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ORIGINAL

Empowering Prostate Cancer Patients and Their Wife's: Assessing Early Self-Management Education

Empoderamiento de los pacientes con cáncer de próstata y sus esposas: evaluación de la educación temprana para el autocuidado

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ABSTRACT

Introduction: prostate cancer stands out as the highest prevalent tumour among males, with an impressive 92 % survival rate beyond the initial 5 years of diagnosis. The study aimed to evaluate Whether information offered to men diagnosed with prostate tumors and their wife's immediately after diagnosis met their needs. It also sought to evaluate the satisfaction levels of patients and Their wife's discussing the received information.
Method: survey data collected prior to the intervention from a pilot randomized controlled experiment involving 41 prostate cancer patients and their wife's. The focus was on examining the psychosocial concerns and needs of the participants before the implementation of a self-self-reliant managing skills involvement.
Results: patient role and theirs wife's shared common psychosocial concerns such as emotional management, future uncertainties, and a perceived loss of control. Information provided to both groups primarily focused on tests and treatment options. In comparison to patients, their wife's indicated a notable disparity in the amount of information received regarding support essential services ($P = 0,02$) and strategies for self-care ($P = 0,02$). Furthermore, their wives reported much poorer satisfaction with the information they got ($P = 0,01$).
Conclusion: patients and their wife's often receive routine medical information, but there is a need for more extensive details on psychosocial aspects of cancer. Despite an increasing acknowledgment of the informational needs of their wife's, these needs remain unmet.

Keywords: Needs Assessment; Medical Informatics; Randomized Controlled Trial.

RESUMEN

Introducción: el cáncer de próstata se destaca como el tumor de mayor prevalencia entre los hombres, con una impresionante tasa de supervivencia del 92 % más allá de los 5 años iniciales del diagnóstico. El estudio tuvo como objetivo evaluar si la información ofrecida a los hombres diagnosticados con tumores de próstata y a sus esposas inmediatamente después del diagnóstico satisfacía sus necesidades. También buscó evaluar los niveles de satisfacción de los pacientes y sus esposas al discutir la información recibida.
Método: datos de la encuesta recopilados antes de la intervención de un experimento piloto controlado aleatorio que involucró a 41 pacientes con cáncer de próstata y sus esposas. El enfoque se centró en examinar las preocupaciones y necesidades psicosociales de los participantes antes de la implementación de una participación de habilidades de manejo autosuficiente.
Resultados: el rol del paciente y el de su esposa compartían preocupaciones psicosociales comunes,

como el manejo emocional, las incertidumbres futuras y una pérdida percibida de control. La información proporcionada a ambos grupos se centró principalmente en pruebas y opciones de tratamiento. En comparación con los pacientes, sus esposas indicaron una disparidad notable en la cantidad de información recibida con respecto a los servicios esenciales de apoyo (P = 0,02) y estrategias para el autocuidado (P = 0,02). Además, sus esposas manifestaron una satisfacción mucho menor con la información que recibieron (PP = 0,01). **Conclusión**: los pacientes y sus esposas a menudo reciben información médica de rutina, pero existe la necesidad de detalles más amplios sobre los aspectos psicosociales del cáncer. A pesar de un reconocimiento cada vez mayor de las necesidades de información de sus esposas, estas necesidades siguen sin satisfacerse.

Palabras clave: Evaluación de Necesidades; Informática Médica; Ensayo Controlado Aleatorio.

INTRODUCTION

Prostate cancer stands out as the highest prevalent tumour among males, with an impressive 92 % survival rate beyond the initial 5 years of diagnosis.(1) However, the aftermath of prostate cancer therapy can bring about enduring side consequences, for instance incontinence and sexual dysfunction, posing challenges to a patient's perception of masculinity and self-identity.(2,3) These repercussions not only affect life satisfaction but also diminish mental and public well-being.(4,5) Although prostate cancer is inherently a male affliction, it is contended that, especially for partnered males, it can be viewed as a "relational disease"(6) due to the substantial impact on intimate relationships caused by both physical and psychosocial consequences. Furthermore, much research underscores the interconnectedness of the well-being-related life quality between patient role and their spouse's during the prostate cancer experience. This underscores a mutual response to the disease and its treatment, emphasizing the necessity to consider the well-being of both individuals within a dyad during the entire malignance journey.(7,8)

