Determinants of seeking psychosocial care in Dutch men with prostate cancer

A cross-sectional study

Laura Daeter MSc

dr. Adriaan Visser

drs. Truus van der Hooft-Leemans

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Laura Daeter, MSc student at University Utrecht, Faculty of Clinical Health Sciences, Master program Nursing Science

Adriaan Visser, PhD, Supervisor, senior researcher Rotterdam University, Rotterdam

Truus van der Hooft-Leemans, MA, lecturer University Utrecht

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Preface

This report is an edited version of the thesis by Laura Daeter on Determinants of seeking psychosocial care in Dutch men with prostate cancer. Universiteit Utrecht (2012) with the supervisors drs. G. van der Hoofd-Leemans (University of Utrecht) & dr. A.P. Visser (Rotterdam University).

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Laura Daeter

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Correspondentie: robin.laura@kpnplanet.nl

Dutch Summary

Achtergrond

Kanker is wereldwijd een van de belangrijkste doodsoorzaken. Naast algemene symptomen, zoals pijn en vermoeidheid, ervaren PCA-patiënten na behandeling, ziekte-specifieke symptomen zoals erectiestoornissen en urine-incontinentie. Onderzoek wijst uit dat PCA-patiënten (psychosociale) ondersteuning wensen. Desondanks maken ze weinig gebruik van bestaande voorzieningen. De invloed van behoefte van patiënten aan ondersteunende zorg is onderzocht met de SCNS. Verder is aan de hand van de Theory of Planned Behavior, onderzocht of attitude, veronderstelde sociale steun en zelf-effectiviteit van invloed zijn op het zoeken van ondersteuning. Ook werd de invloed van externe factoren zoals biografische en medische factoren, psychosociale factoren, maar ook eerder gebruik van hulp en de evaluatie van die hulp onderzocht.

Methode

Een cross-sectionele studie met een conveniëntiesteekproef van patiënten die eenmalig een vragenlijst invulden. De zorgbehoeften naast attitude over ondersteuning, evenals veronderstelde sociale steun en zelfeffectiviteit zijn gemeten. Ook externe factoren zijn onderzocht.

Resultaten

87 patiënten die contact zochten, hebben een digitale of papieren vragenlijst ingevuld. Met Pearson's correlatiecoëfficiënten werden significante correlaties aangetoond tussen de intentie om hulp te zoeken en de variabelen attitude, behoeften, depressie, angst, eerder gebruik van psychosociale zorg, leeftijd, tevredenheid met ontvangen zorg. Multiple Regressie analyse wees uit dat psychologische en fysieke behoeften, en depressie bepalend zijn voor toekomstig gebruik van psychosociale zorg.

Conclusie

Psychologische en fysieke behoefte en depressie zijn belangrijker determinanten voor het zoeken naar hulp dan de ASE factor attitude, ongerustheid, eerder gebruik van psychosociale hulp, de tevredenheid daarmee en leeftijd.

Resultaten laten zien dat eenderde van de respondenten behoefte heeft aan informatie van experts. Oncologie en urologie verpleegkundigen kunnen met deze informatie patiënten beter doorverwijzen naar gepaste ondersteunende zorg terwijl zorginstellingen en professionals deze informatie kunnen gebruiken om evidence-based interventies te ontwikkelen.

Abstract

Objective

Prostate cancer (PCA) has the highest prevalence for men in the western world. Besides general symptoms, these patients experience specific problems like erectyle dysfunction and urinary incontinence, which occur after treatment and may result in feelings of distress. PCA patients express a need for supportive care, although they are often not participating in the offered supportive care interventions. To study determinants of care seeking behavior, the influence of patient's supportive care needs was assessed with the SCNS. With the ASE-model, we studied whether their attitude about supportive care, perceived social support and self-efficacy influence care seeking. Furthermore also the influence of external factors, e.g. distress, biographical and medical factors, previous experience with and evaluation of supportive care was studied.

Methods

A quantitative, cross-sectional study with a convenience sample of patients who completed a questionnaire was conducted. The SCNS measured care needs. Patient's attitude towards care seeking, perceived social support and self-efficacy were assessed as well as several external factors.

Results

We included 87 patients, who returned a questionnaire by email or post. Pearson's correlation coefficients showed significant associations between the future supportive care use and attitude, needs, and external factors depression, anxiety, previous experience with and evaluation of supportive care and age. Results of multiple regression analysis pointed out that psychological, physical needs and depression are the main determinants for future supportive care use.

Conclusion

The results show psychological, physical needs and depression are more important determinants of future supportive care use than ASE-factor attitude towards care seeking, anxiety, previous psychosocial care use, satisfaction with care and age. Results indicated that men look for expert information in more than one third of all cases. Urology/oncology nurses and health-care professionals could use this information for patient centered referrals and to further develop needs and preference based interventions.

Keywords: prostate cancer, needs, future supportive care-use

LIST OF ABBREVIATIONS AND RELEVANT DEFINITIONS

ASE   Attitude, Social Support, Efficacy

CCMO Central Committee on Research Involving Human Subjects (Centrale Commissie Mensgebonden Onderzoek)

EORTC European Organization for Research and Treatment of Cancer

HADS Hospital Anxiety Depression Scale

IC   Informed Consent

IKNL Comprehensive Cancer Center Netherlands (Integraal Kanker Centrum Nederland)

N/A   Not applicable

NP   Not Published

PCA   Prostate cancer

SCNS Supportive Care Needs Survey

SES   Social Economic Status

WHO   World Health Organization

WMO   Medical Research Involving Human Subjects Act (Wet Medisch-wetenschappelijk Onderzoek met mensen)

Introduction

Cancer is a leading cause of death in the world. WHO data (2011) indicate 7,6 million people died of cancer worldwide in 2008. Incidence is anticipated to increase up to 50 million in 2020[1]. In the Netherlands, approximately 42.000 cancer caused deaths were registered, which is almost one third of all deaths. Prevalence figures indicate more than 10.000 Dutch men suffered from prostate cancer (PCA) in 2008[2]. PCA patients are frequently diagnosed in later disease stages because PCA progresses slowly. Symptoms like urinary problems, become manifest in an advanced disease phase and are attributed to age rather than cancer, so patients often seek delayed treatment[3,4].

