

Aus der Geschlechterforschung in der Medizin (GiM)
der Medizinischen Fakultät Charité – Universitätsmedizin Berlin

DISSERTATION

Bewältigungsstrategien und Lebensqualität von Männern mit lokal begrenztem
Prostatakarzinom unter verschiedenen Behandlungsoptionen

Coping Strategies and Quality of Life Among Men with Localized Prostate Cancer
Undergoing Different Treatment Options

zur Erlangung des akademischen Grades
Doctor of Philosophy (PhD)

vorgelegt der Medizinischen Fakultät
Charité – Universitätsmedizin Berlin

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Datum der Promotion: 30.11.2023

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Abbreviations

▪ ANOVA	–	Analysis of Variance (statistical group comparison)
▪ AS	–	Active Surveillance
▪ Brief-IPQ	–	Brief Illness Perception Questionnaire (validated questionnaire)
▪ BRT	–	Brachytherapy
▪ COPCa	–	<i>Coping with Prostate Cancer</i> (abbreviated title of Project 2)
▪ DRS	–	Decision Regret Scale (validated questionnaire)
▪ EBRT	–	External Beam Radiation Therapy
▪ e.g.	–	example given
▪ HAROW	–	<i>Hormone Therapy, Active Surveillance, Radiotherapy, Operation, Watchful Waiting</i> (abbreviated title of a German health care study on prostate cancer)
▪ i.e.	–	id est
▪ IQR	–	Inter quartile range (measure of statistical dispersion)
▪ LPCA	–	Localized Prostate Cancer
▪ M	–	Arithmetic Mean (statistical measure of central tendency)
▪ MAX-PC	–	Memorial Anxiety Scale for Prostate Cancer (validated questionnaire)
▪ Mdn	–	Median (statistical measure of central tendency)
▪ PCa	–	Prostate Cancer
▪ PSA	–	Prostate Specific Antigen
▪ RCT	–	Randomized Controlled Trial
▪ RP	–	Radical Prostatectomy
▪ RT	–	Radiotherapy
▪ SD	–	Standard deviation (measure of statistical dispersion)

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Abstract (German)

Hintergrund: Die Diagnose eines lokal begrenzten Prostatakarzinoms (LPCa) stellt einen Wendepunkt im Leben vieler betroffener Männer dar. Initial berichten viele Männer nach der Diagnose von Todesangst, obwohl die Überlebensraten beim LPCa hoch sind. Wegen der guten Prognose ist eine sofortige invasive Behandlung, die schwere Nebenwirkungen haben kann, nicht zwingend notwendig. Daher gewinnen Fragen an Bedeutung, wie betroffene Männer langfristig mit der LPCa-Erkrankung leben und eine hohe Lebensqualität aufrechterhalten können. Gegenstand dieser Dissertation ist die gesundheitsbezogene Lebensqualität von Männern mit LPCa unter verschiedenen Behandlungen und die Zusammenhänge mit individuellen Bewältigungsstrategien.

Ziel: Ziel war es, zu untersuchen, inwiefern die Informationssuche mit einer erhöhten Krankheitsangst einhergeht (Studie 1), wie die Erektionsfähigkeit mit dem Selbstwert zusammenhängt (Studie 2), welche Faktoren das Bereuen der Behandlungsentscheidung vorhersagen (Studie 3) und wie Coping-Strategien und Angst (Studie 4) bei Männern mit LPCa assoziiert sind.

Methode: Die vier Studien, die die Basis dieser Dissertation bilden, entstanden in zwei Forschungsprojekten mit LPCa Patienten: Das erste Projekt war eine querschnittliche Befragungsstudie ($N=292$), das zweite Projekt war eine prospektive, nicht-interventionelle, multi-zentrische Längsschnittstudie ($N=183$). Daten wurden mithilfe von linearen (Studie 1, Studie 2) und logistischen Regressionsmodellen (Studie 3) sowie mit Wachstumskurven-Analysen (Studie 4) und einem neuen Level-Kontrast Ansatz (Studie 4) analysiert.

Ergebnisse: Eine größere Zahl an Informationsquellen ging mit einer höheren Angst unter Männern einher, die das Internet häufiger nutzten und sich weniger gut über ihre Erkrankung informiert fühlten (Studie 1). Eine veränderte Erektionsfähigkeit sagte Beeinträchtigungen im Selbstwert vorher (Studie 2). Zeitdruck nach der Diagnose und erektile Dysfunktion erhöhten die Wahrscheinlichkeit für ein Bereuen der Behandlungsentscheidung, während eine hohe Zufriedenheit mit dem Sexualleben diese Wahrscheinlichkeit verringerte (Studie 3). Initial war die Krankheitsangst erhöht und verringerte sich mit der Zeit. Mehr emotions-fokussierte Coping-Strategien hingen mit höherer Angst zusammen, während mehr problem-fokussierte Coping-Strategien oder eine Balance dieser beiden Strategien mit weniger Angst assoziiert waren (Studie 4).

Schlussfolgerung: Die Ergebnisse unterstreichen, dass psychologische Faktoren eine wichtige Rolle im Zusammenhang mit LPCa spielen. In zukünftigen Studien sollten Interventionen untersucht werden, die dem Zeitdruck entgegenwirken. Implikationen dieser Arbeit für die klinische Praxis sind Bemühungen, Zeitdruck zu mindern, das psychologische Wohlbefinden und Sexualleben der Männer in der medizinischen Beratung zu thematisieren, eine kurze Übersicht mit validierten Informationsquellen auszuhändigen und Kontakte zu psycho-onkologischen Angeboten zu nennen.

Abstract (English)

Background: The diagnosis of localized prostate cancer (LPCa) presents a disruption in the lives of many men. Initially, many men who receive this diagnosis report death anxiety, although survival rates for LPCa are high. Due to the good prognosis, immediate invasive treatment, which may involve severe side effects, is not imperative. Against this background, questions of how men can live with LPCa in the long term and maintain a good quality of life are increasingly important. The focus of this dissertation is health-related quality of life in men with LPCa undergoing different treatment strategies and associations with individual coping strategies.

Aim: We aimed to investigate how information seeking is associated with disease anxiety (Study 1), how erectile dysfunction relates to self-esteem (Study 2), which factors predict decisional regret (Study 3), and how coping and anxiety are interrelated (Study 4) in men with LPCa.

Method: The four studies comprising the basis of this dissertation arose from two research projects involving men with LPCa: The first project was a cross-sectional survey ($N = 292$ men with LPCa) and, the second project was a prospective, non-interventional, multi-center, longitudinal study ($N = 183$ men with LPCa). Data were analyzed using linear (Study 1, Study 2) and logistic regression models (Study 3), growth curve analyses (Study 4) and a new level-contrast approach (Study 4).

Results: A greater number of information sources was associated with higher anxiety in men, who used the internet more frequently and felt less informed about their LPCa (Study 1). Altered erectile functioning predicted impairment in self-esteem (Study 2). Time pressure after LPCa diagnosis and erectile dysfunction increased chances of decisional regret, while satisfaction with sexual life decreased the probability of regret (Study 3). Initially, illness anxiety was enhanced and diminished over time. More emotion-focused coping was associated with higher anxiety, whereas more problem-focused coping or a balance of the two coping strategies was associated with less anxiety (Study 4).

Conclusion: The findings of this dissertation emphasize that psychological factors play an important role in the context of LPCa. Future studies should examine interventions targeted at counteracting time pressure. Implications of this thesis for clinical practice include efforts to reduce time pressure, addressing men's psychological well-being and sexual life in medical consultations, providing a brief overview with validated sources of information and contact details for psycho-oncological services.

1 Introduction

A diagnosis of prostate cancer (PCa) represents a critical juncture for many men: In the sensitive phase after diagnosis in particular, a lot of men experience their PCa as a death sentence [1, 2], although objective survival rates are favorable [3, 4]. This is critical because PCa is the most common cancer type in men, with many men (about one in seven) diagnosed with the disease during their lifetime [3]. Improved screening methods (e.g. PSA test, see Box 1) allow PCa to be detected frequently at an early stage, when the cancer is confined to the prostate gland (localized PCa (LPCa), see Box 1) and has a very good prognosis [4]. Simultaneously, early detection presents the risk of overdiagnosis (“a cancer diagnosed [...] that would not otherwise result in symptoms or death” [5], p. 205) and overtreatment (“treatment [...] which may not be required or sometimes even prove harmful for the patient” [6], p 3815).

Men with LPCa can choose between different treatment options including Active Surveillance (AS; close urological observation with changing to local therapy in case of disease progression), radiotherapy (RT; including external beam radiation therapy (EBRT) and brachytherapy (BRT), in which radioactive seeds are inserted into the prostate gland) and radical prostatectomy (RP, surgical removal of the prostate). The different treatment strategies (AS, RP, EBRT) do not differ in terms of mortality [7], but clearly do with regard to invasiveness: The main side effects of RP are erectile dysfunction and urinary incontinence, whereas the possible side effects of RT include erectile, urinary, and rectal problems [8]. These treatment side effects do not apply to AS, but disease progression or metastasis may occur more frequently than with local therapies [7]. Additionally, increased disease anxiety under AS compared with local therapies is possible [9].

“More men die with prostate cancer than because of it” (Jacklin, Philippou, Brewster & Bryant, 2021 [10], p.1)

About one in 39 men with PCa will die from the disease [3]. This is a lower mortality rate compared to other cancer types [11], primarily attributable to PCa often being detected at an early stage: Especially in localized tumors, which are diagnosed in the majority (90% of patients) [4], men have good chances of survival (five-year relative survival rates approaching 100%). In light of this, aspects of quality of life are important to discuss: How do men with LPCa cope with their disease? How do treatment side effects (e.g., erectile dysfunction) affect quality of life? How can we ensure that men choose the treatment option that is best for them and that they will not regret in the longer term? This dissertation highlights different aspects of quality of life in men with LPCa, with a focus on sexuality, as this can be markedly affected by local PCa treatment [12, 13]. The following constructs were examined in different projects: Disease-specific anxiety (Study 1 [14], Study 4 [15]), coping strategies (Study 1, Study 4), sexuality (Study 2 [16], Study 3 [17]), self-esteem (Study 2), decisional regret (Study 3), and time pressure (Study 3). In all projects, primary emphasis was placed on men's subjective perspectives, since this is crucial, especially in quality-of-life considerations.

1.1 State of research

1.1.1 Disease-specific anxiety

“I was in a daze, unsure of myself, frightened, and cranky with myself” (PCa patient quote [2], p.6)

For many men, a PCa diagnosis elicits fear of dying from the disease [1, 2]. Particularly before treatment, many PCa patients report anxiety (27.0%); during (15.1%) and after (18.5%) treatment, fewer men indicate experiencing anxiety [18]. It seems that many men learn to cope with the disease over time. Nevertheless, a meta-analysis [19] found that one sixth of PCa patients experienced “significant anxiety symptoms” (p. 4). A large-scale randomized controlled trial (RCT) [20] demonstrated that 15.2% of men with LPCa reported clinically relevant anxiety six years after diagnosis.

Box 1 | Medical Background

The **prostate**, resembling a chestnut in shape and size, is a gland, that provides supporting function in the reproductive system¹. It consists of up to 50 epithelial glands in addition to smooth musculature² and is encased in a fibrillar capsule, surrounded by nerves and blood vessels¹. It is located directly under the bladder (Figure A) and encloses the urethra. The lower apex of the prostate lies on the external urethral sphincter. The prostate has several tubular components extending within it, comprising the proximal urethra and two ejaculatory ducts which intersect within the gland (*seminal colliculus*)¹. Thereby, the prostate assists in the control of ejaculatory and urinary flow. The prostate has complex functions and a sensitive location. Removal can irreversibly damage neural fibers, which can have serious consequences (e.g., erectile dysfunction, urinary incontinence). The primary function of the prostate is the production of secretion protecting sperm cells¹. This contains, i.a., the prostate-specific antigen (PSA), which is also used as a tumor marker in diagnostics.

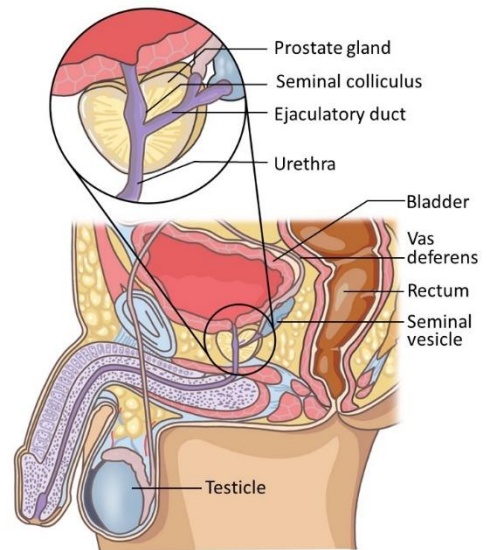


Figure A: The prostate is located directly underneath the bladder (Image source: Antonia Schwarz/sci|vis|to)

Uncontrolled, malignant growth of prostate cells is referred to as **prostate cancer** (PCa). The etiology of PCa is largely unclear, with age and ethnicity as confirmed risk factors³. Additionally, genetic predisposition, hormones, and lifestyle aspects (e.g., smoking, diet) are considered potential causal factors.

Based on digital rectal examination and serum PSA level, suspected PCa diagnosis is made, which needs to be confirmed by biopsy³. After diagnosis, tumor risk is classified to derive appropriate treatment recommendations, whereby three characteristic values are used: TNM classification, PSA value, and Gleason score/ ISUP grade. TNM classification indicates spread of the tumor (*staging*): LPCa (confined to the prostate), locally advanced PCa (capsule is breached and neighboring tissue infiltrated), or metastatic PCa (metastases in regional lymph nodes or distant metastases are present). The Gleason score assesses the tumor regarding the degree of differentiation (*grading*). It evaluates the primary and secondary growth pattern of the tumor with numerical values summed (range: 2-10). The International Society of Urological Pathology (ISUP) revised Gleason grading in 2014⁵ (ISUP grade, range: 1-5). According to D'Amico criteria⁶, LPCa can further be differentiated in terms of risk: low-, intermediate- and high-risk localized carcinomas (see Table A).

Table A: D'Amico and colleagues⁶ divide localized prostate carcinomas into three risk categories (Source: own illustration)

	Low-risk	Intermediate-risk	High-risk
TNM	T1c – 2a	T2b	T2c
	and	or	or
PSA	≤ 10 ng/ml	10.1 – 20 ng/ml	≥ 20.1 ng/ml
	and	or	or
Gleason / ISUP	≤ 6 / 1	7 (7a, 7b) / 2-3	≥ 8 / 4-5

¹Singh O, Bolla SR (2021) StatPearls: Anatomy, Abdomen and Pelvis, Prostate, Treasure Island (FL).

²Zilles K, Tillmann BN (2010) Anatomie. Springer-Lehrbuch. Springer Berlin Heidelberg, Berlin, Heidelberg.

³Bott SRJ, Ng KL (eds) (2021) Prostate Cancer, Brisbane (AU).