Notably for individuals with prostate cancer, there is a growing awareness of unmet psychosocial needs.(9) Research indicates that while the most crucial care delivery needs are generally met, support needs—such as addressing emotional issues and coping with side effects—are often perceived as less important and frequently unmet. Patients with prostate cancer commonly report unfulfilled informational needs, specifically regarding concerns regarding cancer recurrence & treatment-related adverse effects.(10,11,12) Overall, recognizing and addressing these psychosocial and informational needs are crucial aspects of comprehensive cancer care and survivorship support.(13)

Wife's of the individuals facing prostate cancer encounter significant psychosocial challenges, including emotional distress, changes in relationships, sexual dynamics, and the responsibility of helping patients adapt to treatment-related side effects and a transformed future outlook. Research emphasizes personal challenges for their wife's, such as maintaining balance and mental wellness, as well as patient-centered difficulties, including exchange of information issues and concerns about the patient developing depression. Moreover, evidence suggests that their wife's dealing with their own anxiety or depression may exhibit lower coping skills and struggle more with adapting to the diagnosis compared to the patients themselves.(14,15,16)

Cancer self-management, involves individuals actively participating in their recovery to minimize treatment consequences and promote overall welfare. self-care strategies ordinarily focus on providing data and developing coping abilities to cope with cancer care complexities. Although the literature on individualized care in prostate cancer is in its early stages, initial studies show that this approach can effectively manage both the psychological and Physical manifestations of the disease.(17,18)

Addressing the emotional and social needs among men diagnosed with prostate cancer and their spouses can be achieved through information provision.(19) This data, whether obtained from healthcare professionals or independently through sources like internet searches, has been shown to alleviate anxiety, fostering a sense of control and resilience, enhancing treatment compliance, and promoting active involvement in collaborative decision-making, and enhance confidence in self-care abilities according to existing evidence.(19,20) Studies show that Patients' informational needs and their wife's within the scope of prostate cancer may go unmet despite the obvious benefits of having sufficient information.(21,22,23) Notably, wife's of prostate cancer patients, in particular, may be reluctant to seek information from healthcare professionals as a result of feeling disempowered and facing time limitations during therapeutic consultations.(24,25,26)

Research, particularly on breast and prostate cancer patients, indicates that satisfaction with information significantly predicts various aspects of life quality, encompassing emotional, social, and physical health.(27,28) For men facing treatment decisions in prostate cancer, discussions with physicians about treatment outcomes emerge as a crucial source of satisfying information. However, there is currently a gap in research, with no specific studies identified regarding partner satisfaction with information in this context.(29,30,31)

The study's aim was to determine if prostate cancer patients and their wife's taken the necessary data required to report their primary worries during the initial post-diagnostic period. Additionally, the study assessed their pleasure with the information entertained. The present report focuses on the required information of all respondents at the beginning of the study, prior to the randomization of interventions.

METHOD

Design

A preliminary randomized controlled experiment was conducted to assess the effectiveness of a guide for psychosocial information called coping-together for married couples.

Sampling

Potential respondents, referred by clinicians in South Riyadh in a governmental health care center, were considered for the study. Eligibility criteria included recent diagnosis (within the last four months) of early-stage prostate cancer, plans for or currently undergoing treatment options (such as active surveillance), distress outcomes of ≥ 4, according to the distress thermometer for either the patient or wife, proficiency in English, and cognitive ability to complete surveys. Out of 169 referrals, 57 couples didn't meet criteria, 51 declined participation, and 20 couldn't be contacted. Ultimately, 41 couples were randomized for the trial.

Ethical Considerations

Authorization for the trial was granted by the Standing Committee of Bioethics Research at Prince Sattam Bin Abdulaziz University (SCBR-251/2024).

Data Collection and Procedure

Screening for Support

Biopsychosocial involvements were evaluated through a 48-item adjusted version of the Support Screen tool.(32) Participants used a scale of 1-4 to indicate the extent of their concerns or the need for assistance regarding specific issues, such as obtaining reliable information regarding the treatment and diagnosis and experiencing anxiety or fear. Higher records reflected a higher degree of concern or a greater need for support.