Patient's problems

Due to their uncertainty about prognosis and treatment related side effects, PCA patients experience physical, emotional, psychosocial problems, which may develop into feelings of distress in almost 35 % of all cases[4]. Besides general cancer related problems (pain, fatigue), a lot of PCA patients report specific problems like erectile dysfunction, incontinence, urinary and intestinal problems during the first years after treatment[4,5-8]. This often results into distress[9-13]. Voerman et al. found traumatic stress in one third of the respondents. Disease stage, treatment and SES cohere with these stress reactions[14]. Studies distinguished psychological, social and physical dimensions in relations to stress. According to Sanson-Fisher, patients experience needs for support in the psychological, informational and daily living domain[15]. This is contrary to Bisson, who found relatively low levels of psychopathology in PCA patients[16].

Use of supportive care

Studies indicate that, in order to cope with their problems, PCA patients look for supportive care. Voerman et al. argue in their study about determinants of group participation that, based on the theory of planned behavior, the ASE-related factors *attitude*, *perceived social support* and *perceived control*, correlate with supportive care seeking behavior [22]. In 2011 Corboy et al. also concluded that attitudes towards different kinds of support services, instead of experienced problems, are predictive for actual care use[20]. Other studies emphasize the importance of an individualized approach to help men address thoughts and feelings after PCA diagnosis or a more gender adapted approach[17,18]. Carter et al. concluded that men experience *priority needs*, meaning they search information and support in order to be able to do the things important to them. This aligns with Sanson-Fisher's and

Bisson's conclusion that standard care should consist of adequate support and information [16,19].

Not fitting supportive care use

In spite of the problems PCA patients express, studies indicate that men make limited use of supportive care interventions that are not widely available either, as shown in a 2002 review by Voerman et al.[9]. Also Dutch centers for psychosocial oncological supportive care observe this phenomenon[31,33]. Voerman describes seven intervention studies. Emotional support seems to be of minor importance to men. In general, men prefer information about the disease and treatment in a formal setting with expert speakers focusing on information and education. Information packages, telephone interventions and interventions alternating recreation activities with discussion sessions were well received. Further, the effect of interventions on anxiety and distress was limited and studies were small and had other design limitations [9]. Since 2002 12 new intervention studies were published. Their impact is still rather limited. Ineffective interventions, due to organizational problems as well as contradictory study results are reported [23,24,26,30]. Patient information is found to be successful at improving knowledge, quality of life and care satisfaction, especially when combined with a discussion group [27,28,30]. On the other hand, studies found that much of the used PCA educational material omitted important information or was incorrect[29]. The lack of fitting supportive care interventions, the increasing incidence of PCA and the related psychosocial problems, underlines the need for intervention development, which addresses patient's problems. It is imperative for the development of evidence-based interventions to get insight in care needs, the problems of PCA patients as well as the factors that influence their use of supportive care.

Research Question

Dutch therapeutic centers currently offer different psychosocial care interventions for cancer patients. However, despite increasing incidence and the general risk of possible decline in psychosocial wellbeing, and probable needs for information, patient support organizations and healthcare professionals note that men, compared to women with cancer, make limited use of psychosocial support[31-33]. Along with the limited uniformity of the intervention studies, this requires further investigation of needs and determinants of care seeking behavior to develop future care interventions for PCA patients and adequate patient referrals by urology and oncology nurses, based on scientific evidence.

So the research question is: Which determinants influence supportive care seeking behavior of PCA patients in the Netherlands?

Read Figure 1

Objectives

We aimed to understand PCA patient's care seeking behavior and psychosocial care utilization using a theoretical model (figure 1). With the SCNS care we assessed needs in relation to psychosocial and cancer specific physical problems men with PCA experience. Furthermore we used ASE-factors, which can be regarded as an extended version of the *Theory of Planned Behavior* to explain care seeking. We hypothesized that attitude towards psychosocial care, perceived supportive social environment and positively estimated self-efficacy towards finding support, influence care seeking[22,44]. Based on the ASE-model, external factors were also studied such as biographical and medical factors, distress and former experience with supportive care. Understanding supportive care seeking behavior enables healthcare professionals to develop evidence based care interventions and perform patient oriented referrals by urology and oncology nurses.

Ethical considerations

This study was presented to the Central Committee on Research Involving Human Subjects. Patients gave informed consent to study participation by contacting the investigators and returning the filled out survey[34].

Methods

In a cross-sectional design we studied the determinants of supportive care seeking[34,35]. We asked prostate cancer patients to fill out a self-administered hardcopy or digital survey. We recruited prostate cancer patients resident in the Netherlands' southwest region, corresponding with the institute for psychosocial care's working province.

Participants

Inclusion criteria were that patients had a clinical prostate cancer diagnosis and already had treatment or were going to. Patients were eligible if they could read and write in Dutch. Patients received an information letter through their urologist, urology-oncology nurse specialist, patient organization, therapeutic center, or research coordinator. Study announcements were published in local and national newspapers. The patient organization made a study announcement at their website, and in their journal. If they wished to

participate, patients could get in contact with the research coordinator by telephone or email. Patients were recruited between March and April 2012.

Measures

Dependent variables

Supportive care seeking is composed of a general question about looking for support (answers *yes* or *no).* This is combined with a question about finding specific support facilities such as telephonic support, individual counseling, general disease information, fellow patients support groups or support from an institute for psychosocial care (answers *yes*, *no).* We also asked about respondent's intention to use a form of supportive care to be answered on a four-point Likert-scale (certainly no intention - most certainly going to). The total score of these three questions is defined as supportive care seeking.

Independent variables

Patient needs were assessed with the Supportive Care Needs Survey (SCNS). This validated Australian main study parameter describes needs and problems across five domains: daily living/physical activity; psychological functioning; patient care and support; sexuality; informational and healthcare system issues[36]. We received the authors' permission to use this scale. The SCNS was translated in Dutch according to the *backward method* and previously used in a study on care needs in women with breast cancer [22,36,37]. Needs are measured on a 5-point scale. Phrasing of items was adjusted to the general Dutch language practice. Based on the ASE-model, personal attitudes about seeking psychosocial care, perceived social support from partner and relevant others and self-efficacy were measured[22]. Because social support by the partner, medical specialist or significant other showed insufficient scale reliability, we used three separate social support items[38].