⁴Amin MB, Grignon D, Humphrey PA, Srigley JR (eds) (2003) Gleason Grading of Prostate Cancer: A Contemporary Approach, 1st edn. Lippincott Williams & Wilkins, Philadelphia.

⁵Hupe MC, Offermann A, Sailer V, Merseburger AS, Perner S (2019) Status quo 5 years after the introduction of the new ISUP 2014/WHO 2016 prostate cancer grade groups. Aktuelle Urol 50(6):619–624.

⁶D'Amico AV, Whittington R, Malkowicz SB, Schultz D, Blank K, Broderick GA, Tomaszewski JE, Renshaw AA, Kaplan I, Beard CJ, Wein A (1998) Biochemical outcome after radical prostatectomy, external beam radiation therapy, or interstitial radiation therapy for clinically localized prostate cancer. JAMA 280(11):969–974.

The latter RCT [20] found that men under AS, after RT, and after RP did not differ in terms of anxiety, suggesting that treatment strategies for LPCa may not account for differences in anxiety. This raises the question which factors may then explain different expressions of anxiety among men with LPCa. Cognitive illness representations [21], i.e. how patients explain their disease for themselves, represent a possible explanatory approach: A meta-analysis on illness representations [22] showed that patients reported higher anxiety when they anticipated more *consequences* for their disease and lower anxiety when they felt a higher sense of *control* over their condition. The few previous studies on illness representations of PCa patients confirm these associations [23, 24]. Disease-specific anxiety is a construct of utmost relevance, because it is associated with decreased quality of life [25] and increased risk of depression [26] in men with PCa. In addition, anxiety may also affect medical decision making (e.g., treatment decisions), among both patients [27] and physicians [28].

1.1.2 Coping strategies

After a LPCa diagnosis, every patient may sooner or later face the issue of how to deal with the disease. Questions that may arise in men with LPCa include: "Do I want to have local treatment immediately or do I want to observe the tumor first? Do I want to talk to other PCa patients or would I rather not talk about the topic at all? How can I become active in my everyday life to better live with the disease?". Coping strategies can be broadly divided into problem-focused (strategies approaching a stressor; e.g., research information on different PCa treatments) and emotion-focused coping (strategies avoiding a stressor; e.g., activities that are unrelated to PCa to distract oneself from the emotions related to the disease) [29]. Green and colleagues [30] showed that lower emotion-focused coping according to this definition was associated with a higher quality of life in men with PCa. Another study with PCa patients [31] revealed a suppressive effect of emotion-focused coping: The negative association between illness uncertainty and mental well-being demonstrated in this study was increased by avoidant coping strategies.

"We put ourselves through a crash course on prostate cancer" (PCa patient quote [32], p.394)

Information search is one facet of problem-focused coping which is widely adopted by PCa patients [33]: Shortly after PCa diagnosis, men have a high need for information, which may persist in the long term if symptoms (e.g., sexual/urinary problems) are pronounced [34]. Cuypers and colleagues [35] showed that at one year, about one-third of men with LPCa were not satisfied with the information received shortly after diagnosis. Urologists are still the most important source of information for men with PCa [36]. The internet also plays an important role with one-sixth of PCa patients citing it as their main source of information [37]. How using different information sources is related to anxiety is an open question.

1.1.3 Sexuality

"Sexuality is not just if you can do it" (PCa patient quote [1], p.21)

Since local treatment strategies of LPCa (RP, RT) can severely impact sexual functioning, sexuality holds an important position as a part of quality of life among men with PCa. Many men after local treatment (up to three quarters of men after RP [12, 38], one third of men after RT [13]) report impaired erectile functioning. Some studies demonstrate improvements of erectile dysfunction over time, however, pre-treatment functional levels can usually not be regained [39]. Most studies concentrate on physical aspects of sexuality (e.g., erectile dysfunction), though this only represents one facet of sexuality.

Aspects such as the importance of sexuality or satisfaction with sexual life represent more psychological facets of sexuality. Previous studies with PCa patients suggest that satisfaction with sexual life is a distinct construct from erectile functioning and is largely recoverable [40]. However, an altered sexual life after cancer has been linked to decreased sexual satisfaction [41]. At the time of PCa diagnosis, men

are on average 66 years old [3, 4]. While age-related stereotypes might suggest that sexuality is no longer of great importance in this phase of life, a systematic review of qualitative studies among older adults in the general population revealed that sexuality also plays an important role in this age group, although sexual activity may be affected by diseases [42].

1.1.4 Self-esteem

“[Prostate cancer] definitely affects your sense of self” (PCa patient quote [43], p.7)

Bailey defined self-esteem as [44] “the summary judgment of the collected separate assessments of one's self-meaning, self-identity, self-image, and self-concepts” (p. 393). Self-esteem and PCa may relate in many ways: The self-image of one's own body might be altered after a severe surgery like RP. The self-concept of being strong and healthy may be violated by a cancer diagnosis. Self-identity as a partner/husband may be affected by impaired erectile functioning after local treatment. These associations are confirmed by previous research: In an online survey with PCa patients and their partners [2] more than half of partners indicated that PCa had affected PCa patients' self-esteem. Self-esteem is important because it is connected to distress and quality of life in PCa patients [45]. Factors that may predict self-esteem in this cohort include treatment side effects, altered body image, and sexual orientation [46–48].

1.1.5 Decisional regret

*“If I had known how this would affect me after surgery, I would have decided against therapy”
(PCa patient quote [17], p.3759)*

Why do men with PCa later regret their treatment decision? Previous studies demonstrated that severe treatment side effects, such as erectile dysfunction [49, 50] and urinary incontinence [51, 52], are associated with greater regret. Additionally, unmet expectations [53] also play a role: If men assume that they will have little or no impairment in their erectile functioning after PCa treatment and this expectation is not confirmed, this may promote later regret. Accordingly, regret is less likely to occur after an informed treatment decision [54, 55, 52] and after shared decision-making [56]. Especially since men with LPCa have a good prognosis, it is essential that they can live with their disease well in the long term. In this context, regret acquires an important role. Regarding the question of how many men with PCa regret their treatment decision, evidence varies: Most studies find proportions of decisional regret ranging from 4% [57] to 31% [58] of PCa patients. However, a recent population-based retrospective observational study [49] showed that nearly two-thirds of men with nonmetastatic PCa reported some form of decisional regret. Here, the authors distinguished between mild and moderate/severe regret.

1.1.6 Time pressure

“[I have] decided too quickly” (PCa patient quote [17], p.3757)

Although time pressure is ubiquitous in clinical settings, there is surprisingly little research on this topic. In a qualitative study, Kendel and colleagues [59] found that men with LPCa perceive time pressure after their diagnosis, which can be particularly challenging in the treatment decision phase. To the best of our knowledge, the role of time pressure after the diagnosis of LPCa and its association with later regret have not yet been investigated. However, studies from other research fields demonstrated that time pressure is associated with affective outcomes (e.g. emotional exhaustion [60]), less adherence to medical guidelines [61], and enhanced decisional regret [62].

1.2 Relevance to the field of research

A diagnosis of PCa represents a disruption in the lives of many men. Particularly shortly after diagnosis, men are in a sensitive phase that can be characterized by fear and uncertainty [1, 63]. In this sensitive phase, however, men have to make far-reaching decisions, some involving irreversible consequences.

“I would rather have a life than a sex life” (PCa patient quote [1], p.19)

Despite the objectively good survival rates of LPCa, the cancer diagnosis is often perceived as a death sentence resulting in a desire for immediate tumor removal in many men [32, 59]. The initial focus on survival and cancer eradication supersedes other aspects of quality of life, such as sexuality, which regain importance over time. This constellation is critical as it may promote later decisional regret, especially if the treatment decision is made under perceived time pressure. It is essential to have a better understanding of the (information) needs of men after PCa diagnosis, how treatment side effects relate to psychological well-being and how PCa patients cope with their disease to best support them in the sensitive phase of decision making and thus allow a high level of satisfaction with the treatment decision and good quality of life in the longer-term (survivorship-phase).

1.2.1 Aims

Four publications are incorporated into this dissertation to address the following objectives:

1. So far, the role of different information sources, notably the internet, regarding illness anxiety in men with PCa remains largely unclear. The purpose of the study was hence to investigate, how the internet, the number of information sources used and subjective information on PCa predict disease-specific anxiety in men with LPCa.
 - Study 1: Hilger, C.*, Otto, I.*, Hill, C., Huber, T., & Kendel, F. (2019). „Dr. Google“ – Informationssuche und Krankheitsangst bei Männern mit lokal begrenztem Prostatakarzinom. *Der Urologe*, 58, 1050-1056. *shared first authorship [14]
2. To date, there is limited data on the importance of sexuality among men with PCa, thus the aim of this study was to assess the importance and compare between men after RP and under AS. In addition, a further goal was to analyze the associations of erectile functioning and self-esteem, considering the role of the importance of sexuality.
 - Study 2: Hilger, C., Schostak, M., Neubauer, S., Magheli, A., Fydrich, T., Heuse, S. & Kendel, F. (2019). The importance of sexuality, changes in erectile functioning and its association with self-esteem in men with localized prostate cancer: data from an observational study. *BMC Urology*, 19(1): 9. [16]
3. In the context of PCa, time pressure has not yet been studied and the focus of previous research regarding sexuality has mostly been on functional/physiological aspects. We aimed to bridge these research gaps by examining the associations of erectile dysfunction, satisfaction with sexual life, information provided by the urologist, and time pressure after diagnosis with decisional regret among men with LPCa.
 - Study 3: Hilger, C., Schostak, M., Otto, I., & Kendel, F. (2021). Time pressure predicts decisional regret in men with localized prostate cancer: data from a longitudinal multicenter study. *World Journal of Urology*, 39(10): 3755–3761. [17]

4. To our knowledge, longitudinal studies of how illness representations, coping strategies, and anxiety are associated among men with LPCa have not been conducted. The objective of this study was to analyze how these constructs develop over the course of LPCa and how they are interrelated.

- **Study 4:** Otto, I., Hilger, C., Magheli, A., Stadler, G., & Kendel, F. (2021). Illness representations, coping and anxiety among men with localized prostate cancer over an 18-months period: A parallel vs. level-contrast mediation approach. *Psycho-Oncology*. [15]

2 Methods

The four studies providing the basis of this dissertation arose from two research projects involving men with LPCa, which will be described subsequently in detail.

2.1 Project 1: Disease anxiety and coping strategies in tumor patients

This study was nested in the non-interventional, multicenter HAROW (*Hormone Therapy, Active Surveillance, Radiotherapy, Operation, Watchful Waiting*) study [64] which recruited men after the diagnosis of LPCa from 2008 to 2013. For the current project, men who initially opted for RP ($n = 378$) were matched to men who chose AS as their primary treatment ($n = 378$) based on time since treatment decision (Figure 1). Men with LPCa of the low and intermediate risk category according to D’Amico [65] (see Box 1) were included in this study (TNM: $\leq T2a$; PSA: ≤ 10 ng/ml; ISUP Grade ≤ 2). Men with a tumor of the high-risk category were excluded to ensure comparability between treatment groups (according to the German S3 [66] guideline for the treatment of LPCa, RP is recommended for all risk categories of LPCa, AS is only possible in low-risk LPCa and under studies in intermediate-risk LPCa). All participants had previously agreed in written form to take part in further surveys. The study was approved by the ethics commission of the Charité – Universitätsmedizin Berlin (EA 1/242/13). Self-report questionnaires were sent to participants by mail ($M = 42.0 \pm 16.6$ months after treatment decision).

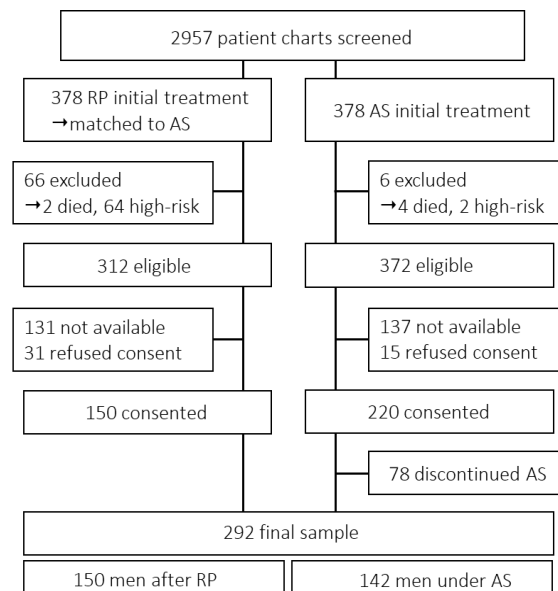


Figure 1: Flow-chart of participants for Project 1 (Study 1 & 2), AS = Active Surveillance, RP = Radical Prostatectomy (Image source: own illustration)

2.1.1 Project 1 – Materials and main outcome measures

In Study 1, the Memorial Anxiety Scale for Prostate Cancer (MAX-PC) was used to assess *prostate cancer-related anxiety*. A global score (range: 0-54) can be calculated with higher scores indicating higher

anxiety. Levels from a cut-off value of 27 are considered clinically relevant anxiety [67]. Information sources were captured according to Huber and colleagues [68]. Response categories were dichotomized and a sum score was calculated across all items to determine *number of information sources used*. *Subjective information on PCa* was measured with a self-constructed single item, whereby higher values indicated higher information. For Study 2, the questionnaires contained items on *changes in erectile functioning*, *impairment of self-esteem* (two single items adapted from Johansson and colleagues [69]), *subjective importance of sexuality* and *satisfaction with sexual life* (two single items adapted from van den Bergh and colleagues [70]). For all items, either a five- (self-esteem, satisfaction) or a four-point Likert scale (erectile functioning, importance of sexuality) was used, with higher values indicating higher expressions on the respective variable.

2.1.2 Project 1 – Statistical analyses

Study 1: For statistical comparisons between the two treatment groups (RP, AS), independent *t*-tests and robust Mann-Whitney *U*-tests were performed. A sequential multiple regression analysis was run to analyze the relationship between internet use (predictor 1), number of information sources (predictor 2), subjective information (predictor 3), and disease-specific anxiety (criterion). We calculated moderation analyses with internet use and number of information sources as moderators, subjective information as predictor of anxiety using the PROCESS macro for SPSS (model 3). Simple-slope analyses were carried out to examine interaction effects.

Study 2: Treatment groups (RP, AS) were compared with regard to variables under study using independent *t*-tests. We conducted a sequential multiple regression analysis to investigate the association of the importance of sexuality (predictor 1), changes in erectile functioning (predictor 2), and self-esteem (criterion). Moderation analyses were computed with the importance of sexuality as a moderator, changes in erectile functioning as a predictor and self-esteem as the criterion. Interaction effects were tested using simple slope analyses. We used the PROCESS macro for SPSS (model 1) to perform moderation analyses.

