (26) |
| Retired/unemployed | 31 (74) |
| Place of residence |  |
| Rural | 22 (52) |
| Urban | 20 (48) |
| Clinical characteristics |  |


| Primary operation |  |
| :--- | :---: |
| Minor surgery (circumcision) | 2 (4) |
| Glansectomy | 20 (48) |
| Penile resection/Penectomy | 20 (48) |

Table 2. Perceived social support in patients with PC $(\mathrm{n}=42)$

| Content of the item | n | Mean ${ }^{1}$ | SD | Median | Q1 | Q3 | Cronbach <br> 's alpha |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Social support received | 37 | 4.34 | 1.06 | 4.61 | 3.56 | 5.00 | 0.963 |
| Emotional support (6 items) | 39 | 4.14 | 1.16 | 4.33 | 3.50 | 5.00 | 0.935 |
| Showing compassion for me | 41 | 4.49 | 1.29 | 5.00 | 4.00 | 5.00 |  |
| Feedback related to family involvement in care | 40 | 3.88 | 1.47 | 4.00 | 3.00 | 5.00 |  |
| Showing interest in family affairs | 40 | 3.55 | 1.52 | 3.00 | 3.00 | 5.00 |  |
| Showing appreciation for family involvement in my care | 40 | 3.75 | 1.37 | 4.00 | 3.00 | 5.00 |  |
| Showing consideration for my well-being | 41 | 4.61 | 1.16 | 5.00 | 3.25 | 5.00 |  |
| Showing interest in coping with aftercare | 41 | 4.68 | 1.21 | 5.00 | 4.00 | 5.75 |  |
| Affirmation (7 items) | 40 | 4.65 | 1.07 | 5.00 | 3.89 | 5.68 | 0.941 |
| Explanation related to involvement in care planning | 42 | 4.52 | 1.45 | 5.00 | 3.00 | 6.00 |  |
| Explanation related to my care | 42 | 4.83 | 1.08 | 5.00 | 4.00 | 6.00 |  |
| Counselling related to matters involved in my care | 41 | 4.76 | 1.22 | 5.00 | 4.00 | 6.00 |  |
| Discussions related to course of illness | 42 | 4.67 | 1.18 | 5.00 | 4.00 | 5.75 |  |
| Discussions related to condition during hospital stay | 42 | 4.76 | 1.10 | 5.00 | 4.00 | 5.75 |  |


| Discussions related to progress of care | 42 | 4.88 | 1.13 | 5.00 | 4.00 | 6.00 |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Discussions related to treatment options | 41 | 4.63 | 1.45 | 5.00 | 4.00 | 6.00 |  |
|  |  |  |  |  |  |  |  |
| Concrete aid (5 items) | 38 | 4.16 | $\mathbf{1 . 2 0}$ | $\mathbf{4 . 2 0}$ | 3.40 | 5.10 | $\mathbf{0 . 8 8 9}$ |
| Explanation related to prognosis of the <br> illness <br> treatment | 42 | 4.79 | 1.22 | 5.00 | 4.00 | 6.00 |  |
| Explanation related to side effects of the | 41 | 4.34 | 1.37 | 5.00 | 3.00 | 5.00 |  |
| Information regarding how illness affects | 40 | 3.95 | 1.58 | 4.00 | 3.00 | 5.00 |  |
| sexual life |  |  |  |  |  |  |  |
| Family involvement in the patient's care | 40 | 3.80 | 1.64 | 4.00 | 2.50 | 5.00 |  |
| Space for expressing feelings | 41 | 4.37 | 1.34 | 5.00 | 3.00 | 5.00 |  |