EORTC Quality of Life module

Participants' perspective as well as the satisfaction with the provided information they got were measured using the EORTC Quality of Life Group's information module.(33) This module has 26 items, covering various aspects such as information on the illness, diagnostic tests, therapy, other support services, healthcare facilities, and self-regulation. Additionally, fulfilment with the knowledge was measured employing a single component. The pre-intervention survey incorporated various measures to assess different aspects, including psychological well-being (Hospital Depression and Anxiety Scale,(34) Revised Impact of Event Scale),(35) quality of life (Assessment of Quality of Life-8 Dimensions),(36) relationship adjustment (Revised Dyadic Adjustment Scale),(37) cognitive appraisal of health (Cognitive Appraisal of Health Scale),(38) uncertainty in illness (Mishel's Uncertainty in Illness Scale),(39) cancer self-efficacy (Lewis Cancer Self-efficacy Scale),(40) communication and attitudinal self-efficacy for cancer, coping strategies (Brief Cope), and dyadic coping (Dyadic Coping Inventory). Additionally, their wife's completed assessments related to caregiver quality of life (Caregiver Quality of Life Index)(41) and caregiving appraisal (Appraisal of Caregiving Scale).(42)

Procedures

Patients and their wife's completed a preintervention survey addressing information needs and psychosocial challenges before being randomly assigned to either the Coping-Together intervention or minimal ethical care (MEC). The intervention group received Coping-Together booklets, a relaxation CD, DVD, and newsletters, while the MEC group received cancer-related booklets. A follow-up survey identical to the preintervention one was conducted about two months later, and the trial results were reported elsewhere.

RESULTS

Participant Characteristics

In summary, the patients had an average age of 58,3 years (SD = 5,9), their wife's had an average age of 52,2 years (SD = 6,1), and the average time since diagnosis was 40 days (SD = 21,1, range = 11-221 days). Additional demographic information can be found in table 1.

Table 1. Participant attributes

Characteristics	**Patients (%)**	**Their wife's (%)**
Relationship status		
Mean relationship length (SD)	26,5 years (8,3)	
County of birth		
Saudi Arabia	35 (85)	32 (78)
Other	6 (15)	9 (22)
Education		
Primary/secondary school	15 (36)	20 (48)
Diploma qualification	13 (32)	12 (29)
University qualification	13 (32)	9 (23)
Employment		
Fulltime/self-employed	18 (44)	26 (64)
Part time	23 (56)	15 (36)
Treatment modalities Surgery		
Surgery	15 (37)	
Radiotherapy	7 (17)	
Hormone treatment	1 (2,5)	
Brachytherapy	1 (2,5)	
Active surveillance	3 (7)	

Key Considerations in Patient and Partner Demographics: Insights from Age and Diagnosis Duration

In summary, the SupportScreen questionnaire highlighted psychosocial issues like managing emotions, worrying about the future, and self-managing treatment side effects as the most significant concerns, despite generally low mean scores indicating mild problems (range = 1-4). The top 10 concerns for patients and their wife's are detailed in table 2, with managing side effects being the most prominent. Interestingly, medical-related concerns, including obtaining reliable data about diagnosis and treatment, did not rank within the top 10 for both patients and their wife's , placing 20th and 16th, respectively. Additional information can be found in table 2.

Table 2. Top 10 concerns of patients and their wife's

Screening for Support item	**Patient (n = 41)**		**Wife (n = 41)**	
	Mean (SD)	**Ranking**	**Mean (SD)**	**Ranking**
Treatment-related side effects	3,06 (0,90)	1	1,83 (0,99)	4
Losing control over things that are important to me	1,89 (0,90)	2	1,65 (0,97)	7
Concern about the future	1,91 (0,83)	3	2,25 (0,73)	1
How my family will cope	1,68 (0,77)	4	1,65 (0,97)	7
Managing emotions	1,93 (0,88)	5	1,73 (0,79)	3
Being unable to care for myself or my wife	1,81 (1,22)	6	1,37 (0,63)	26
Feeling anxious or afraid	1,56 (1,32)	7	1,71 (0,99)	2
Experiencing down or depressed	1,27 (0,91)	8	1,53 (0,70)	5
Experiencing irritable or angry	1,63 (0,91)	8	1,43 (0,47)	6
Finances	1,71 (0,67)	9	1,52 (0,45)	9
Understanding how to support my wife.	1,44 (0,72)	9	1,49 (0,61)	13
Questions and Fears regarding the End of Life	1,69 (1,75)	10	1,88 (0,42)	10
Thinking clearly	1,30 (0,43)	12	1,35 (0,16)	8

Reception of Information and Contentment: Exploring the Relationship between Information Provision and Satisfaction Levels

In summary, both patients and their wife's received the most information regarding medical tests and treatment alternatives, with patients finding the information on accessing support services and self-management more adequate than their wife's. Patients expressed a relatively high level of satisfaction with the information received (mean = 3,65, SD = 0,67), while their wife's reported significantly lower satisfaction overall (mean = 2,98, SD = 0,89, P = 0,01). Additional information can be found in table 3.