Read Table 1

To assess distress, we used the HADS as a general measure of anxiety and depression, often used in psycho oncology studies[40,41].

Applying the *theory of planned behaviour,* also external factors are studied: biographical factors socio-economic status, age and marital status. Medical characteristics, e.g. treatment, side effects and comorbidity, are also examined as well as experience with and evaluation of former used psychosocial care interventions[13,22,44,47].

Sample size

Sample size calculations were based on Israel, by using two equations[46]. 1455 PCA patients are identified in the southwest of the Netherlands. Figures about prevalence of distress in PCA patients indicate that 30 % suffer from these problems[14]. Confidence interval was of 95% with Z-score of 1.96 and alpha at .05. Sample size was estimated at 262 patients[45].

Statistical Analysis

The data were analysed by SPSS 18.0. Descriptive statistics were applied for the sample characteristics. Cronbach's alpha determined scale reliability in case of SCNS, ASE variables, HADS, SES, the former use and evaluation of care interventions, and intention to future supportive care use[35]. With Pearson's correlation coefficients the strength of the relationship between the intention to seek support with needs, ASE-factors, and external factors such as biographical, medical, psychosocial factors and former care use and evaluation of received care was measured[45]. Dependent of results we applied multiple regression according to the forward method, based on significant correlations of p ≤.05[38].

Results

Response

From March to April, 87 patients responded to the announcement via urologists, other healthcare professionals or (social) media. Because patients were not requested directly by the researcher (LD), the number of approached men could not be identified. All patients, consenting to participate by approaching the investigators, returned a hardcopy or digital questionnaire (figure 2)

Read Figure 2

Reliability assessment of used measurement scales

Table 2, informs about used measurement scales. Inter- item correlations were performed in case of 2 item scales and were acceptable. *Perceived social support* is composed of 3 separate items because inter-item correlations were low. All other scales show admissible reliability.

Read Table 2

Socio-demographic characteristics

Respondents were between 44 and 84 years, with mean age 66,4 years (Table 3). Most participants were married or having a relationship (91%), higher educated (49,4 %) and worked in the field of higher management, management or as academic professionals [47]. Sixty percent of the participating men earn between 2300 to 4800 euro's per month and almost half of the men live in the southwest of the Netherlands.

Almost 60 % of the participants in the sample have a midrange to high SES-score. Frequency analysis reveals that these men have an average to high level of education, income above 2300 euro's and work in the higher professional segment.

Read Table 3

Medical characteristics

All participants were diagnosed with PCA. Some mentioned diagnosis and treatment up to 20 years ago. Almost half of the men have had surgery and 56 % has had either internal or external radiation therapy (Table 4). All known therapies were reported. Few men are not only treated with the evidence-based methods but also used acupuncture and homeopathy or other alternative therapies.

Read Table 4

Attitude, perceived social support and efficacy

Respondents mainly hold positive beliefs regarding care seeking and value these beliefs as important to them. A low, negative, score (< 0) either means that subjects consider the beliefs, phrased as statements regarding supportive care, negative because they are not present or they don't evaluate the belief as high. Values vary from -2 to -1. High, positive, scores stand for present beliefs (> 0), which are evaluated as very important to the participant (values +1 and +2). Perceived social support was not valued positively. Especially perceived support for seeking help by the physician and other people was valued negatively (Table 5). All participants valued their efficacy positively.

Read Table 5

Supportive care needs

All of the six need-scales were reported as applicable to the participant's situation (table 6). For all cases on all domains the patient experienced some problems. Needs are mainly experienced in five areas: physical, psychological, sexual, healthcare system-related and

care and support related. A value zero-score means the item was not applicable to the patient's situation; score one indicated that existing problems were solved; two to four means that participants experience increasing needs.

Read Table 6

Distress

Applied cut off scores are in line with the HADS syntax[38]. Results show that men experience anxiety more frequently than depression (table 7). Almost 10 % of the participants experience feelings of depression and less than 20% of the study sample suffers from anxiety.

Read Table 7

Former use of psychosocial care

More than one third of the participants had some experience with supportive care. More than 30% of the participants used some kind of supportive care by the general practitioner while one fifth consulted their medical specialist and, less frequently, the oncology nurse (table 8). Almost one third of the participants had some experience with psychosocial care. Half of the respondents indicate they didn't visit a centre for psychosocial care.

Insert Table 8

Looked for and found support

In order to assess what supportive care patients want, we asked what kind of supportive care they already looked for and found (table 9). In general, 95% of the participants succeeded in looking for and finding some kind of support, information or counseling. Expert information was both looked for and found by most of the respondents. Some men mentioned that they found their expert information from their urologist or urology nurse while others contacted the PCA patient support society.

Other participants also mentioned that support for men with PCA has not always been available in the past.

Read Table 9

Satisfaction with received supportive care

Participants are mainly satisfied with the received supportive care, both from hospitals and other institutions for supportive care. They also benefit from it, although more than 20% of the participants value their support from the hospital as unsatisfactory (table10).

We asked respondents to mark the received support from the hospital. They rewarded the support with mean score of 6,7.

Read Table 10

Determinants of supportive care use

Correlations between *future supportive care use* and all studied independent variables are presented in table 11. A positive correlation means increasing values on independent variable result in increasing future care use. The results show significant correlations with all needs domains except for needs concerning incontinence and the attitudinal component of the ASE-model as well as external factors age, distress and experience with and evaluation of psychosocial care interventions.

Read Table 11

Multiple regression analysis

Multiple regression analysis (table 12) showed significant relations between dependent variable *behavioral intention to care use and independent variables* physical needs, psychological needs and depression *(* p ≤ .05). The best predictive independent variables for behavioral intention are physical and psychological needs and depression.

Read Table 12

Respondents mentioned they wish to receive expert supportive care from their medical specialist and general practitioner. Participants also prefer psychological support and supportive care from the urology nurse and sexual therapist.