[^0]Table 3. Association between background variables of patients with PC $(\mathrm{n}=42)$ and their received social support

|  | Received social support |  | Emotional support |  | Affirmation |  | Concrete aid | pvalue |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | $\mathrm{r}^{*}$ | $\mathrm{p}-$ <br> value | $\mathrm{r}^{*}$ | $\mathrm{p}-$ value | $\mathrm{r}^{*}$ | $\mathrm{p}-$ <br> value |  |  |
| Age | 0.184 | 0.277 | 0.314 | 0.052 | 0.026 | 0.876 | 0.200 | 0.228 |
|  | Md (Q1;Q3) | pvalue | Md (Q1;Q3) | pvalue | Md (Q1;Q3) | pvalue | Md (Q1;Q3) | pvalue |
| Partner status |  | 0.706 |  | 0.966 |  | 0.285 |  | 0.559 |
| Partner | 4.58(3.68;5.15) |  | 4.33(3.46;5.00) |  | 5.00(4.00;5.86) |  | 4.20 (3.70;5.20) |  |
| No partner | 4.89(2.36;5.00) |  | 4.67(2.50;5.00) |  | 5.00(2.64;5.07) |  | 4.80(1.80;5.00) |  |
| Children |  | 0.404 |  | 0.279 |  | 0.586 |  | 0.498 |
| Yes | 4.67(3.67;5.00) |  | 4.42(3.50;5.00) |  | 4.93(3.89;5.68) |  | 4.20(3.70;5.20) |  |
| No | 4.50(3.22;4.69) |  | 3.83(2.67;4.25) |  | 5.21(3.21;5.82) |  | 4.20(2.90;4.50) |  |
| Education level |  | 0.458 |  | 0.421 |  | 0.306 |  | 0.519 |
| High <br> (Polytechnic/Un <br> iversity degree) | 4.72(3.72;5.00) |  | 4.50(3.50;5.00) |  | 4.92(2.89;5.18) |  | 4.40(3.85;5.20) |  |
| Middle <br> (Vocational <br> degree) | 4.83(4.22;5.22) |  | 4.50(4.00;5.33) |  | 5.14(4.71;5.86) |  | 4.60(3.80;4.80) |  |
| Low <br> (None/short <br> qualification) | 4.44(2.64;5.07) |  | 4.08(2.63;4.88) |  | 4.86(3.96;6.00) |  | 4.10(2.35;5.25) |  |
| Employment <br> status |  | 0.089 |  | 0.006 |  | 0.962 |  | 0.076 |
| Employed | 4.00(2.97;4.75) |  | 3.50(2.25;4.17) |  | 4.86(3.75;5.46) |  | 3.60(2.60;4.40) |  |


| Retired/unempl |  |  |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| oyed |  |  |  |  |  |  |  |  |
| 4.78(3.74;5.26) |  | $4.67(3.50 ; 5.00)$ |  | $5.00(3.96 ; 5.75)$ |  | $4.40(3.80 ; 5.30)$ |  |  |
| Place of <br> residence |  | 0.104 |  | 0.499 |  | 0.149 |  | 0.053 |
| Rural | $4.39(2.89 ; 4.94)$ |  | $4.25(3.13 ; 5.00)$ |  | $4.71(3.00 ; 5.43)$ |  | $4.00(2.60 ; 4.80)$ |  |
| Urban | $4.78(3.76 ; 5.33)$ |  | $4.50(3.50 ; 5.00)$ |  | $5.00(4.71 ; 6.00)$ |  | $4.60(3.80 ; 5.80)$ |  |
| Primary |  | 0.039 |  | 0.061 |  | 0.059 |  | 0.067 |
| operation |  |  | $2.58(2.50 ; 2.67)$ |  | $2.71(2.43 ; 3.00)$ |  | $2.30(2.20 ; 2.40)$ |  |
| Minor surgery | $2.56(2.39 ; 2.72)$ |  |  |  |  |  |  |  |
| (circumcision) |  |  |  |  |  |  |  |  |
| Glansectomy | $4.83(4.44 ; 5.14)$ |  | $4.67(4.08 ; 5.00)$ |  | $5.00(4.71 ; 5.71)$ |  | $4.40(4.00 ; 5.20)$ |  |
| Penile resection | $4.11(3.10 ; 5.06)$ |  | $4.08(3.13 ; 5.00)$ |  | $4.71(3.86 ; 5.86)$ |  | $4.20(3.00 ; 5.00)$ |  |

[^1]

Figure 1. Perceived social support, as described by patients with PC


[^0]:    ${ }^{1}$ Range 1-6

[^1]:    *Spearman's correlation