2.2 Project 2: COPCa – Coping with Prostate Cancer

The prospective, non-interventional, multi-center COPCa study focused on men with low- and intermediate-risk LPCa (TNM: \leq T2a; PSA: \leq 10 ng/ml; ISUP Grade \leq 2, see Box 1). Urology clinics and practices ($N = 33$) recruited men who were diagnosed within the last six months, who had not started local treatment (RP, RT) and who were not older than 80 years (Figure 2). All participants declared their written consent to the study before the beginning thereof. The study was approved by the ethics commission of the Charité – Universitätsmedizin Berlin (EA1/003/14). Urologists provided clinical data (e.g., tumor risk category, date of diagnosis, comorbidities) at baseline. Self-report questionnaires were mailed to participants at four measurement points (T0 (baseline) = prior to treatment commencement, T1 = 6, T2 = 12, T3 = 18 months after baseline).

2.2.1 Project 2 – Materials and main outcome measures

The variables analyzed in Study 3 included *impairment of erectile functioning* (single item adapted from Johansson and colleagues, T0-T3), *satisfaction with sexual life* (single item adapted from van den Bergh and colleagues, T0-T3) and *subjective information by the urologist* (self-constructed single item, T0). At baseline, perceived *time pressure* was assessed using a self-constructed scale comprising four items. The Decision Regret Scale (DRS) [71] assessed *decisional regret* at all follow-up points (T1-T3). A score (ranging from 0-100) is derived whereby higher scores indicate higher regret. To date, a validated cut-off value on the DRS for clinically relevant regret does not exist. Regret scores were dichotomized due to a right-skewed distribution (0–5: no regret vs. \geq 6: at least some amount of regret).

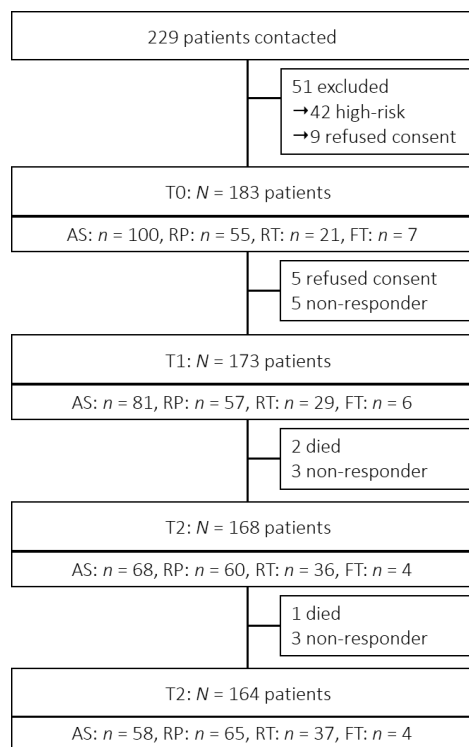


Figure 2: Flow-chart of participants for Project 2 (Study 3 & 4); men under focal therapies (FT) were excluded from the analyses of Study 3; AS = Active Surveillance, RP = Radical Prostatectomy, RT = Radiation Therapy (Image source: own illustration)

In Study 4, the Brief COPE [72, 73] measured an evidence-based [74, 75, 59] selection of coping strategies (distraction coping, active coping, planning). As all coping strategies were correlated at each measurement point (for all: $r \geq .36$, $p < .05$), a Principal Component Analysis was performed. This revealed two factors that were employed in statistical analyses: *problem-focused coping* (active coping, planning) and *emotion-focused coping* (distraction coping). The Brief Illness Perception Questionnaire (B-IPQ) [76] assessed cognitive illness representations. Disease-specific anxiety was measured using the Memorial Anxiety Scale for Prostate Cancer (MAX-PC [67], see chapter 2.1.1).

2.2.2 Project 2 – Statistical analyses

Study 3: Men after local therapies (RP, RT) and men after AS were compared using independent *t*-tests and non-parametric Mann-Whitney *U*-tests. In additional analyses, the three treatment groups were compared using ANOVA and post-hoc tests. Men under focal therapies were excluded from analyses due to insufficient cell frequency. We examined changes over time in study variables using ANOVA with repeated measures (*satisfaction with sexual life*) and McNemar tests (*impairment of erectile functioning, decisional regret*). To evaluate whether *time pressure, information by the urologist, impairment of erectile functioning, and satisfaction with sexual life* were predictive of decisional regret (criterion), logistic regression models were used.

Study 4: A growth curve model including time variables (dummy coded and linear time slope) was fitted to analyze changes in anxiety, illness representations and coping over time. As 37 men changed treatment strategy over the follow-up period, treatment was integrated as time-varying covariate. We investigated between-group differences in trajectories by including an interaction term (treatment x time). Whenever possible, a random intercept and a random time slope were integrated into each model and their covariance. Two different methods were conducted to investigate mediation models:

classic parallel mediation analyses and (due to the high correlation between problem- and emotion-focused coping, $r = .44 - .67$) a novel level-contrast approach [77] including the overall coping level and the difference between problem-focused and emotion-focused coping.

All of the above-described statistical analyses (Studies 1-4) were performed using different versions of statistical software SPSS developed by IBM. Statistical significance was assumed from an alpha level of $p < 0.05$ in all analyses.

3 Results

3.1 Project 1: Disease anxiety and coping strategies in tumor patients

3.1.1 Information search and disease-specific anxiety (Study 1)

The total sample comprised of $N = 292$ men with LPCa. Of these, $n = 142$ men were under AS during the study period, while $n = 150$ had opted for RP as their primary treatment. General practitioner/urologist (85.6%) was the most used information source, followed by newspapers/magazines (62.4%) and health literature (60.1%). Medical conferences were the least used for information search (14.4%). More than one third of participants (38.9%) used the internet to find information on their PCa. Disease-specific anxiety was low with no significant differences between treatment groups. Sequential multiple regression analyses demonstrated that the *use of the internet* ($\Delta R^2 = 0.085$, $p = 0.001$), *number of information sources* used ($\Delta R^2 = 0.066$, $p < 0.001$), and *subjective information* were predictive of disease-specific anxiety, after controlling for relevant sociodemographic and clinical characteristics. In addition, the three-way interaction (Figure 3) of these three predictors explained a significant amount of variance in the criterion ($\Delta R^2 = 0.016$, $p = 0.017$).

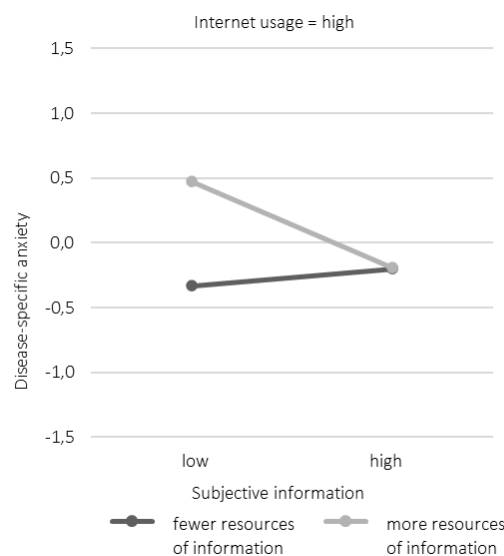


Figure 3: PCa patients who used the internet more often and who felt less informed about their disease, showed higher anxiety with increasing number of information sources; in patients who felt well-informed about their disease, anxiety was unrelated to number of information sources despite high internet usage (Image source: According to Figure 2, Study 1 [14], translated by permission from Springer Nature: Springer; Der Urologe; "Dr. Google" – information-seeking behavior and disease-specific anxiety among men with localized prostate cancer; Hilger, Otto, Hill, Huber & Kendel, 2019: license number: 5147741171461)

Moderation analyses demonstrated that the association of subjective information and disease-specific anxiety was moderated by both, the number of information sources used and the use of the internet ($p < .001$). Simple slope analyses showed that PCa patients who used the internet more often and who felt less informed about their disease, showed higher anxiety with increasing number of information sources; in patients who felt well-informed about their disease, anxiety was unrelated to number of information sources despite high internet usage (Figure 3).

3.1.2 Importance of sexuality, erectile functioning, self-esteem (Study 2)

The sample composition was identical to Study 1 ($n = 142$ under AS, $n = 150$ after RP). Treatment groups differed in terms of initial cancer risk classification ($p < 0.001$), inter alia, with more men after RP being classified as having an intermediate-risk tumor compared to men under AS. Men after RP reported more changes in erectile functioning ($p < 0.001$, $d = 1.2$), stronger impairment of self-esteem ($p < 0.001$, $d = 0.51$), higher importance of sexuality ($p < 0.001$, $d = 0.42$), and less satisfaction with sexual life ($p = 0.002$, $d = 0.38$) than men under AS. Two thirds of participants (total: 66.5%; AS: 59.0%; RP: 73.5%) indicated that sexuality was “rather important” or “very important” to them.

Sequential multiple regression analyses revealed that *importance of sexuality* ($\Delta R^2 = 0.048$, $p < 0.001$) and *changes in erectile functioning* ($\Delta R^2 = 0.207$, $p < 0.001$) were significant predictors for *impairment of self-esteem*, after controlling for relevant sociodemographic and clinical parameters. Additionally, the interaction of both predictors (Figure 4) explained a significant amount of variance in the criterion ($\Delta R^2 = 0.062$, $p < 0.001$). Moderation analyses showed that the *importance of sexuality* moderated the effects of *changes in erectile functioning* on *impairment of self-esteem*. Simple slope analyses displayed higher *changes in erectile functioning* more greatly affecting self-esteem (compared to less changes in erectile functioning) in both cases, for individuals reporting higher and lower *importance of sexuality*. This effect was weaker, however, for lower *importance of sexuality*. Additional analyses showed no association between *changes in erectile functioning* and self-esteem if sexuality was “not at all” important.

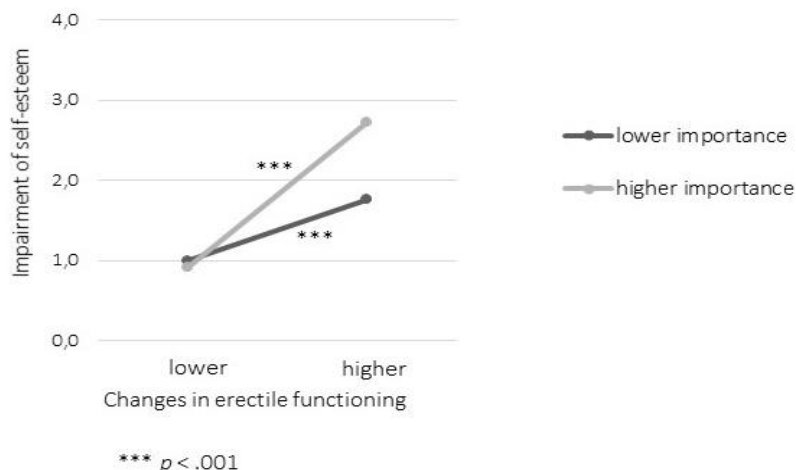


Figure 4: The association of changes in erectile functioning and impairment of self-esteem is stronger for men who report higher importance of sexuality (Image source: Figure 1, Study 2 [16], open access publication)

3.2 Project 2: COPCa – Coping with Prostate Cancer

3.2.1 Time pressure, sexuality, decisional regret (Study 3)

The final sample included $N = 176$ men at baseline, of whom $n = 100$ were under AS and $n = 76$ had chosen local treatment (RP, RT; Figure 5). The drop-out rate was 10.1%. There were no differences between treatment groups in terms of sociodemographic and clinical parameters, apart from ISUP grade, with men in the local treatment group more frequently having intermediate-risk PCa ($p < 0.001$, Cramér's $V = 0.42$).

While there were no differences in erectile functioning at baseline ($p = 0.96$), men after local treatment reported stronger impairment of erectile functioning after treatment implementation (T1) than men under AS. Subgroup analyses revealed that men after RP reported the highest impairment relative to men after RT and under AS. Impairment of erectile functioning was higher at all follow-up time points

compared to baseline ($p < 0.001$). Nearly half of participants (40.3 – 47.7%) indicated at least some amount of decisional regret. At 12 (T2) and 18 (T3) months after baseline, men after local therapies reported to regret their treatment decision more than men under AS. Men after RP reported higher decisional regret in comparison to men under AS. While no association was found between *information by the urologist* and *decisional regret*, *time pressure*, *impairment of erectile functioning* and *satisfaction with sexual life* were predictive of *decisional regret*, after controlling for relevant sociodemographic and clinical variables.

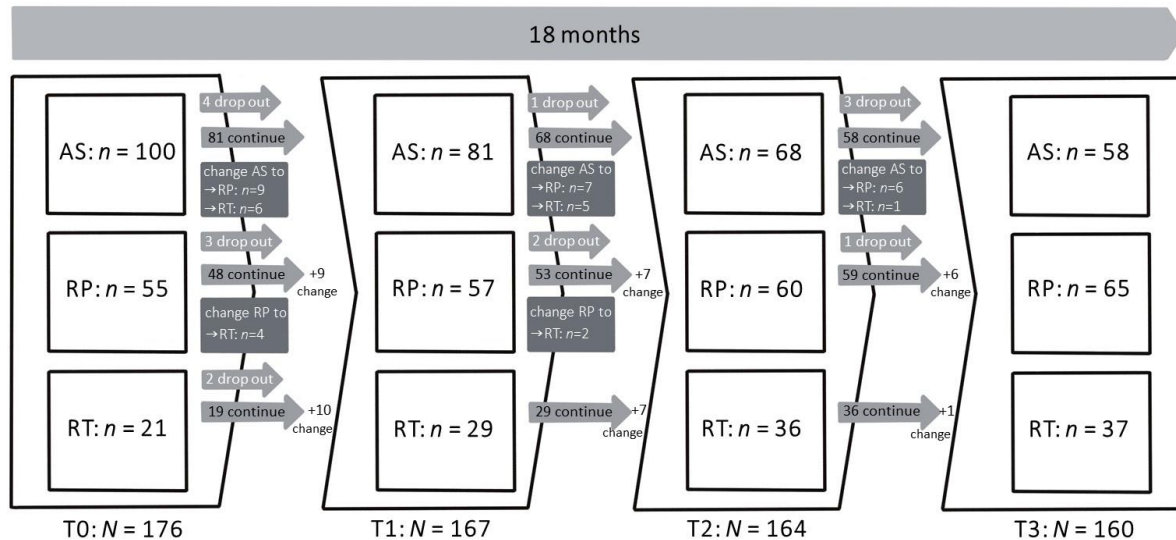


Figure 5: Treatment strategies (AS = Active Surveillance; RP = Radical Prostatectomy, RT = Radiation Therapy) and (sub-) sample sizes of Study 3 over the study period (T0 = baseline, T1 = 6, T2 = 12, T3 = 18 months after baseline), (Image source: According to Figure A1 (appendix), Study 3 [17], open access publication)

3.2.2 Illness representations, coping, disease-specific anxiety (Study 4)

The final sample of this study (including men under focal therapies) comprised $N = 183$ men at baseline, of whom 9.3% dropped out over the follow-up period. Disease-specific anxiety was higher at baseline compared to all follow-up time points ($p < 0.05$). Men after local treatments did not differ from men undergoing AS in terms of anxiety. The illness representation of *consequences* was related to anxiety at T0 and for subsequent change scores ($\beta = 0.204 - 0.471$). No consistent significant associations were found between other illness representations and anxiety. Consequently, only the dimension *consequences* was considered as a predictor in the mediation models. Results of parallel mediation analyses demonstrated that the association of *consequences* and anxiety was mediated by both, problem- and emotion-focused coping (baseline). Changes in coping did not mediate the relationship between changes in *consequences* and change in anxiety. Using a new level-contrast approach, we showed that two variables (mediator 1: overall coping level; mediator 2: level-contrast problem-focused deducted emotion-focused coping) mediated the relationship between *consequences* and anxiety at baseline. Comparing parallel mediation analyses and the new level-contrast approach, we showed that the ratio of problem- to emotion-focused coping makes a difference: Men who applied emotion- more than problem-focused coping strategies reported greater anxiety than men who employed more problem-focused coping or who used a balanced ratio of emotion- to problem-focused coping.