Discussion

In this study we studied determinants that influence supportive care seeking of men with PCA. This will contribute to a better understanding for healthcare professionals and

organizations, about patient needs and for future development of supportive care interventions.

Patient needs were assessed for the first time in a Dutch PCA-study. We also measured the ASE- factors comparable to Voerman et al. in their 2007 study[22]. Compared to previous studies that focussed on ASE-factors only, we used a mixed model, measuring needs as well as ASE-factors.

Our decision to measure external variables was based on requirements of the *Theory of planned behavior*[22,44]. We assessed biographical factors, e.g. socio-economic status, age, marital status and medical characteristics e.g. treatment, side effects and comorbidity [33,41-43]. A second set of external characteristics was distress. A third set was evaluation of psychosocial interventions as well as satisfaction with received supportive care.[22,34,47].

Needs are experienced by participants in all six life-domains, especially needs concerning psychological, healthcare system, sexual and physical issues.

We found high scores on ASE-factors attitude and perceived self-efficacy, which aligns with the results of Voerman and Corboy[20,22]. Patients suffer less from depression than respondents in other studies. Low levels of depression, coincides with previous studies that showed moderate levels of psychopathology[16].

Looking at biographical factors, the SES in other study samples was lower compared to ours [14], but further general demographical features, such as age and disease related factors are in line with those in other Dutch samples[14]. Voerman et al. concluded that lower age and higher socio-economic status relate to interest in care support, which could mean that our respondents report more interest in supportive care. Differences in SES-scores may also be of influence on the extent of coping with the PCA diagnosis. Compared to our study it could mean that since our respondent's SES scores are relatively high, they are better adjusted to the cancer diagnosis and therefore report fewer care needs. Voerman also argued that less experienced distress relates to better adjustment to the cancer diagnosis. Bias may also be caused by a respondent group with higher SES-scores because studies indicate that patients with high SES-scores report lower anxiety.

Multivariate analysis shows that the ASE-factors *attitude*, *social support* and *efficacy* do not modify future supportive care seeking behavior, eventhough previous studies by Corboy et al. and Voerman et al. indicate that using support interventions relate especially to attitudes towards care and perceived efficacy[20,22]. Our results show a significant predictable value of psychological and physical needs and depression to future care use. Also that needs are more important than attitude in relation to care seeking behavior, as also found by Sanson-

Fisher[15]. The limited role of attitude in our study could be explained by the absence of needs measurements in former studies by Voerman et al. and Corboy et al.[20,22]. Other studies confirm the coherence between ASE factors and needs, as did our study. Performing Pearson's correlations coefficients, we found significant correlations ($p \leq .05$) between attitude and healthcare system ($r = 0.27$) and sexual needs ($r = 0.28$), which could mean that positive attitude and healthcare system needs and sexual needs are mutually influencing factors. We also found significant correlations between support from other's and physical needs ($r = 0.33$) as well as efficacy and needs concerning incontinence ($r = -0.22$). This indicates that men with high efficacy deal well with needs concerning incontinence.

Strengths and Limitations

Response was positive. All participants that contacted the investigator to receive an extensive questionnaire returned it. We used several validated standardized measurement scales. We combined the predictive value of ASE-model and Needs model for the first time. We also measured various external factors according to the Theory of Planned behavior. The planned sample-size wasn't achieved due to time limitations and also by difficulty in reaching the patient population via hospitals and healthcare professionals. Mentioned reasons for limited participation were work-load at outpatient clinics. Other arguments were hospital's own research activities. Recruitment via the psychosocial supportive care-center was difficult because of ethical and organizational arguments. To evaluate the risk of selection bias due to limited sample size, we compared our sample with previous Dutch studies[14]. Comparison on disease related factors showed no sample differences. Our sample mainly compounds of respondents approached by the patient organization. From previous studies we know that patient organization members experience more distress [13,22]. Our sample showed higher depression rates compared to anxiety, so we could conclude that anxiety is not so much an issue for the respondents.

Conclusion

Determinants that influence care-seeking behavior are mainly needs related. Determinants that contribute to supportive care seeking are patient's attitude, sexual needs, support and care needs, health system needs, anxiety, age, previous psychosocial care use and satisfaction with former care.

Most important factors that influence patient's intention to seek support are psychological and physical needs, and depression. This information will substantiate patient referral to appropriate supportive care facilities by oncology/urology nurses.

Recommendations

Our results provide useful information about specific influencing care seeking factors in PCA patients. Many patients experience problems concerning physical, psychological and social issues[9,13,14]. Nevertheless they don't attend supportive care as much[9,31,33]. Given the important role of oncology nurses and other healthcare professionals in psychosocial support for PCA patients, the results may have practical implications for their daily practice and for further research. Previous research indicated that men look for expert information and programs that combine information and physical training rather than emotional support [9,26,27]. Healthcare organizations and professionals could use this information to further develop needs and preference based interventions. Based on our study and previous research, interventions could comprehend clear expert information on psychological and physical issues[9,13,16].

This study focused on patient needs. Further research could examine factors that impair those needs. Also studies about specific care interventions, that patients consider helpful, could be of interest because information may reduce anxiety[27,28]. On the other hand, different interventions have been developed to support patients with problems in different life domains. However, the effectiveness of those interventions is still unclear. Randomized intervention studies with a large enough sample give insight in (cost-) effectiveness and efficiency of those interventions[49]. With a predicted increasing PCA incidence in the next decade, this could be of great importance to both patients and Dutch healthcare in general.

References

(1) World Health Organization. Accessed November 2011.

(2) IKNL. Accessed October, 2011.

(3) National Compass. Accessed October 2011.

(4) Muilekom HAM, Spil JA (editors). Handboek Prostaatcarcinoom. Maarssen: Elsevier Gezondheidszorg 2006.

(5) McDowell M, Occhipinti S, Ferguson M, Chambers S. Prospective predictors of psychosocial support service use after cancer. Psycho oncology 2010;20:788-91.

(6) Huang GJ, Sadetsky N, Penson DF. Health related quality of life for men treated for localized prostate cancer with long-term followup. J Urol 2010;183:2206-12.