Table 3. Level of information obtained by patients and their wife's

INFO25 subscale	Mean (SD)		P
	Patient	Wife	
Information regarding the disease	2,88 (0,80)	2,99 (0,98)	0,42
Information on medical testing	3,55 (0,64)	3,48 (0,96)	0,43
Information regarding therapy	2,65 (0,88)	2,97 (0,77)	0,81
Information on additional services	1,87 (0,79)	1,55 (0,57)	0,02*
Information on various locations of care	1,88 (0,86)	1,51 (0,78)	0,17
Information to help you get	2,40 (0,98)	1,92 (0,95)	0,02*

Note: SD represents standard deviation, while *P < 0,05.

DISCUSSION

The study found that men with prostate cancer and their wife's are well-informed about their medical diagnosis, tests, and treatment options, which is positive for decision-making and mental well-being. Despite this proficiency in medical information, both patients and their wife's expressed psychosocial concerns as their primary issues, indicating a lack of information on these aspects. This aligns with recent findings by Majumder et al.(43) suggesting room for improvement in providing information on additional services, different care locations, and self-help strategies.(43) Overall, the results highlight a potential oversight or undervaluation of psychosocial needs compared to medical concerns, echoing previous studies calling for enhancements in addressing information gaps related to psychosocial matters.

The notable decrease in the amount of information received by their wife's regarding support services and self-management of health/well-being is a significant discovery. As cancer patients increasingly receive treatment through outpatient clinics and experience shorter postoperative hospital stays, their wife's are assuming a more substantial role in providing necessary support and care. Past studies have shown that caregivers for cancer patients often experience elevated levels of anxiety, depression, sleep disturbances, fatigue, and a lower quality of life. In light of these findings, (44,45,46) Galbraith et al.(47) advocate for the integration of partner needs into treatment plans, care strategies, and post-treatment follow-up processes.

In general, men diagnosed with prostate cancer expressed a high level of contentment with the information provided to them.(47,48,49) Previous studies have indicated that satisfaction with information can contribute to an improved quality of life, foster active participation in decision-making, lead to the adoption of effective coping strategies, and enhance overall vitality and positive mental health.(50,51) The significant finding that their wife's reported notably lower satisfaction with the information they received suggests potential unmet information needs on their part. This corresponds with the findings of Echlin and Rees, who observed that their wife's of prostate cancer patients, despite actively seeking information, often had unfulfilled information needs.(52) These findings carry significant implications, especially if, similar to patients, satisfaction with information is linked to quality of life and mental well-being. Addressing this gap is identified as a crucial area for future research.

The study's limited sample size reduces its statistical power and constrains the range of analyses that can be conducted, necessitating caution in interpreting the findings. Recruiting couples for health-related research poses challenges, such as reluctance from patients to involve their wife's, one member of the dyad expressing interest, and declination due to the time commitment for study participation. These challenges were encountered in the current study. However, given the scarcity of studies investigating both patient and partner information needs in the context of prostate cancer, the present study offers valuable insights that may prove useful in clinical applications. It is important to note that, although we assessed satisfaction with the information received by patients and their wife's, we cannot determine whether it aligns with the support preferences (e.g., information, access to services, support groups) that each member of the dyad may have desired, potentially impacting their satisfaction levels. Future research using a mixed methodology to explore patient and partner preferences for support would enhance our understanding in this area.

CONCLUSIONS

The study revealed that men diagnosed with prostate cancer and their wife's are sufficiently informed about treatment options and medical tests. However, there is a notable deficiency in the information provided on psychosocial issues, despite both groups identifying psychosocial concerns as their primary issues. These findings underscore the necessity for increased provision of psychosocial information to effectively address the core concerns of both men with prostate cancer and their wife's. It emphasizes the importance of paying more attention to the information needs of their wife's , ensuring that the information provided aligns with and addresses their main concerns.

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CONFLICT OF INTEREST

The author declares that they have no competing interests.

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