4 Discussion

Publications developed as part of this dissertation demonstrated the following key findings: (1) About one-third of men with PCa used the internet to seek information about their disease. Increased anxiety was associated with a higher number of information sources for men, who used the internet more frequently and who felt less informed about their PCa. (2) The majority of men with PCa considered

sexuality an important area of their life. For men who regarded sexuality as more important, the impact of altered erectile functioning on self-esteem was particularly pronounced. (3) About half of men with PCa reported to regret their treatment decision, at least to some extent, several months after diagnosis. Time pressure after diagnosis and erectile dysfunction enhanced the chances of decisional regret, while satisfaction with sexual life diminished the likelihood of regret. (4) Shortly after diagnosis, illness anxiety was elevated and it decreased over time. Anticipated consequences predicted anxiety. More emotion-focused coping was associated with higher anxiety, whereas more problem-focused coping or a balance of the two coping styles was associated with less anxiety.

4.1 Clinical implications

Our findings have important implications for clinical practice: The association of erectile functioning and self-esteem, which was moderated by the importance of sexuality (Study 2) has several implications for the doctor-patient conversation: First, consultation of PCa patients in addition to possible physical treatment side effects (e.g., erectile dysfunction) should also include comprehensive information on how these side effects could affect psychological well-being and quality of life (e.g., self-esteem). This implication is also supported by our finding that erectile dysfunction predicted decisional regret (Study 3). Second, physicians should openly address the topic of sexuality. Instead of assuming that sexuality is no longer important for a patient (e.g., because of their age) they can ask which role sexuality plays for them (see Practice digression 1). According to how the patient evaluates sexuality, appropriate treatment options can then be discussed.

“It’s like someone hit me on the head with a sledgehammer. It’s a bit of a shock when you hear the word ‘cancer’” (PCa patient quote [63], p.1369)

When informing PCa patients about possible treatment side-effects and quality of life, it is important to be aware that there may be a timing issue: As we revealed, illness anxiety is elevated shortly after PCa diagnosis (Study 4). This result is supported by other studies indicating that the period shortly after diagnosis and around the time of treatment decision is particularly sensitive: Many men with PCa experience a diagnosis shock involving questions of life and death. Initially, they focus on survival and are less concerned with quality of life, such as sexuality [1, 78]. This can result in issues in the long term (e.g., decisional regret, see Study 3). Especially in the case of LPCa where the prognosis is favorable, however, this fear of death does not correspond to objective mortality rates. The challenge for urologists is taking the patients' fear seriously, while conveying that survival rates are high and that they can take time for decision-making.

“Nothing was ever rushed and they took time and I really valued that” (PCa patient quote [79], p.39)

In the context of treatment decision-making, time pressure plays an important role. We showed that time pressure after diagnosis was predictive of longer-term decisional regret in men with LPCa (Study 3). Although time pressure is pervasive in clinical settings, it has received surprisingly little attention in research to date. Time pressure can arise from various circumstances: The diagnosis of LPCa can be perceived as being “handed a death sentence” [32] (p. 393) that can trigger a desire for rapid local treatment in many men [27, 59]. As one man with PCa in a qualitative study by Eliat-Tsanani and colleagues [46] put it: “When I learned that I had cancer the first thing I said to the doctor was to take it out. They told me I could have radiation therapy. I said: nothing doing, just cut it out” (p. 154). Besides patients' assessment of the situation, system characteristics may also add to time pressure, such as increasing economization of clinics, high bureaucracy in tumor centers, personnel shortage and closely scheduled consultations, just to name a few. How structural factors promote time pressure could be the subject of future healthcare research studies.

Practice digression 1 | Implications for the doctor-patient conversation

Sexuality is a sensitive topic to discuss in medical consultation. Especially in the case of PCa, where treatment can directly affect sexuality, it should be addressed. The physician needs to initiate the subject, otherwise it is unlikely to be broached.¹ Barriers identified in other studies can be circumvented with the following options:

Barrier 1: Offending¹ patients by raising the issue

- Short questionnaires about which topics patients want to talk about at this appointment
- When sexuality is explicitly mentioned, the topic is normalized, and the patient can give prior consent to discuss it.

Barrier 2: "The stereotype of the 'asexual older person'"²

- Instead of making assumptions based on the patient's age, ask about the importance³.
- Referring to the patient's answer, possible treatment side-effects regarding sexuality and consequences for quality of life can be discussed.

"Which role does sexuality play in your life?"

"On a scale from 1 to 10, how important is sexuality for you?"

Barrier 3: Lack of time and knowledge¹

- Communicate basic information; provide the patient with further resources/contact to experts.
- Interdisciplinary consultation (PCa: urologist, oncologist, radiologist, psycho-oncologist)

Barrier 4: Specific patient groups¹ (e.g., opposite gender, ethnic minorities, non-heterosexual patients)

- This barrier is based more on assumptions and less on practical experience¹.
- Nevertheless, it can be helpful to reflect on own stereotypes, to choose an inclusive language and, if applicable, to attend advanced trainings.

Hordern and colleagues⁴ (p.57) formulated questions for raising sexuality in medical consultations, e.g.:

"Many of the patients I see express concerns about how treatment may affect their sex lives. How has this been for you?"

"Has your role as a parent, partner, spouse or intimate friend changed since you were diagnosed or treated for cancer?"

"Is this the right time or place to discuss these issues further?"

"In my experience, many people find that this disease or treatment has a major impact on their sexual activity or intimacy."

"How can I best provide information, support or practical strategies to help you adjust to life after cancer?"

¹Dyer K, das Nair R (2013) Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *Journal of Sexual Medicine* 10(11): 2658–2670.

²Hilger C, Schostak M, Neubauer S, Magheli A, Fydrich T, Burkert S, Kendel F. (2019) The importance of sexuality, changes in erectile functioning and its association with self-esteem in men with localized prostate cancer: data from an observational study. *BMC Urology* 19(1): 9.

³Gott M, Hinchliff S (2003) Barriers to seeking treatment for sexual problems in primary care: a qualitative study with older people. *Fam Practice* 20(6): 690–695.

⁴Hordern AJ, Street AF (2007) Let's talk about sex: Risky business for cancer and palliative care clinicians. *Contemporary Nurse* 27(1): 49–60.

Furthermore, the findings on time pressure (Study 3) have precise implications for the doctor-patient conversation: Immediately after diagnosis, physicians need to communicate to their patients that they have time to carefully consider the benefits and risks of each treatment option. A comparative study among PCa patients [80] extracted the most important questions to be addressed in core information. One of the questions was: “How long can I safely take to make up my mind?” (p.332; see Practice digression 2). Our results on time pressure and decisional regret (Study 3) highlight the necessity of clarifying this question after PCa diagnosis. Urologists may thoroughly explain to their patients that oncologic deterioration is highly unlikely for low/intermediate-risk carcinomas within the first six months after diagnosis [81, 82]. Additionally, individual patient parameters (e.g., inconsistent diagnostics of biopsy and MRI, micturition at diagnosis) should be communicated transparently, possibly constraining this timeframe. Men with LPCa should understand that a rapid treatment decision is not necessary and, if appropriate, be encouraged to acquire a second opinion.

“We as men try our best to say we are alright, we cover up” (PCa patient quote [79], p.39)

We found that about half of participants reported at least some amount of decisional regret (Study 3). This is comparable with the results of Wilding and colleagues [49], demonstrating that 63.3% of PCa patients reported to later regret their treatment decision at least to some extent. A recent review [83] showed that many men still have difficulties openly addressing emotional topics. Therefore, we chose a conservative cut-off on the Decision Regret Scale [71], which should be scientifically evaluated in future studies. Applied to clinical practice, this means that PCa patients reporting little emotional distress need to also be considered. For doctor-patient interaction, this means remaining sensitive throughout medical aftercare and carefully but directly raising potential issues like regret rather than waiting for the patient to address them (see Practice digression 1).

The same applies to the topic of sexuality: Previous studies demonstrated that patients often avoid broaching the subject of sexuality themselves out of shame [84, 85]. For physicians, sexuality is also a difficult topic, hence they often do not address it [41, 86]. This can create a collusion, an unconscious process where both, patient and doctor do not raise the issue because it is uncomfortable for them. The patient may then think that talking about sexuality is not appropriate as the physician does not mention it. The physician could explain the situation by the patient not wanting to talk about sexuality. This collusion can be overcome by a routine of open questions and doctors taking an active role in counseling on sexual side-effects (see Practice digression 1). The findings that half of PCa patients indicated worse than expected erectile dysfunction after local treatment (RP, EBRT, BT) and that unmet expectations were linked to decisional regret [53] reinforces how important it is to breakdown potential collusion around the topic of sexuality. Awareness of collusion mechanisms is needed, to the extent that the issue of sexuality is not automatically irrelevant to patients if they do not approach it themselves.

*“I just want to know so I could make a decision. If you hear too much of it, you get too confused”
(PCa patient quote [63], p.1368)*

We showed that men with PCa seek information about their disease using a variety of channels (Study 1), underlining a marked need for information among PCa patients that has also been demonstrated in other studies [87]. More than one third of PCa patients reported using the internet for information (Study 1). We conducted the study in 2014 with participants who had received the PCa diagnosis four years prior, on average. Current data show that, in Germany, three quarters of men over the age of 70 use the internet, while in the age of 60-69 years and 50-59 years, the figure is 93% and 96%, respectively [88]. This means that a generation of men will be diagnosed with LPCa in future, for whom internet use is common. The internet offers many advantages because it makes information accessible at low thresholds. Simultaneously, unverified information can circulate online, potentially fostering uncertainty. Our results (Study 1) indicate that men who use the internet frequently and feel

insufficiently informed about their disease, are particularly at risk of feeling scared in the context of information search. Therefore, reliable information is important as it may affect anxiety. Online-based counseling tools providing information for patients beyond consultation offer great opportunities in this context [89]. Moreover, physicians may give their patients a short list with links to reputable online sources, thereby helping patients navigate through a jungle of information. This increases the chances for patients to acquire evidence-based information without feeling overwhelmed.

Practice digression 2 | Implications for prostate cancer patients' decision-making

What does 'making up your mind' imply for men with LPCa? Immediately after diagnosis, men with PCa primarily consider survival and tumor removal¹. Particularly in the case of LPCa, however, treatment can have far-reaching and sometimes irreversible consequences for men's quality of life. Therefore, men need to be made aware of the different life areas that PCa treatment may impact. In this context, mitigating time pressure is important, as it can create space to bring quality-of-life aspects back to the fore.

Bio-psycho-social models are normally used to explain the development and maintenance of various diseases (e.g., post-traumatic stress disorder², pain³). It is a holistic approach taking different domains of human experience into consideration. We propose to adapt bio-psycho-social models to the circumstances of men with PCa, thereby inciting informed decision-making which covers all relevant areas (Figure I). In counseling, patients could be presented with similar models so that they can reflect on all domains in their treatment decision-making. How important each life area is, and which therapy is most suitable in light of this, is an individual question. Making up one's mind about this is a process that takes time, which LPCa patients mostly have. Communicating a time frame for how long they can take to make their decision is essential.

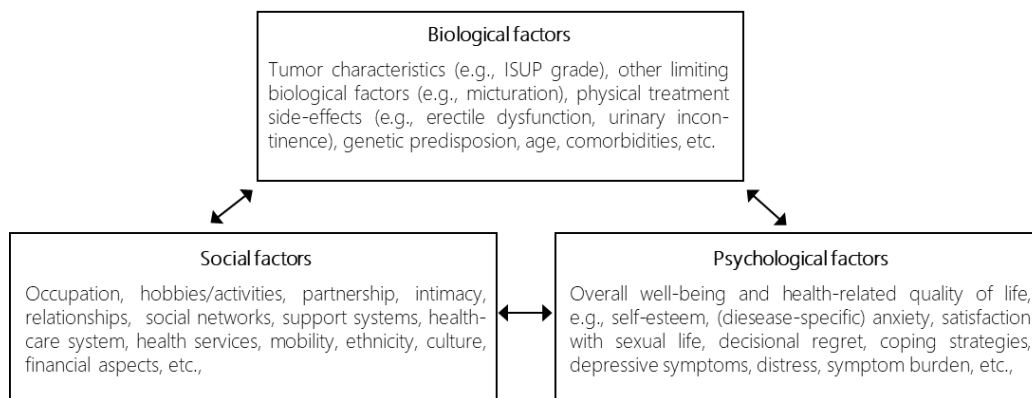


Figure I: The bio-psycho-social model adjusted to the situation of men with PCa (Image source: own illustration)

¹Speer SA, Tucker SR, McPhillips R, Peters S (2017) The clinical communication and information challenges associated with the psychosexual aspects of prostate cancer treatment. *Social Science & Medicine* 185: 17–26.

²Marsac ML, Kassam-Adams N, Delahanty DL, Widaman KF, Barakat LP (2014) Posttraumatic stress following acute medical trauma in children: a proposed model of bio-psycho-social processes during the peri-trauma period. *Clinical Child And Family Psychology Review* 17(4): 399–411.

³Kim J, Ahn H, Lyon DE, Stechmiller J (2016) Building a biopsychosocial conceptual framework to explore pressure ulcer pain for hospitalized patients. *Healthcare* 4(1): 7.

“Don’t sweep it under the carpet” (PCa patient’s spouse quote [90], p.5)

We demonstrated that high anticipated consequences predicted higher anxiety (Study 4). Providing patients with detailed information on possible treatment ramifications without causing excessive anxiety is a challenge for physicians. For instance, some men opting for RP incorrectly assume that they

will no longer have to deal with PCa after surgery [27]. This is not the case, since men after RP have to attend regular follow-up appointments and can also experience cancer recurrence [91]. It is important that men can realistically assess the consequences of RP (and other treatment options) although higher anticipated consequences are associated with greater anxiety (Study 4). Physicians walk a fine line between adequate information and emotional strain on patients when counseling men with PCa, which may be cushioned by interdisciplinary consultation involving psycho-oncologists.