(7) Fowler FJ,Jr, Barry MJ, Lu-Yao G, Wasson JH, Bin L. Outcomes of external-beam radiation therapy for prostate cancer: a study of Medicare beneficiaries in three surveillance, epidemiology, and end results areas. J Clin Oncol 1996;14:2258-65.

(8) Madalinska JB, Essink-Bot ML, de Koning HJ, Kirkels WJ, van der Maas PJ, Schroder FH. Health-related quality-of-life effects of radical prostatectomy and primary radiotherapy for screen-detected or clinically diagnosed localized prostate cancer. J Clin Oncol 2001;19:1619-28.

(9) Voerman B, Fischer M, Visser A, Andel Gv, Garssen B. Prostate cancer: a review of the literature on psychosocial problems and psychosocial interventions. (Dutch) Gedrag en Gezondheid: Tijdschrift voor Psychologie en Gezondheid 2004;32:251-70.

(10) Dale W, Bilir P, Han M, Meltzer D. The role of anxiety in prostate carcinoma: a structured review of the literature. Cancer 2005;104:467-78.

(11) Pirl WF, Mello J. Psychological complications of prostate cancer... including commentary by Dineen K, Eton DT, Von Gunten CF, Corboy KJ, and Loscalzo MJ. Oncology 2002 11;16:1448.

(12) van Andel G, Bottomley A, Fossa SD, Efficace F, Coens C, Guerif S, et al. An international field study of the EORTC QLQ-PR25: a questionnaire for assessing the health-related quality of life of patients with prostate cancer. Eur J Cancer 2008;44:2418-24.

(13) Visser A, van Andel G. Psychosocial and educational aspects in prostate cancer patients. Patient Educ Couns 2003;49:203-06.

(14) Voerman B, Visser A, Fischer M, Garssen B, Andel Gv, Bensing J. Elderly male patients: traumatic stress and need for support in prostate cancer patients. 2012 submitted.

(15) Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. Cancer 2000;88:226-37.

(16) Bisson JI, Chubb HL, Bennett S, Mason M, Jones D, Kynaston H. The prevalence and predictors of psychological distress in patients with early localized prostate cancer. BJU Int 2002;90:56-61.

(17) Halbert CH, Wrenn G, Weathers B, Delmoor E, Ten Have T, Coyne JC. Sociocultural determinants of

men's reactions to prostate cancer diagnosis. Psychooncology 2010;19:553-60.

(18) Helgason AR, Dickman PW, Adolfsson J, Steineck G. Emotional isolation: prevalence and the effect on well-being among 50-80-year-old prostate cancer patients. Scand J Urol Nephrol 2001;35:97-101.

(19) Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The supportive care needs of men with advanced prostate cancer. Oncol Nurs Forum 2011;38:189-98.

(20) Corboy D, McLaren S, McDonald J. Predictors of support service use by rural and regional men with cancer. Aust J Rural Health 2011;19:185-90.

(21) Voerman B, Fischer M, Visser A, Garssen B, van Andel G, Bensing J. Health-related quality of life in Dutch men with prostate cancer. J Psychosoc Oncol 2006;24:49-64.

(22) Voerman B, Visser A, Fischer M, Garssen B, van Andel G, Bensing J. Determinants of participation in social support groups for prostate cancer patients. Psychooncology 2007;16:1092-99.

(23) Oliffe JL, Halpin M, Bottorff JL, Hislop TG, McKenzie M, Mroz L. How prostate cancer support groups do and do not survive: British Columbian perspectives. Am J Mens Health 2008;2:143-55.

(24) Helgeson VS, Lepore SJ, Eton DT. Moderators of the benefits of psychoeducational interventions for men with prostate cancer. Health Psychol 2006;25:348-54.

(25) Livingston PM, White VM, Hayman J, Maunsell E, Dunn SM, Hill D. The psychological impact of a specialist referral and telephone intervention on male cancer patients: a randomised controlled trial. Psychooncology 2010;19:617-25.

(26) Berglund G, Petersson LM, Eriksson KC, Wallenius I, Roshanai A, Nordin KM, et al. "Between Men": a psychosocial rehabilitation programme for men with prostate cancer. Acta Oncol 2007;46:83-89.

(27) Templeton H, Coates V. Evaluation of an evidence-based education package for men with prostate cancer on hormonal manipulation therapy. Patient Educ Couns 2004 10;55:55-61.

(28) Tarnhuvud M, Wandel C, Willman A. Nursing interventions to improve the health of men with prostate cancer undergoing radiotherapy: a review. Eur J Oncol Nurs 2007;11:328-39.

(29) Walling AM, Maliski S, Bogorad A, Litwin MS. Assessment of content completeness and accuracy of prostate cancer patient education materials. Patient Educ Couns 2004;54:337-43.

(30) Lepore SJ, Helgeson VS, Eton DT, Schulz R. Improving quality of life in men with prostate cancer: a randomized controlled trial of group education interventions. Health Psychol 2003;22:443-52.

(31) Annual report 2009 De Vruchtenburg. Rotterdam. 2010.

(32) Gray RE, Fitch M, Phillips C, Labrecque M, Fergus K. To tell or not to tell: Patterns of disclosure among men with prostate cancer. Psycho oncology 2000;9:273-82.

(33) Annual Report 2009 Heln Dowling Institute. 2010.

(34) Polit D, Beck C. Nursing research: Generating and assessing evidence for nursing practice. Philadelphia. Wolters-Kluwer Health; 2008.

(35) Portney L, Watkins M editors. Foundations of Clinical Research. third edition ed. New Jersey: Pearson Education International; 2009.

(36) Boyes A, Hall A, Zucca A, Girgis A. Supportive Care Needs Survey: supplement 2: reference data for cancer survivors 5-9 months post-diagnosis. The University of New Castle. 2010.

(37) Schoustra D, Visser AP. The unmet psychosocial care needs in breast cancer patients in the Netherlands. Thesis University of Leiden. Rotterdam. De Vruchtenburg. 2012.

(38) Pallant J editor. SPPS Survival Manual. New York. Open University Press; 2007.

(39) McElduff P, Boyes A, Zucca A, Girgis A. Supportive Care Needs Survey: a guide to administration, scoring and analysis. New Castle. The University of New Castle. 2004.

(40) Bjelland I, Dahl A, Tangen Haug T, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale: an updated literature review. Journal of Psychosom Res 2002;52:69-77.

(41) Hinz A, Krauss O, Hauss JP, Hockel M, Kortmann RD, Stolzenburg JU, et al. Anxiety and depression in cancer patients compared with the general population. Eur J Cancer Care (Engl) 2010;19:522-29.

(42) Korfage IJ, Essink-Bot ML, Janssens AC, Schroder FH, de Koning HJ. Anxiety and depression after prostate cancer diagnosis and treatment: 5-year follow-up. Br J Cancer 2006;94:1093-98.

(43) Visser A, van Andel G. Psychosocial and educational aspects in prostate cancer patients. Patient Educ Couns 2003;49:203-06.

(44) Segaar D, Bolman C, Willemsen MC, Vries H. Determinants of adoption of cognitive behavioral interventions in a hospital setting: example of a minimal-contact smoking cessation intervention for cardiology wards. Patient Educ Couns 2006;61:262-71.

(45) Vocht Ad editor. SPSS 16 voor Windows. second edition ed. Utrecht: Bijleveld Press; 2009.

(46) Israel G. Determining Sample Size. Florida Cooperative Extension Service 1992.

(47) Hagoort K, van der Linden F. Uurlonen per beroepsgroep; centrum voor beleidsstatistiek. Centraal Bureau voor de Statistiek, Voorburg/ Heerlen 2007.

(48) Templeton H, Coates V. Evaluation of an evidence-based education package for men with prostate cancer on hormonal manipulation therapy. Patient Educ Couns 2004;55:55-61.

(49) Berglund G, Petersson LM, Eriksson KC, Wallenius I, Roshanai A, Nordin KM, et al. "Between Men": a psychosocial rehabilitation program for men with prostate cancer. Acta Oncol 2007;46:83-89
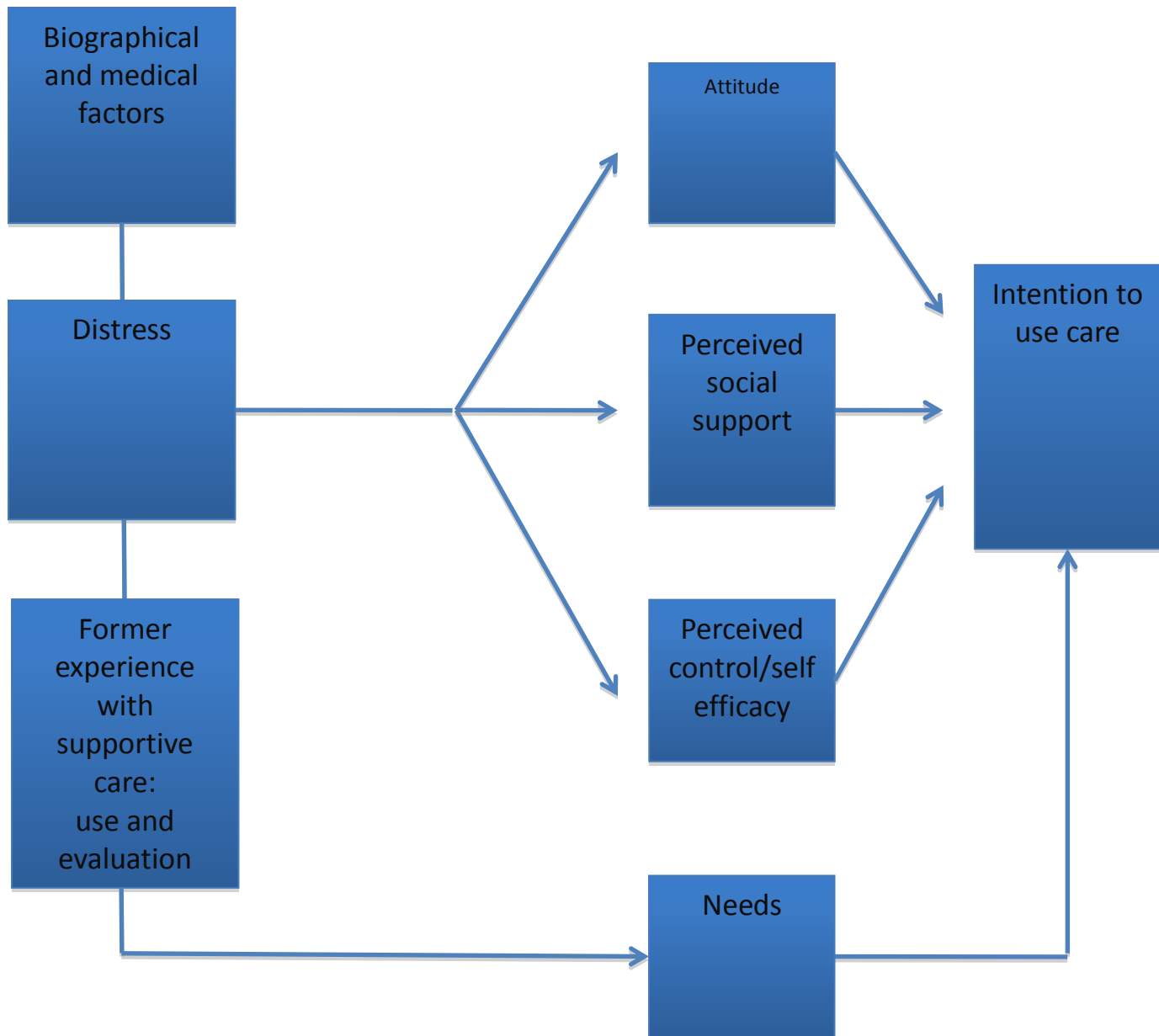
Figure 1: *Model for studying supportive care seeking behavior, based on Voerman et al.(2007) and Segaar et al.(2004, 2007)[44]*