Furthermore, we showed that more emotion-based coping (compared to more problem-based coping or a balance of the two) was associated with more anxiety. Anxiety can be adaptive: Activation of the sympathetic nervous system supplies the organism with resources to react adequately in stressful situations. Anxiety can also be problematic, however, because it can negatively impact attentional focus, information processing and decision-making [92, 93]. Physicians can tackle this problem in different ways: If there is enough time in the patient consultation, they can directly ask what patients do in their everyday life to cope with the disease. Based on the patient's response, clinicians can then explain which coping strategies are particularly adaptive regarding anxiety. If there is not enough time to elaborate on coping, physicians can draw from the concept of nudging. Nudging "refers to interventions that organize the choice architecture in order to alter people's behaviour in a predictable way without forbidding any options or significantly changing their economic incentives" (Thaler & Sunstein, 2008, p. 6, as cited in Harbers and colleagues, p.2 [94]) and has been shown to be effective particularly in the area of public health (primarily interventions aimed at changing nutrition) [95]. Providing patients with a short list of validated information sources/websites as suggested earlier may serve as a nudge to motivate information search as a form of problem-focused coping. Equipping patients with contact information for psycho-oncologists, counseling centers, or support groups can represent an intervention to promote more adaptive emotion-focused coping (i.e., reduce avoidant coping strategies).

4.2 Limitations

This dissertation lies at the intersection of medicine and psychology. This intersection contributes to one of the underlying strengths of this research, namely shifting the focus away from an exclusive consideration of physical side effects to the broader experience of men with PCa. Other strengths include that we conducted two of the largest surveys with PCa patients under AS, the length of follow-up in all studies, and the low drop-out rate in the longitudinal studies (3 and 4). Moreover, we adopted a treatment-received-approach (Study 3), which allows more precise assessments than intention-to-treat-analyses. Yet, the studies also have some limitations: The cross-sectional design of Project 1 does not provide information about a time course. Based on these results, no conclusions can be drawn about how, for example, information source use, anxiety (Study 1), erectile functioning, or self-esteem (Study 2), change over the course of PCa. This methodological constraint was resolved by the longitudinal design of Project 2. Nevertheless, none of the study designs allow causal interpretations. For example, for the finding that a higher number of information sources used predicts illness anxiety (Study 1), it is not clear whether a great number of information sources causes anxiety or whether particularly anxious men tend to search for information more extensively. Causal inferences are only permissible for randomized controlled designs. However, practical experience shows that it can be difficult to randomly assign men to different treatment options. The majority of PCa patients wants to choose treatment based on consultation with their physician and in accordance with their own preference. Furthermore, evidence from other RCTs [20] demonstrating significant differences in side effects between various LPCa treatments also raises the question of whether random assignment would still be ethically admissible at this point. Additionally, external validity increases in non-interventional observational studies, in which patients decide on a treatment strategy together with their physicians under realistic conditions.

Another limitation is that all variables were collected using self-report questionnaires, which may imply a risk for bias (e.g., through memory effects). In some cases, (e.g., assessing time pressure) validated scales were not yet available. However, since the aim of all studies was to primarily reflect the patients' perspective, self-report questionnaires provide the highest possible validity. In future studies, however, they could be supplemented by objective parameters. By demonstrating that time pressure after PCa diagnosis predicts longer-term decisional regret (Study 3), we identified it as critical variable. With this initial finding, we hope to stimulate future research on the effects of time pressure in clinical settings. The scale we developed to capture time pressure certainly yields a first impression into the construct but should be psychometrically evaluated in the future. We cannot completely exclude statistical type 1/type 2 errors. Thus, the influence of certain variables could be over- (α -error) or underestimated (β -error). In addition, despite of the high motivation to participate and low drop-out rates, we cannot rule out the risk of bias due to sampling effects in each of the presented studies: Men who cope particularly well with their disease and are satisfied with their treatment may be more amenable to participating in a study compared with severely burdened men. This may result in underestimating psychological issues (e.g., decisional regret) in men with PCa.

We measured self-esteem in the context of erectile functioning (Study 2), which seems reasonable in our population with a majority reporting altered erectile functioning. Nonetheless, the exact amount of variance explained by erectile functioning in self-esteem should be interpreted with caution as it may be artificially inflated by this approach. Independent measures of self-esteem may be used in future studies to corroborate this finding. In Project 1, we did not include men after RT in the analyses because of an inadequate sample size. In Project 2, men after local treatments were analyzed jointly due to insufficient cell frequency of men after RT. The subsample of men after RT should be large enough to analyze separately in future research, not only in supplemental analyses (Study 3). Additionally, future studies should be powered to perform differential evaluations of distinct forms of radiation (EBRT, BT). Only one analysis (Study 4) included a small group of men on focal therapies, hence we cannot generalize our findings for this subsample. There are preliminary findings on decisional regret in men under focal therapies, for instance [96]. Further studies are needed to draw reliable conclusions. Lastly, we recognize that men with PCa may face further severe treatment side effects (e.g., urinary incontinence) that could be associated with self-esteem, decisional regret, or other quality of life aspects. These go beyond the scope of this dissertation, however, as we focused on side effects concerning sexuality.

4.3 Outlook

As previously mentioned, online tools that can support consultation for men with PCa hold great promise for the future. Particularly in this context, the associations between information sources and illness anxiety (Study 1) deserve further investigation: In an RCT, half of the participants could receive counseling with an online tool while the other half would receive standard counseling. If differences between groups in illness anxiety were shown, they could be causally attributed to the intervention. If the groups did not differ in their illness anxiety, however, it could be concluded that the use of online tools in counseling does not cause increased anxiety. Based on our results regarding self-esteem (Study 2), future research should investigate whether these results can be replicated with independent measures of self-esteem.

We found that satisfaction with sexual life predicted decisional regret in the short- and in the longer term (Study 3). This finding raises some interesting questions for future research. As Agochukwu and colleagues [40] pointed out, satisfaction with sexuality is largely recoverable (in contrast to erectile functioning). On this basis, interventions targeting sexual satisfaction could be developed, which would first need to be tested in feasibility studies. Subsequently, an RCT with a larger sample might evaluate

whether such intervention influences satisfaction with PCa treatment and/or decisional regret. In general, the issue of time pressure deserves more attention in research. In a first step, a scale for assessing time pressure in the clinical context may be developed and psychometrically evaluated. By using this validated scale, future studies should examine if our results on time pressure and decisional regret (Study 3) can be replicated in LPCa patients. Additionally, it would be interesting to investigate the associations of time pressure with further quality-of-life parameters in men with PCa and other patient populations. Interventions aimed at counteracting time pressures (e.g., direct approach by physicians, patient academies focusing on time pressure) could also be developed and compared with standard care in RCTs. Such intervention studies can help generate more robust data.

We showed that the illness representation of consequences is associated with anxiety and that this association is mediated by coping strategies (Study 4). Basis for this research was the Common-Sense Model [21], which focuses on intraindividual processes. Future studies could expand the focus including interactions of PCa patients with their physicians, as illness representations may shape medical encounters (or vice versa). A suitable theoretical basis would be the ecological model of communication in medical encounters according to Street [97], which was extended by another context, everyday interpersonal context, in 2018 [98]. Figure 6 displays Street’s original model (black) with the added context (blue). We suggest including a cognitive disease concept (green) integrating illness representations. This addition is essential, especially in the interaction between physicians and patients, since different disease concepts (expert knowledge vs. non-professional knowledge) converge and the challenge for physicians is to convey their knowledge to patients as comprehensibly as possible in a short period of time. Possible outcomes (operationalizing verbal and non-verbal behaviors) that could be captured for testing the model involve the amount of patient/physician speaking in the consultation, the number of questions asked by the patient, the number of physician contacts with the patient, and treatment choice. Furthermore, the recently postulated everyday interpersonal context [98] in addition to Street’s model [97] could be tested in prospective diary studies with PCa patients. Additionally, one could collect illness representations (operationalizing patients’ disease concept) and behavioral outcomes (e.g., number of questions asked, treatment choice), thereby examining if interpersonal context is predictive of health behavior and if this association is mediated by illness representations.

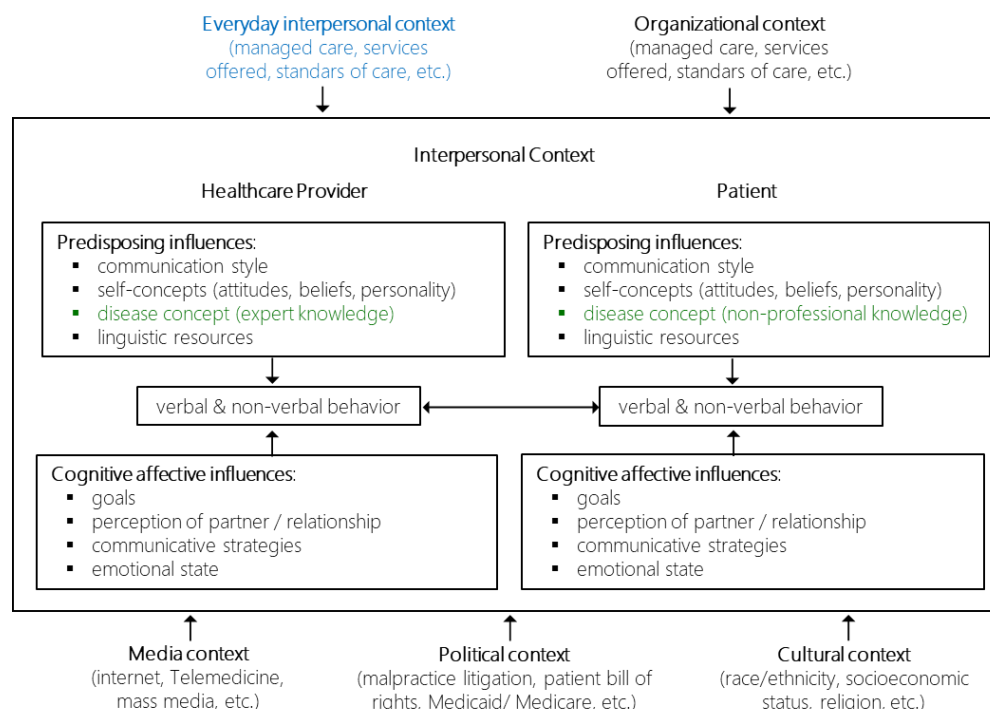


Figure 6: Street’s (2003) ecological model of communication in medical encounters (black), augmented by Head & Bute, 2018 (blue), with a new extension of ‘predisposing influences’ by cognitive disease concepts (green) (Image source: own illustration)

4.4 Conclusion

The diagnosis of PCa represents an incisive experience in the lives of many affected men. Together with their physician, they need to weigh the risk of overtreatment (including the risk of prolonged erectile dysfunction and urinary incontinence) against the risk of eventual disease progression. The results of this dissertation stress that psychological factors play a crucial role in LPCa patients' quality of life, especially in the longer-term. Important variables in this context are information needs, disease-specific anxiety, self-esteem, perceived time pressure, satisfaction with sexual life, decisional regret, and coping strategies.

One major added value of this thesis is that we investigated subjective time pressure for the first time in a quantitative study involving PCa patients. To establish a more reliable database, interventions targeting subjective time pressure in the context of decisional regret should be conducted future research. Implications for healthcare research include analyzing how time pressure may also derive from organizational structures and identifying ways in which these structures may be adapted to the needs of patients receiving a cancer diagnosis.

To address the challenges identified in this dissertation in clinical practice, urologists may: (a) alleviate time pressure by communicating how much time patients can take for decision-making based on the individual situation, (b) articulate the ways in which physical treatment side-effects are related to psychological well-being, (c) regularly initiate conversations about sexuality and comparable difficult topics in medical consultations, (d) provide their patients with a short and clear pre-selection of validated online information sources; thereby helping patients to navigate through a jungle of information and encouraging more problem-focused coping, and (e) encourage patients to use additional services like psycho-oncologists and self-help groups that for many man are a source of emotional support and may promote adaptive coping strategies.

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Affidavit

Eidesstattliche Versicherung

„Ich, Caren Hilger, versichere an Eides statt durch meine eigenhändige Unterschrift, dass ich die vorgelegte Dissertation mit dem Thema: „Bewältigungsstrategien und Lebensqualität von Männern mit lokal begrenztem Prostatakarzinom unter verschiedenen Behandlungsoptionen“ („Coping Strategies and Quality of Life Among Men with Localized Prostate Cancer Undergoing Different Treatment Options“) selbstständig und ohne nicht offengelegte Hilfe Dritter verfasst und keine anderen als die angegebenen Quellen und Hilfsmittel genutzt habe.

Alle Stellen, die wörtlich oder dem Sinne nach auf Publikationen oder Vorträgen anderer Autoren:innen beruhen, sind als solche in korrekter Zitierung kenntlich gemacht. Die Abschnitte zu Methodik (insbesondere praktische Arbeiten, Laborbestimmungen, statistische Aufarbeitung) und Resultaten (insbesondere Abbildungen, Graphiken und Tabellen) werden von mir verantwortet.

Ich versichere ferner, dass ich die in Zusammenarbeit mit anderen Personen generierten Daten, Datenauswertungen und Schlussfolgerungen korrekt gekennzeichnet und meinen eigenen Beitrag sowie die Beiträge anderer Personen korrekt kenntlich gemacht habe (siehe Anteilserklärung). Texte oder Textteile, die gemeinsam mit anderen erstellt oder verwendet wurden, habe ich korrekt kenntlich gemacht.

Meine Anteile an etwaigen Publikationen zu dieser Dissertation entsprechen denen, die in der untenstehenden gemeinsamen Erklärung mit dem/der Erstbetreuer/in, angegeben sind. Für sämtliche im Rahmen der Dissertation entstandenen Publikationen wurden die Richtlinien des ICMJE (International Committee of Medical Journal Editors; www.icmje.org) zur Autorenschaft eingehalten. Ich erkläre ferner, dass ich mich zur Einhaltung der Satzung der Charité – Universitätsmedizin Berlin zur Sicherung Guter Wissenschaftlicher Praxis verpflichte.

Weiterhin versichere ich, dass ich diese Dissertation weder in gleicher noch in ähnlicher Form bereits an einer anderen Fakultät eingereicht habe.

Die Bedeutung dieser eidesstattlichen Versicherung und die strafrechtlichen Folgen einer unwahren eidesstattlichen Versicherung (§§156, 161 des Strafgesetzbuches) sind mir bekannt und bewusst.“

Datum

Unterschrift

Declaration of shares in publications

Anteilserklärung an den erfolgten Publikationen

Caren Hilger hatte folgenden Anteil an den folgenden Publikationen:

Publikation 1: **Hilger, C.***, Otto, I.*, Hill, C., Huber, T., & Kendel, F. (2019). „Dr. Google“ – Informationssuche und Krankheitsangst bei Männern mit lokal begrenztem Prostatakarzinom. *Der Urologe*, 58, 1050-1056. * shared first authorship

Beitrag im Einzelnen:

- Data entry (about one third of patient questionnaires were entered)
- Conducting literature research (→ information about the current state of research)
- Preparation of current research results in synopses
- Creation of a data analysis plan
- Conduct of statistical analyses
- Drafting the results (pp. 1051 – 1053) and the discussion section (pp. 1053 – 1055) of the manuscript (first version)
- Incorporation of co-authors comments (result & discussion section, pp. 1051 – 1055)
- Incorporation of reviewer comments (result & discussion section, pp. 1051 – 1055)
- Drafting a response letter to the reviewers (concerning result & discussion section, pp. 1051 – 1055)

In collaboration with Isabella Otto (shared first authorship)

- Development of the scientific question
- Formulation of hypotheses
- Submission of the manuscript
- Revision of the final (print) version

Publikation 2: **Hilger, C.**, Schostak, M., Neubauer, S., Magheli, A., Fydrich, T., Heuse, S. & Kendel, F. (2019). The importance of sexuality, changes in erectile functioning and its association with self-esteem in men with localized prostate cancer: data from an observational study. *BMC Urology*, 19(1): 9.