Table 1. *The used measurement scales*

Instruments	Measurement	Validity	Reliability
Behavioral intention to seek supportive care	Sumscore of three variables: • General question about care seeking • Question about specific care seeking: sumscore of six items, answered yes or no • Question about intention to seek support on four-point Likert scale	Questions were used and validated in former studies on psychosocial care needs in prostate cancer patients [42, 43]	Applied comparable questions showed reliable scales: Cronbach's alpha 0.82 [42,43]
Needs (SCNS)	• Psychological needs: ten items • Physical needs: five items • Sexuality needs: four items • Care and support needs: five items • Incontinence needs: three items • Health system needs: 11 items three items were added concerning incontinence. sumscores were standardized according to the instrument's syntax and were calculated. Score 0-1 indicate no need, or problem solved/satisfied; 2 means low need for help; 3 means some need and 4 indicates high need.	Five factors accounting for 72.1 % of the total variance. Translated into Dutch by backward method by Schoustra et al. for breast cancer patients(2011; NP)	Internal reliability: Cronbach's alpha of the 5 factors ranged between 0.87-0.97 (37)
ASE - variables: Measurement of attitude, social norms and peceived control	• Attitude: six items Items are compounded of the product of six belief items and six evaluation of the beliefs. Each item valued from -2, -1, 0 to +1, +2; product of belief and evaluation is attitude score for item. • Social norms: three items Items are compounded of the product of three beliefs and three evaluations of the beliefs Each item valued from -2, -1, 0 to +1, +2 Product of belief and evaluation is perceived support score for that item. Items measured seperately due to low	Attitude and perceived control are important factors determining both interest and actual care seeking behavior Used and published in a Dutch study showing a predictive value of psychosocial care seeking (33).	Cronbach's alpha: Attitude items: 0.76 Perceived social support: 0.68 Perceived control/self efficacy: 0.60 (33)

	inter-item correlations. • Self efficacy: three items.		
Anxiety and depression (HADS)	Seven items on anxiety and seven items on depression;	Correlations between .49 and .83 Validated in Dutch	Cronbach's alpha between 0.68- 0.93 (38,39)
Social economic status (SES)	• Education: • Income • Profession All variables measured with one question assessed with three-point scale, three separate scores combined in SES	Inter item correlations between 0.60 and 0.72 According to previous study in PCA patients(12)	Cronbach's alpha 0.84 (12)
Former experience with psychosocial care • **The measure of former psychosocial care use** • **The use of specific care facilities**	Sumscore of items about • previous use of psychsocial care: one item • items about specific healthcare professionals: 16 items	Questions were used and validated in former studies on psychosocial care needs in prostate cancer patients [42, 43]	Applied comparable questions showed reliable scales: Cronbach's alpha 0.82 [42,43]
Evaluation of received care: • **satisfaction with received supportive care** • **evaluation of hospital care**	Sumscore of items about • satisfaction with received support: one item • care proved profitable: one item • quality and quantity of received information in hospital: one item • schoolmark for received hospital support: one item	Questions were used and validated in former studies on psychosocial care needs in prostate cancer patients [42, 43]	Applied comparable questions showed reliable scales: Cronbach's alpha 0.82 [42,43]
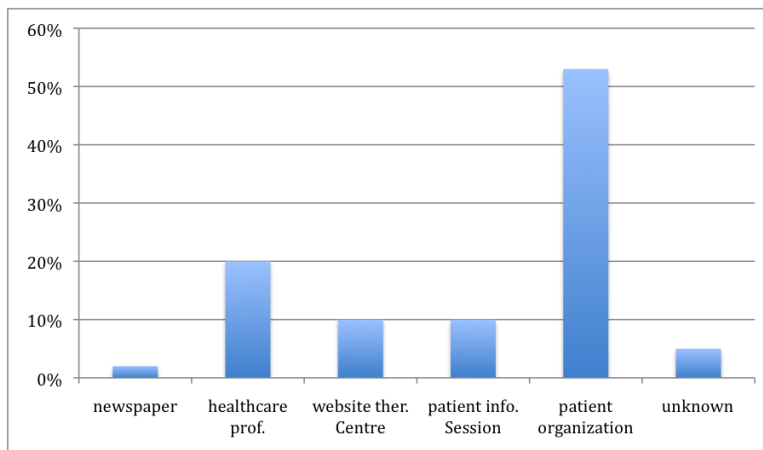
Figure 2. *Patient recruitment*

Table 2. *Reliability assessment*

Instruments	Number of items	Empirical range	Scale mean	SD	Reliability
SCNS					
• Physical	5	5 – 23	58.5	4.95	.79
• Psychological	10	10 – 48	17.3	10.60	.90
• Sexuality	4	4 – 20	7.7	5.41	.93
• Incontinence	3	3 – 15	2.6	3.24	.86
• Patient care/support	5	5 – 25	6.6	5.50	.83
• Health system	11	11 - 54	18.4	12.76	.91
ASE variables					
• Attitude	6	- 3 – +19	3.9	4.22	.58
• Social support					
- Physician	1	Not applicable	0.3	1.39	Not applicable
- Partner/friend	1	Not applicable	1.4	1.63	Not applicable
- Other person	1	Not applicable	- 1.9	1.73	Not applicable
• Efficacy	3	3 – 15	12.4	2.49	.66
HADS					
• Anxiety	7	00 - 12	4.6	3.68	.83
• Depression	7	00 - 16	3.9	3.41	.77
SES					
• Education					
• Income	3	3 - 9	6.8	1.56	.70
• profession					

Experience with psychosocial care interventions					
• previous use of psychosocial interventions	1	0 - 3	18.2	2.62	.61*
• sumscore specific professionals	1	0 - 1			
Evaluation of received care factors:					
• **care and support in general**	1	0 - 4	12.3	3.10	.86*
	1	0 - 4			
• **supportive hospital care**	1	0 – 5	9.4	2.80	.55*
	1	0 - 10			
Behavioral intention					
• intention to seek supportive care in the future	1	0 - 1	1.18	1.39	.80
• looked for supportive care	1	0 - 1			
• sumscore specific supportive care interventions	6	0 - 1			

* inter-item correlations

Table 3. *Frequencies of socio-demographic characteristics* (N=87)