Beitrag im Einzelnen:

- Data entry (about one third of patient questionnaires were entered)
- Development of the scientific question
- Formulation of hypotheses
- Conducting literature research (→ information about the current state of research)
- Preparation of current research results in synopses
- Creation of a data analysis plan
- Conduct of statistical analyses
- Processing of results
- Preparation of all tables, figures (Table 1 – 3, Figure 1)
- Drafting the entire manuscript (first version)
- Incorporation of co-authors comments
- Submission of the manuscript
- Incorporation of reviewer comments
- Drafting a response letter to the reviewers
- Revision of the final (print) version

Publikation 3: **Hilger, C.**, Schostak, M., Otto, I., & Kendel, F. (2021). Time pressure predicts decisional regret in men with localized prostate cancer: data from a longitudinal multicenter study. *World Journal of Urology*, 39(10): 3755–3761.

Beitrag im Einzelnen:

- Study management, data collection
- Development of the scientific question
- Formulation of hypotheses
- Conducting literature research (→ information about the current state of research)
- Preparation of current research results in synopses
- Creation of a data analysis plan
- Conduct of statistical analyses
- Processing of results
- Preparation of all tables, figures (Table 1; supplementary material: Figure A1, Table A1, A2, A3)
- Drafting the entire manuscript (first version)
- Incorporation of co-authors comments
- Submission of the manuscript
- Incorporation of reviewer comments
- Drafting a response letter to the reviewers
- Revision of the final (print) version

Publikation 4: Otto, I., **Hilger, C.**, Magheli, A., Stadler, G., & Kendel, F. (2021). Illness representations, coping and anxiety among men with localized prostate cancer over an 18-months period: A parallel vs. level-contrast mediation approach. *Psycho-Oncology*.

Beitrag im Einzelnen:

- Study management, data collection
- Participation in the development of the scientific question
- Participation in the development of a data analysis plan
- Participation in the selection of presented results
- Discussion of results; ideas for interpretation of selected results in the discussion section and literature research for appropriate references, e.g.:
 - Lower anxiety in men with localized prostate cancer compared to individuals with other tumor entities possibly due to traditional concepts of masculinity that may impede emotional expression (p. 6)
 - Less problem- and emotion-focused coping strategies of men under Active Surveillance compared with men after surgery may possibly be explained by men after surgery being more integrated into the care system (e.g., rehabilitation clinic) and receiving more information through these channels than men under AS (p. 9)
- Revision of preliminary versions of the manuscript, providing revision comments
- Writing singular text passages of the manuscript
- Participation in incorporating reviewer comments
- Writing individual text passages for the response letter to the reviewers
- Proofreading of the final manuscript

Unterschrift, Datum und Stempel der erstbetreuenden Hochschullehrerin

Unterschrift der Doktorandin

Printed copies of selected publications

Study 1: Hilger C, Otto I, Hill C, Huber T, Kendel F (2019) „Dr. Google“ – Informationssuche und Krankheitsangst bei Männern mit lokal begrenztem Prostatakarzinom. *Der Urologe. Ausg. A* 58(9): 1050–1056. DOI:10.1007/s00120-018-0769-1

Journal Data Filtered By: **Selected JCR Year: 2016** Selected Editions: SCIE,SSCI
 Selected Categories: **“UROLOGY and NEPHROLOGY”** Selected Category
 Scheme: WoS

Gesamtanzahl: 76 Journale

Rank	Full Journal Title	Total Cites	Journal Impact Factor	Eigenfactor Score
1	EUROPEAN UROLOGY	27,172	16.265	0.066790
2	Nature Reviews Nephrology	3,710	12.146	0.014830
3	JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY	35,795	8.966	0.054330
4	KIDNEY INTERNATIONAL	41,438	8.395	0.055150
5	Nature Reviews Urology	2,439	7.735	0.007720
6	AMERICAN JOURNAL OF KIDNEY DISEASES	21,660	7.623	0.032640
7	Kidney International Supplements	1,501	5.593	0.007290
8	JOURNAL OF UROLOGY	49,702	5.157	0.055450
9	Clinical Journal of the American Society of Nephrology	14,077	4.780	0.035400
10	NEPHROLOGY DIALYSIS TRANSPLANTATION	24,509	4.470	0.041050
11	BJU INTERNATIONAL	19,691	4.338	0.034390
12	PROSTATE	7,638	3.820	0.011850
13	UROLOGIC ONCOLOGY-SEMINARS AND ORIGINAL INVESTIGATIONS	4,321	3.767	0.012890
14	PROSTATE CANCER AND PROSTATIC DISEASES	1,751	3.723	0.004540
15	AMERICAN JOURNAL OF PHYSIOLOGY-RENAL PHYSIOLOGY	16,787	3.611	0.022770
16	SEMINARS IN NEPHROLOGY	2,590	3.598	0.005350
17	NEUROUROLOGY AND URODYNAMICS	4,778	3.560	0.007690
18	CURRENT OPINION IN NEPHROLOGY AND HYPERTENSION	3,154	3.509	0.006830
19	EUROPEAN UROLOGY SUPPLEMENTS	674	3.462	0.000760
20	NEPHRON PHYSIOLOGY	389	3.455	0.000510

Rank	Full Journal Title	Total Cites	Journal Impact Factor	Eigenfactor Score
21	KIDNEY & BLOOD PRESSURE RESEARCH	1,489	3.104	0.003000
22	ASIAN JOURNAL OF ANDROLOGY	3,118	2.996	0.006400
23	Journal of Sexual Medicine	9,411	2.978	0.018400
24	ADVANCES IN CHRONIC KIDNEY DISEASE	1,412	2.757	0.003210
25	WORLD JOURNAL OF UROLOGY	4,353	2.743	0.010120
26	AMERICAN JOURNAL OF NEPHROLOGY	4,004	2.542	0.008130
27	Clinical Genitourinary Cancer	1,182	2.535	0.003860
28	PEDIATRIC NEPHROLOGY	8,248	2.516	0.012290
29	JOURNAL OF RENAL NUTRITION	1,563	2.318	0.002850
30	UROLOGY	20,984	2.309	0.026090
31	BMC Nephrology	2,511	2.289	0.009290
32	JOURNAL OF ENDOUROLOGY	6,030	2.270	0.009900
33	NEPHRON EXPERIMENTAL NEPHROLOGY	675	2.238	0.001110
34	UROLOGIC CLINICS OF NORTH AMERICA	1,782	2.220	0.001680
35	JOURNAL OF NEPHROLOGY	2,395	2.153	0.004080
36	NEPHRON CLINICAL PRACTICE	1,800	2.138	0.004220
37	Current Urology Reports	1,082	2.124	0.002700
38	Aging Male	727	2.108	0.001310
39	NEPHRON	2,761	1.939	0.001060
40	INTERNATIONAL UROGYNECOLOGY JOURNAL	5,428	1.937	0.010000
41	CardioRenal Medicine	305	1.844	0.001130
41	INTERNATIONAL JOURNAL OF UROLOGY	3,709	1.844	0.006030
43	Urolithiasis	486	1.816	0.001480
44	CURRENT OPINION IN UROLOGY	1,550	1.796	0.003270
45	Clinical and Experimental Nephrology	1,879	1.764	0.004550
46	International Neurourology Journal	300	1.739	0.000830
47	BMC Urology	942	1.720	0.002700
48	SEMINARS IN DIALYSIS	2,391	1.671	0.004640

Rank	Full Journal Title	Total Cites	Journal Impact Factor	Eigenfactor Score
49	Journal of Pediatric Urology	1,935	1.611	0.004440
49	UROLOGIA INTERNATIONALIS	2,675	1.611	0.003580
51	INTERNATIONAL UROLOGY AND NEPHROLOGY	3,190	1.564	0.006570
52	NEPHROLOGY	2,499	1.563	0.005230
53	PERITONEAL DIALYSIS INTERNATIONAL	3,165	1.557	0.003030
54	BLOOD PURIFICATION	1,646	1.535	0.003180
55	THERAPEUTIC APHERESIS AND DIALYSIS	1,400	1.529	0.002490
56	Scandinavian Journal of Urology	418	1.513	0.001630
57	Hemodialysis International	1,208	1.353	0.002490
58	INTERNATIONAL JOURNAL OF IMPOTENCE RESEARCH	2,123	1.293	0.001260
59	NEFROLOGIA	961	1.183	0.001640
60	Actas Urologicas Espanolas	779	1.181	0.001090
61	Canadian Journal of Urology	872	1.141	0.001760
62	CUAJ-Canadian Urological Association Journal	1,299	1.082	0.003810
63	CLINICAL NEPHROLOGY	3,047	1.066	0.003030
64	Minerva Urologica E Nefrologica	280	0.984	0.000410
65	Nephrologie & Therapeutique	428	0.917	0.000360
66	Iranian Journal of Kidney Diseases	556	0.916	0.001200
67	Urology Journal	608	0.824	0.000940
68	International Braz J Urol	1,120	0.815	0.002140
69	RENAL FAILURE	2,167	0.790	0.003770
70	PROGRES EN UROLOGIE	1,056	0.606	0.001090
71	Nephrology Nursing Journal	485	0.535	0.000460
72	Contributions to Nephrology	1,239	0.388	0.002530
73	ARCHIVOS ESPANOLES DE UROLOGIA	505	0.323	0.000530
74	AKTUELLE UROLOGIE	105	0.306	0.000150
75	LUTS-Lower Urinary Tract Symptoms	75	0.302	0.000210
76	UROLOGE	595	0.289	0.000580

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„Dr. Google“ – Informationssuche und Krankheitsangst bei Männern mit lokal begrenztem Prostatakarzinom

Hintergrund und Fragestellung

Die Diagnose Prostatakarzinom wirft bei den betroffenen Männern viele Fragen auf. Welche Therapie ist am besten geeignet? Welche Folgen hat die Krankheit? Wie lange wird sie andauern? Obwohl die wichtigsten Informationen im Arzt-Patienten-Gespräch vermittelt werden, suchen viele Patienten nach zusätzlichen Informationen. Die Informationssuche ist eine wichtige Strategie im Umgang mit Angst und Unsicherheit. Jedoch sind nicht alle Quellen gleichermaßen unterstützend, v. a. wenn die Validität der Informationen zweifelhaft ist. Vor diesem Hintergrund wird insbesondere das Internet als Informationsquelle kontrovers diskutiert.

Krankheitsangst und Informationssuche bei Männern mit lokal begrenztem Prostatakarzinom

Bis zu 30 % der Männer mit einem Prostatakarzinom (PCa) berichten Angstwerte, die als klinisch relevant einzustufen sind [28]. Eine erhöhte Krankheitsangst mindert nicht nur die Lebensqualität [21], sondern beeinflusst auch die Therapieentscheidung und -adhärenz [25]. Gemäß der S3-Leitlinie [17] stehen Männern mit lokal begrenztem PCa (LPCa) vier Therapieoptionen zur Verfügung: die radikale Prostatektomie (RP), perkutane

Radiotherapie (EBRT), Brachytherapie (BRT) und Active Surveillance (AS). Der langfristige Verlauf der Krankheitsangst scheint nicht mit der gewählten Therapiestrategie zusammenzuhängen [27]. Dennoch spielt zum Zeitpunkt der Therapieentscheidung die Krankheitsangst und die damit verbundene psychische Belastung eine große Rolle [2] und bei etwa einem Fünftel der Männer unter AS erfolgt der Wechsel zu einer invasiven Therapie aufgrund der Krankheitsangst und nicht aufgrund einer klinisch relevanten Krankheitsprogression [3].

Um ihre Angst zu bewältigen, suchen viele Patienten aktiv nach Informationen. Eine direkte Auseinandersetzung mit der Erkrankung geht mit einem besseren psychischen Wohlbefinden einher. Das aktive Vorgehen kann ein Gefühl von Kontrolle vermitteln und Unsicherheit verringern [18]. Insbesondere Krebspatienten haben ein großes Informationsbedürfnis, das sie häufig nicht erfüllt sehen [10]. Der Eindruck, nicht ausreichend informiert zu sein, kann die Krankheitsangst verstärken, v. a. dann, wenn rezipierte Informationen widersprüchlich und verwirrend sind [14]. In diesem Zuge wird das Internet als Informationsquelle intensiv diskutiert, da es einerseits niedrigschwellig Informationen anbietet, andererseits jedoch keine inhaltliche Korrektheit garantiert. Eine Studie [24] mit 1613 Melanompatienten zeigte, dass 94 % der Befragten das Internet als Informationsquelle als nützlich bewerteten. Ein Drittel der Befragten gab an, dass die Krankheitsangst durch die Internet-

recherche abgenommen habe, während ein Drittel einen Anstieg der Angst berichtete. Die Nutzung des Internets hat in den vergangenen Jahren stark zugenommen: Im Jahr 2017 verfügten bereits 93 % der deutschen Privathaushalte über einen Internetzugang [9] und etwa drei Viertel der über 60-Jährigen nutzten das Internet [8].

Ziel der Studie

Ziel der Studie war es zu untersuchen, inwiefern verschiedene Arten von Informationsquellen, die Anzahl der genutzten Informationsquellen und die wahrgenommene Informiertheit die krankheitsspezifische Angst bei Männern mit LPCa vorhersagen.

Studiendesign und Untersuchungsmethoden

Studiendesign und Rekrutierungsprozedere

Die prospektive nicht-interventionelle Beobachtungsstudie basierte auf einer Nachbefragung der multizentrischen Versorgungsstudie HAROW, welche detailliert an anderer Stelle beschrieben wurde [12]. Männer, die sich initial für eine RP entschieden hatten, wurden basierend auf der Zeit seit der Therapieentscheidung zu Männern unter AS gematcht. Die Stichprobe umfasste 150 Männer nach RP und 142 Männer unter AS. Die Zeit zwischen der Behandlungsentscheidung und der Be-

Die Autorinnen C. Hilger und I. Otto haben zu gleichen Anteilen an der Publikation gearbeitet und teilen sich die Erstautorenschaft.

fragung reichte von 19 bis 78 Monaten ($M = 47,96 \pm SD = 15,4$). Ein positives Votum der Ethikkommission der Charité-Universitätsmedizin Berlin lag vor (EA 1/242/13).

Materialien und Instrumente

Die krankheitsspezifische Angst wurde mit der deutschen Version der *Memorial Anxiety Scale for Prostate Cancer* (MAX-PC; [16]) erhoben ($\alpha = 0,93$). Der MAX-PC umfasst 18 Items und ist in drei Subskalen gegliedert (Angst bezogen auf Prostatakrebs, PSA-Test, Rezidiv). Ein globaler Medienscore indiziert die Intensität der prostatakrebspezifischen Angst (0–54 Punkte, Cut-off klinisch relevante Angst = 27 Punkte; [1]).

Die Art der genutzten Informationsquellen wurde in Anlehnung an Huber et al. [13] erfasst ($\alpha = 0,75$): Anhand von acht verschiedenen Informationsquellen (Hausarzt/Urologe, andere Betroffene/Selbsthilfegruppe, Familie/Freunde, Internet, Radio/Fernsehen, Tageszeitungen/Zeitschriften, Gesundheitsliteratur, Medizinische Veranstaltungen/Kongresse) beurteilten die Teilnehmer, wie häufig sie diese in den vergangenen 12 Monaten genutzt hatten (Antwortkategorien: 1 = niemals bis 4 = oft). Zur Ermittlung der Anzahl genutzter Informationsquellen wurden die Antwortkategorien dichotomisiert (1 = nicht genutzt, 2–4 = genutzt) und ein Summenwert über alle Items gebildet. Die

wahrgenommene Informiertheit wurde mit einem Item erhoben („Ich fühle mich gut über meine Erkrankung informiert“; Antwortkategorien von: 1 = stimme voll zu bis 4 = stimme gar nicht zu).

Statistische Analyse

Gruppenunterschiede zwischen RP- und AS-Patienten (Alter, Zeit seit der Therapieentscheidung, PSA-Wert, Anzahl der Informationsquellen) sowie zwischen Männern mit klinisch relevanter und nicht klinisch relevanter Krankheitsangst wurden mit dem *t*-Test für unabhängige Stichproben überprüft, bezüglich kategorialer Variablen (Gleason-Score) mit dem χ^2 -Test. Da bei der Zahl der Komorbiditäten, der wahrgenommenen Informiertheit, der Internetnutzung und der krankheitsspezifischen Angst die Normalverteilungsannahme verletzt war, wurde der non-parametrische Mann-Whitney-U-Test durchgeführt. Zur Vorhersage der Krankheitsangst wurde eine sequentielle multiple Regressionsanalyse berechnet. Im ersten Schritt wurde für Kovariablen kontrolliert, danach wurde die Informationsquelle „Internet“ in das Regressionsmodell aufgenommen, gefolgt von der Anzahl der Informationsquellen, der wahrgenommenen Informiertheit und den Interaktionstermen. Zur Berechnung der Effektstärke der inkrementellen Varianzaufklärung wurde f^2 nach Cohen [5] herangezogen.

Es bestand keine Multikollinearität zwischen den Prädiktorvariablen.

Für die Moderationsanalyse wurden die Prädiktorvariablen und die Interaktionsterme um ihre jeweiligen Gesamtmittelwert zentriert. In die Moderationsmodelle wurden die Anzahl der Informationsquellen und das Internet als Moderatoren, die wahrgenommene Informiertheit als Prädiktor der Krankheitsangst aufgenommen. Interaktionseffekte wurden mithilfe von Simple-slope-Tests überprüft [22]. Geringe und hohe Ausprägungen der kontinuierlichen Moderatorvariablen wurden berechnet, indem eine Standardabweichung von dem zentrierten Mittelwert der jeweiligen Variable subtrahiert bzw. addiert wurde. Die Moderationsanalyse wurde mit der PROCES-Makro für SPSS (Modell 3) berechnet. Alle weiteren Analysen wurden mit der Statistiksoftware IBM SPSS Statistics 24 durchgeführt. Für die Analysen wurde ein Signifikanzniveau von $\alpha = 0,05$ festgelegt.

Ergebnisse

Die Stichprobe ist in **Tab. 1** beschrieben. Das mittlere Alter betrug 70 Jahre ($SD = 7,2$). Männer unter AS waren im Durchschnitt 4,3 Jahre älter und hatten einen durchschnittlich $1,4 \text{ ng/ml}^3$ geringeren PSA-Wert.

Abb. 1 veranschaulicht die Nutzung der Informationsquellen. Die meisten Männer konsultierten ihren Arzt, gefolgt

Hier steht eine Anzeige.

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Zusammenfassung · Abstract

Urologe 2019 · 58:1050–1056 <https://doi.org/10.1007/s00120-018-0769-1>
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„Dr. Google“ – Informationssuche und Krankheitsangst bei Männern mit lokal begrenztem Prostatakarzinom

Zusammenfassung

Hintergrund und Ziel. Nach der Diagnose „lokal begrenztes Prostatakarzinom“ (LPCa) suchen viele Männer nach zusätzlichen Informationen zu ihrer Erkrankung. Inwiefern unterschiedliche Informationsquellen die Unsicherheit und Angst beeinflussen, ist bislang nicht eindeutig. In dieser Studie soll deshalb untersucht werden, wie verschiedene Arten von Informationsquellen, die Zahl genutzter Quellen und die wahrgenommene Informiertheit mit der Krankheitsangst zusammenhängen.

Material und Methoden. Männer mit LPCa ($N=292$; $n=150$ radikale Prostatektomie, $n=142$ aktive Überwachung) wurden im Rahmen einer querschnittlichen Beobachtungsstudie hinsichtlich sozio-

demographischer Variablen, Anzahl und Art der verwendeten Informationsquellen, wahrgenommener Informiertheit und krankheitsspezifischer Angst befragt. Der Zusammenhang von Informationssuche und Krankheitsangst wurde mit einer moderierten sequentiellen multiplen Regression getestet. **Ergebnisse.** Die Männer waren $70 \pm 7,2$ Jahre alt und befanden sich $47,9 \pm 15,4$ Monate nach Therapieentscheidung. Die multiple Regressionsanalyse zeigte, dass die Internetnutzung ($\beta=3,28$; $p>0,001$), die Anzahl der Informationsquellen ($\beta=1,09$; $p>0,01$) und eine geringere Informiertheit ($\beta=4,49$; $p>0,001$) unabhängige Prädiktoren für die Krankheitsangst waren. Außerdem erklärte die Dreifachinteraktion ($\beta=2,03$; $p>0,05$) einen

signifikanten Varianzanteil. Insgesamt erklärte das Modell 30 % der Kriteriumsvarianz.

Diskussion. Unsere Ergebnisse zeigen, dass bereits viele Männer mit LPCa das Internet als Informationsquelle nutzen und dass die Online-Informationssuche mit einer erhöhten Krankheitsangst assoziiert ist. Möglicherweise können Angst und Unsicherheit reduziert werden, wenn Ärzte ihre Patienten bei der Auswahl von verlässlichen Online-Quellen beraten.

Schlüsselwörter

Active Surveillance · Radikale Prostatektomie · Internet · Informationsquellen · Gesundheitsinformationen

„Dr. Google“—information-seeking behavior and disease-specific anxiety among men with localized prostate cancer

Abstract

Background and objective. After the diagnosis of localized prostate cancer (LPCa), many men seek additional information about their disease. However, it is not yet proven how different sources of information influence uncertainty and disease-specific anxiety. The aim of this study is to investigate to what extent different types of information sources, the number of used sources and the perceived level of information are predictive of disease-specific anxiety.

Materials and methods. Men with LPCa ($N=292$; $n=150$ radical prostatectomy, $n=142$ active surveillance) completed questionnaires assessing sociodemographic variables, number and type of sources

of information used, perceived level of information, and disease-specific anxiety. The association of information-seeking behavior with anxiety was tested using moderated sequential multiple regression.

Results. Men were 70 ± 7.2 years old and the survey was taken 47.9 ± 15.4 months after decision for therapy. The multiple regression analysis showed that, after controlling for potential covariates, internet usage ($\beta=3.28$; $p>0.001$), number of sources ($\beta=1.09$; $p>0.01$) and a lower level of informedness ($\beta=4.49$; $p>0.001$) independently predicted variability of anxiety. In addition, the 3-way interaction ($\beta=2.03$; $p>0.05$) accounted for a significant proportion of variance. Overall,

the model explained 30% of the criterion variance.

Conclusions. Our results show that many men with LPCa already use the internet as a source of information and that this online search is associated with increased disease-specific anxiety. It may be possible to reduce disease-specific anxiety and uncertainty if physicians advise their patients on the selection of reliable online sources.

Keywords

Active surveillance · Radical prostatectomy · Internet · Information sources · Consumer health information

von Zeitschriften und Gesundheitsliteratur. Das Internet wurde von 38,9 % der Männer als Informationsquelle genutzt.

Die Krankheitsangst war in der gesamten Stichprobe gering ($M=10,88$; $SD=9,73$) und es zeigten sich keine signifikanten Unterschiede zwischen den Behandlungsgruppen. 8,57 % der Männer berichteten Angstwerte, die über dem klinischen Cut-off lagen. Diese Männer benutzten signifikant mehr Informationsquellen ($M=5,67$; $SD=1,49$) als

Männer mit geringerer Angst ($M=3,72$; $SD=2,13$; $p=0,01$). Um zu überprüfen, welche Faktoren die Krankheitsangst vorhersagen, wurde eine sequentielle multiple Regression durchgeführt (■ Tab. 2). Soziodemographische und klinische Variablen (Schritt 1) erklärten 13,3 % der Varianz im Kriterium Krankheitsangst ($p<0,001$). Die Nutzung des Internets (Schritt 2) erklärte einen zusätzlichen Varianzanteil von 8,5 % ($p<0,001$; $f^2=0,31$). Die Anzahl

der konsultierten Quellen (Schritt 3) leistete eine inkrementelle Varianzaufklärung von 3,6 % ($p=0,001$; $f^2=0,19$). Die wahrgenommene Informiertheit (Schritt 4) klärte weitere 6,6 % Varianz auf ($p<0,001$; $f^2=0,27$). Die Zweifachinteraktionen (Schritte 5–7) leisteten keine signifikante Varianzaufklärung ($p=0,168–0,465$), während die Dreifachinteraktion (Informiertheit \times Anzahl der Quellen \times Internetnutzung) einen kleinen, aber signifikanten Varianzanteil auf-

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Tab. 1 Deskriptive Stichprobenbeschreibung

	Gesamt (n = 292)	RP (n = 150)	AS (n = 142)	p
Alter, Jahre, M (SD)	70 (7,2)	67,9 (6,8)	72,2 (7,1)	^b
Zeit seit Therapieentscheidung (Monate), M (SD)	42 (16,6)	41,7 (16,3)	42,3 (17,1)	0,774
Tumorrisikokategorie ^c				
Gleason-Score (niedrig), n (%)	221 (76,7)	85 (57,8)	136 (96,5)	^a
PSA, M (SD)	6,2 (3,2)	6,9 (2,8)	5,5 (3,3)	
Anzahl der Komorbiditäten ^d , M (SD)	1,8 (1,5)	1,8 (1,5)	1,8 (1,5)	0,666
Krankheitsspezifische Angst ^e , M (SD) (Range 0–3)	10,9 (9,7)	10,4 (10,1)	11,4 (9,3)	0,229
Wahrgenommene Informiertheit, M (SD) (Range 1–4)	1,45 (0,59)	1,46 (0,61)	1,44 (0,57)	0,976
Anzahl der Informationsquellen, M (SD) (Range 0–8)	3,82 (2,16)	3,73 (2,21)	3,92 (2,11)	0,498
Internetnutzung, M (SD) (Range 1–4)	1,76 (0,94)	1,92 (1)	1,59 (0,85)	0,576

AS Active Surveillance, RP radikale Prostatektomie
^ap < 0,01
^bp < 0,001
^cRisikoklassifikation nach D'Amico et al. [7]
^dSCQ-D, Streibelt et al. [26]
^eMAX-PC, Lehmann et al. [16]

Tab. 2 Multiple lineare Regression der krankheitsspezifischen Angst

Kriterium: krankheitsspezifische Angst	B	SE	β	R ²	Adj. R ²	R ² Δ
Schritt 1: Kovariablen ^a	-2,36-2,67	0,04-2,44	-0,22-0,22	0,133	0,100	0,133
Schritt 2: Quelle – Internet ^c	3,28	0,65	0,32	0,218	0,185	0,085
Schritt 3: Anzahl der Quellen ^b	1,09	0,32	0,24	0,254	0,219	0,036
Schritt 4: wahrgenommene Informiertheit ^d	4,49	0,94	0,27	0,320	0,285	0,066
Schritt 5: 2-fach-Interaktion Internet × Anzahl der Quellen	0,262	0,368	0,198	0,321	0,284	0,002
Schritt 6: 2-fach-Interaktion Internet × Informiertheit	1,331	0,963	0,250	0,327	0,286	0,006
Schritt 7: 2-fach-Interaktion Informiertheit × Anzahl der Quellen	0,463	0,555	0,204	0,329	0,285	0,002
Schritt 8: 3-fach-Interaktion Informiertheit × Anzahl der Quellen × Internetnutzung ^a	1,551	0,646	2,028	0,345	0,300	0,016

n = 292
B unstandardisierter Regressionskoeffizient, SE Standardfehler, β standardisierter Regressionskoeffizient, R² Bestimmtheitsmaß, Adj. R² Adjustiertes Bestimmtheitsmaß, R² Δ inkrementelles Bestimmtheitsmaß
^ap < 0,05
^bp < 0,01
^cp < 0,001
^dAlter, Berufstätigkeit, Schulbildung, Beziehungsstand, PSA bei Diagnose, Komorbiditäten (SCQ-D, Streibelt et al. [26]), Zeit seit Diagnose, Risikokategorie (D'Amico et al. [7]), Behandlungsstrategie

klärte ($\Delta R^2 = 0,016$, $p = 0,017$, $f^2 = 0,13$). Insgesamt erklärte das Modell 30% (R^2 adjustiert) Varianz der krankheitsspezifischen Angst.

Die Moderationsanalyse zeigte, dass der Zusammenhang zwischen wahrgenommener Informiertheit und Krankheitsangst sowohl durch die Anzahl der Informationsquellen als auch durch die Internetnutzung moderiert wird ($p = 0,017$). Simple-slope-Analysen (Abb. 2) ergaben, dass der Effekt der wahrgenommenen Informiertheit auf die Krankheitsangst für Männer, die eine hohe Anzahl an Informationsquellen

nutzen, signifikant ist ($B = 1,26$; $t = 2,88$; $p < 0,01$), wenn gleichzeitig das Internet oft genutzt wurde. Das bedeutet, dass für Männer, die das Internet häufig als Informationsquelle nutzten und sich wenig über ihre Erkrankung informiert fühlten, eine höhere Anzahl genutzter Informationsquellen mit einer stärkeren Krankheitsangst assoziiert war.