Age (mean)	66,2 years
Range	44-84 years
Age ≤ 65	39 (44,8)
Age > 65	48 (55,2)
Marital status	
Married and living apart together	79 (91,8)
Presently no stable relationship (divorced, widower, single)	7 (8,2)
Missing	1
Education	
Primary education/primary vocational	9 (10,3)
Secondary education, technical and vocational training	35 (40,2)
College or university	43 (49,4)
Employment Status	
Working	17 (19,5)
Unable to work due to illness, Job seeking	7 (8,0)
Retired	63 (72,4)

Profession
    Skilled work/craftsman   9 (10,3)
    Vocational trained/administrative worker   34 (39,1)
    Higher management, management   42 (48,3)
    Academic professionals
    Missing   2

Income status
    < 2300 euro   14 (16,1)
    2300 – 4800 euro   53 (60,9)
    > 4800 euro   20 (23,0)

Residential area
    South west Netherlands   40 (46,0)
    Other parts of Netherlands   47 (54,0)

Table 4. *Medical characteristics* N= 87 (%)

Medical treatment
    Surgery/Prostatectomy   44 (50,6)
    Radiation treatment (Intern/ext)   49 (56,3)
    Hormonal therapy   32 (36,8)
    Watchful waiting   16 (18,4)
    Other   7 (7,7)

Metastasis
    Yes   19 (21,8)
    Unknown yet   12 (13,8)
    No   56 (64,4)

Comorbidity
    Yes   37 (42,5)
    No   50 (57,5)

Other diseases
    Arthritis & rheumatic problems   6 (6,9)
    Heart related & hypertension   11 (12,6)
    Intestinal problems   3 (3,4)
    Lung & airway diseases   2 (2,3)
    Metabolism   6 (6,9)
    Neurological complaints   9 (10,3)
    Cancer, other types   2 (2,3)
    Other   7 (8,0)

Table 5. *Attitude, perceived social support and efficacy (N: between 84 – 87: missing values)*

	< 0*	%	> 0**	%
Attitude	11	13	73	83
Support other	80	94	5	3
Support partner	36	42	50	57
Support physician	52	72	24	27
Efficacy	0	0	86	99

* < 0: belief or evaluation not present or unimportant
** > 0: belief or evaluation present or important

Table 6. *Supportive Care needs survey (SCNS)*

	0 (%)	1 (%)	2-4 (%)	Stand.Mean	SD
Psychological needs*	0 (0)	2 (3,7)	80 (91,9)	43	42,5
Healthcare system needs*	0 (0)	6 (7,2)	77 (88,2)	42	29,1
Sexual needs*	0 (0)	13 (15,1)	73 (83,8)	48	33,7
Care and support needs*	0 (0)	16 (18,4)	70 (80,3)	31	27,4
Physical needs*	0 (0)	16 (18,8)	69 (78,9)	29	24,5
Incontinence needs*	0 (0)	41 (48,2)	44 (49,5)	22	27,1

* N is between 82 and 87 due to missing values

Table 7. *Hospital Anxiety and Depression Scale*

	N (%)
Anxiety : cut off score ≥ 8 (N=85)	19 (16.5)
Depression: cut off score ≥ 8 (N=84)	14 (11,9)

Table 8. *Experience with psychosocial care (N=87)*

	Yes %
Previous care use*	31 (36,5)
Use of specific healthcare professionals	
• oncology nurse*	14 (16,1)
• specialist*	19 (22,1)
• general practitioner*	28 (32,6)
Centre for psychosocial supportive care*	43 (50,0)

* missing values 1

Table 9. *Looking for and finding supportive care   (N = 86)*

	Looked for (%)	Found (%)	Looked for & found (%)
General support Seeking	47,7%	50,0%	95,1%
Telephone support	8 (9,2)	9 (10,3)	62,5%
Individual counseling	14 (16,1)	14 (16,1)	71,4%
Expert information	33 (37,9)	30 (34,5)	84,8%
Contact with fellow-patients	8 (9,2)	7 (8,0)	75,0%
Prostate cancer society	8 (9,2)	2 (2,4)	25,0%
Therapeutic center	3 (3,4)	3 (3,4)	100%
Other	5 (5,5)	5 (8,0)	100%

Table 10. *Satisfaction with psychosocial care satisfaction (N=87)*

	Yes (%)	No (%)	not used
Content with received * psychosocial support in general	47 (54,0)	7 (8,4)	29
Benefit from psychosocial support *	46 (52,8)	6 (7,2)	31
Hospital care			
• content with received care/support	49 (56,3)	38 (43,7)	
• schoolmark			
0-5	19 (21,8); SD 2.05		
6-10	68 (79,2); SD 2.05		

* missing values ≤ 4

Table 11. *Correlations between behavioral intention to care use and all studied independent factors*

	Pearsons correlation		Pearsons correlation
ASE-model		**Satisfaction**	
Attitude	.29*	Satisfaction hospital care	.19
Support physician	.07	Satisfaction general care	.22
Support others	.17		
Support partner	.02		
Efficacy	.03	**Biographic characteristics**	
		Age	-.26*
Needs (SCNS)		Socio-economic status	.05
Physical needs	.45**	Marital status	-.02
Psychological needs	.55**	Region of residence	-.16
Sexual needs	.49**		
Incontinence needs	.18		
Support and care needs	.46**	**Medical characteristics**	
Health system needs	.45**	Metastisis	.12
		Surgical therapy	.06
Distress (HADS)		Radiation therapy	-.07
Anxiety	.32**	Hormonal therapy	.02
Depression	.38**	Comorbidity	.19
Experience			
Former use of			
- psychosocial care	.45**		
- psychosocial supportive care centre	.23*		

* p ≤ .05   ** p ≤ .01

Table 12. *Results of forward multiple regression analysis*

Independent variable	standardized ß	t-test	sign.
Psychological needs	.40	3.564	.00
Physical needs	.23	2.150	.04
Depression	-21	2.123	.04

Model summary

Independent variable	R	R square	R square Change
Psychological needs	.63	.39	.39
Psychol. needs, Physical needs	.67	.44	.05
Psychol. needs, Physical needs, Depression	.69	.48	.04