Diskussion

Je mehr Patienten das Internet als Informationsquelle nutzen, desto wichtiger wird ein Verständnis der Zusammen-

hänge von Online-Informationssuche und krankheitsspezifischer Angst. Die drei Kerneergebnisse unserer Studie sind, dass (1) die Internetnutzung, die Zahl genutzter Informationsquellen und eine geringere wahrgenommene Informiertheit unabhängig voneinander die krankheitsspezifische Angst bei Männern mit LPCa erklären; (2) das Zusammenspiel der Zahl genutzter Informationsquellen und der wahrgenommenen Informiertheit nur bei Männern signifikant ist, die das Internet häufig nutzen; (3) fast 40% der betroffenen Männer das Internet nut-

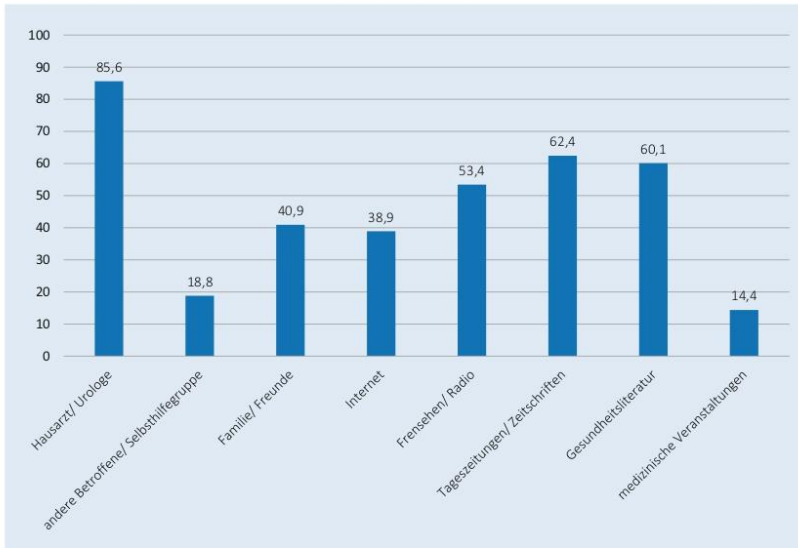


Abb. 1 ◀ Nutzung der verschiedenen Quellen in Prozent (Mehrfachantworten möglich)

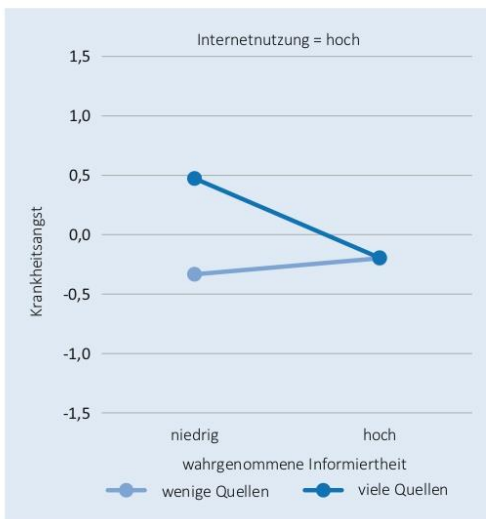


Abb. 2 ◀ Signifikante 3-fach-Interaktion

zen, um sich über ihren Prostatakrebs zu informieren [19].

In vorangegangenen Studien wurde bereits gezeigt, dass die Krankheitsangst sowohl mit der Informationsquellennutzung als auch mit der Informiertheit assoziiert ist [6]. Es war jedoch nicht klar, ob PCa-Patienten mit einer höheren Krankheitsangst eher dazu neigen, sich über

möglichst viele Kanäle zu informieren [20] oder ob umgekehrt erst eine breitere Informationssuche zu einer höheren Krankheitsangst führt [23]. Unsere Ergebnisse geben Hinweise darauf, dass auch das Zusammenspiel von Internetnutzung, Zahl der Informationsquellen und Informiertheit eine entscheidende Rolle spielt: Nur bei Männern, die das

Internet verstärkt nutzen und die sich gleichzeitig weniger gut über ihren Prostatakrebs informiert fühlen, scheint eine höhere Zahl genutzter Informationsquellen mit einer höheren Krankheitsangst assoziiert zu sein. Folglich sind internet-affine Männer, die sich noch zu wenig zu ihrer Erkrankung informiert fühlen, besonders gefährdet, sich von der Informationssuche verunsichern zu lassen.

Das Internet stellt für Krebspatienten eine zunehmend wichtige Informationsquelle dar [4]. Ein Vorteil liegt in dem niedrighen Zugang zu Informationen. Mehr als ein Drittel der Teilnehmer unserer Studie gab an, sich im Internet über ihre Erkrankung informiert zu haben. Dabei ist zu beachten, dass unsere Studie im Jahr 2014 durchgeführt und die Diagnose im Mittel vier Jahre zuvor gestellt wurde. Mittlerweile benutzen bereits drei Viertel der Männer über 60 Jahren das Internet, im Alter von 50–59 Jahren sind es bereits 87 % und im Alter von 40–49 Jahren 95 % [8]. Zukünftig wird eine Generation von Männern mit einem LPCa diagnostiziert werden, für die die Internetnutzung zur Informationssuche bereits fester Bestandteil ihres (beruflichen und privaten) Lebens ist. Vor diesem Hintergrund sollte nicht diskutiert werden, ob das Internet eine geeignete Infor-

mationsquelle ist, sondern vielmehr wie Patienten das Internet nutzen können, um verlässliche Informationen zu ihrer Erkrankung zu erhalten.

Behandelnden Ärzten kommt hier eine zentrale Rolle zu: Sie müssen ihren Patienten helfen, sich in dem Dschungel an Informationen zurechtzufinden. Die Nutzung von Online-Informationen sollte im Arzt-Patienten-Gespräch thematisiert und der Patient über mögliche Risiken aufgeklärt werden. Viele Patienten wünschen sich eine Übersicht mit Links zu nützlichen Internetseiten [15]. Damit könnte das Risiko reduziert werden, dass Patienten mit ungeprüften und falschen Informationen konfrontiert werden. Auch onlinebasierte Beratungstools haben großes Potential, da sie den Patienten auch außerhalb des Beratungsgesprächs Zugang zu gesicherten Informationen bieten. Erste positive Befunde liegen z. B. für die onlinegestützte „Entscheidungshilfe Prostatakrebs“ der Patientenakademie der Deutschen Urologen vor [11].

Stärken der vorliegenden Arbeit sind die hohe externe Validität durch das multizentrische, nicht-interventionelle Studiendesign und eine vergleichsweise große Stichprobe. Eine Limitation unserer Studie ist das querschnittliche Design, das keine kausalen Interpretationen zulässt. Die Wirkungsrichtung sollte zukünftig im Rahmen von randomisiert kontrollierten Studien getestet werden.

Fazit für die Praxis

- In zukünftigen Studien sollte erfasst werden, durch welche Quellen sich Patienten am besten informiert fühlen.
- In Bezug auf das Internet sollten die unterschiedlichen Typen von Online-Quellen (z. B. Informationsvideos, Fachzeitschriften, Themenforen/ Erfahrungsberichte) erhoben und von den Patienten bezüglich ihrer Nützlichkeit bewertet werden.
- Immer mehr Patienten fragen „Doktor Google“ um Rat. Damit ändert sich auch die Rolle der Ärzten: diese sollten ihre Patienten dabei unterstützen, die Vielzahl an Informatio-

nen aus unterschiedlichen Quellen zu strukturieren und zu interpretieren.

- Eine Beratung zur kritischen Informationsquellennutzung könnte einen Weg darstellen, dem Patientenwunsch nach aktiver Informationssuche gerecht zu werden und dabei gleichzeitig die Verunsicherung zu reduzieren.

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Danksagung. Die Autorinnen danken der Stiftung Oskar Helene Heim für die Förderung des Forschungsprojektes sowie der Else Kröner-Fresenius-Stiftung für die Förderung der wissenschaftlichen Mitarbeiterinnenstellen von IO und CH.

Einhaltung ethischer Richtlinien

Interessenkonflikt. C. Hilger, I. Otto, C. Hill, T. Huber und F. Kendel geben an, dass kein Interessenkonflikt besteht.

Dieser Beitrag beinhaltet keine von den Autoren durchgeführten Studien an Menschen oder Tieren.

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20	NEPHRON PHYSIOLOGY	389	3.455	0.000510

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RESEARCH ARTICLE

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The importance of sexuality, changes in erectile functioning and its association with self-esteem in men with localized prostate cancer: data from an observational study

Caren Hilger^{1*}, Martin Schostak², Stephan Neubauer³, Ahmed Magheli⁴, Thomas Fydrich⁵, Silke Burkert^{1,6} and Friederike Kendel¹

Abstract

Background: Treatment for localized prostate cancer (PCa) can cause long-term changes in erectile functioning. However, data on the importance of sexuality and possible consequences of altered erectile functioning on self-esteem in men with localized PCa are lacking.

Methods: Self-report questionnaires were completed by 292 men with PCa, initially managed with active surveillance (AS) or radical prostatectomy (RP). Independent t-tests were conducted to evaluate group differences. A sequential multiple regression model was fitted to analyze the associations between the importance of sexuality, changes in erectile functioning and impairment of self-esteem. Interaction effects were tested using simple slope analyses.

Results: Participants were 70 ± 7.2 years old and 66.5% rated sex as being "rather/very important". The two groups differed markedly in changes in erectile functioning, importance of sexuality and impairment of self-esteem ($p < .001$), with higher values in RP patients. Regression analysis showed that after adjustment for control variables and importance of sexuality, changes in erectile functioning were still associated with impairment of self-esteem ($B = .668, SE = .069, p < .001$). The interaction of changes in erectile functioning and importance of sexuality reached significance ($B = .318, SE = .062, p < .001$).

Conclusions: RP patients report more changes in erectile functioning than AS patients. Moreover, in men with localized PCa, erectile functioning and self-esteem are closely related. Sexuality seems to be important for the majority of these men. Physicians should address the possibility of erectile dysfunction and its potential effects on psychological well-being before the treatment decision.

Keywords: Active surveillance, Erectile functioning, Importance of sexuality, Localized prostate cancer, Radical prostatectomy, Self-esteem

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Background

Men who are diagnosed with localized prostate cancer (PCa) have to choose among treatment options that differ considerably in their invasiveness, [1] ranging from active surveillance (AS) to radical prostatectomy (RP). In AS, treatment is delayed until a predefined histological or biochemical disease progression occurs, or until the patient chooses a different treatment strategy due to other reasons, for example, cancer-related anxiety. [2] One of the most important reasons that men opt for AS is the possible impairment of sexual function as a side effect of invasive treatment. [3] Negative effects of RP on sexual function compared to AS have been summarized in systematic reviews [4, 5] and were confirmed by the latest results from the randomized controlled trial ProtecT that compared RP to AS directly. [6] Recent research has also highlighted a close association of PCa treatment and psychosexual outcomes, such as sexual bother [7] and an impaired sense of masculinity. [8] However, most studies dealing with sexuality in PCa patients still focus on the physiological aspects of sexuality despite the fact that an impairment of erectile function has far-reaching consequences on men's quality of life. [9, 10] For most men, sexuality is a vital aspect of their male identity and an impairment of erectile functioning may also affect their self-esteem (i.e. men's appraisal of their individual abilities combined with a sense of self-worth [11]). [12–14]

Prostate cancer is typically a disease of older men. [16] Therefore, one may assume that an impairment of erectile functioning is negligible in most PCa patients. Eventually, at the time of diagnosis, men are an average of about 70 years old. [17] However, to draw the conclusion that sexuality plays a subordinate role in the process of decision-making could mean to adapt the stereotype of sex unjustifiably being “unseemly, even unnatural in the old.” [15] Indeed, sexual activity decreases with increasing age. Nevertheless, most older men still seem to experience sexual desire [15, 18] and also report being sexually active. [9, 19]

Although the relationship between erectile dysfunction and self-esteem has been subject to previous studies [13, 20], no study, to the best of our knowledge, has examined this association in men with localized PCa undergoing different treatment options. Additionally, data on the importance of sexuality in this population are lacking. The diagnosis of PCa might represent a critical life-event for some men. One could therefore assume that the diagnosis entails a change in men's priorities: PCa and its treatment may become the main focus whereas other aspects of quality of life, such as sexuality, may become of diminishing relevance. In fact, studies with colorectal cancer patients showed that the importance of sexuality decreased due to the cancer experience [21]. It remains unclear, however, whether this also applies to men with localized PCa. Our study therefore seeks to find out how important sexuality

actually is for men with localized PCa. In addition, PCa treatment and RP in particular can result in an abrupt change of erectile functioning (in contrast to a normative, more gradual worsening of erectile functioning with increasing age). This does not allow for anticipating non-normative changes in erectile functioning for men with localized PCa after invasive treatment, which could also have an impact on self-esteem.

This study seeks to close a twofold gap: On the one hand, we wanted to assess the consequences of erectile dysfunction on PCa patients' self-esteem and, on the other hand, we wanted to shed light on the importance of sexuality in this population of older men with PCa. More specifically, we aimed at (1) comparing perceived changes in erectile functioning, self-esteem, and the importance of sexuality in men having opted for either RP or AS, and (2) assessing how changes in erectile functioning for the worse affect PCa patients' self-esteem, considering the importance of sexuality.

Methods

Study design, procedure and participants

The study was nested within the prospective, multicenter, observational HAROW study, which included patients newly diagnosed with localized PCa between July 2008 and July 2013. [22] The present study was conducted in 2014: 378 men who had chosen RP as their primary treatment were matched based on the time since treatment decision to 378 men who had opted for AS. Men who opted for radiation therapy were excluded from this study as it aimed at comparing the two extremes of possible treatment strategies (AS = minimally invasive vs. RP = maximally invasive). All men contacted had agreed to take part in future studies. Men in the high risk category, as defined by D'Amico and colleagues, [23] were excluded from the study to improve the balance of the two treatment groups (see Kendel and colleagues for more details [24]). Those participants who gave written consent to the follow-up were mailed a self-report questionnaire. The average time from treatment decision to follow-up was 42 ± 16.6 months (range: 1–6 years).

The final sample comprised 292 men (150 RP patients, 142 AS patients). All participants had given informed consent prior to the study. IRB approval was obtained from the Charité – Universitätsmedizin Berlin (EA 1/242/13).

Materials and main outcome measures

Baseline clinical parameters were abstracted from case report forms. Changes in erectile functioning (“*Did your erectile function change due to your prostate cancer or its treatment?*”) and impairment of self-esteem due to decreased erectile functioning (“*If your erectile function has decreased, did this impair your self-esteem?*”) were measured using items adapted from Johannson and colleagues.

[25] The item measuring subjective importance of sexuality (“How important is sexuality for you?”) was adapted from van den Bergh and colleagues. [26] A five-point Likert scale was used for the item on impairment of self-esteem (range 0–4 with 0 indicating no changes in erectile functioning and therefore no impairment of self-esteem, 1 indicating changes in erectile functioning but no impairment of self-esteem due to these changes and 2–4 indicating changes in erectile functioning with lower to high impairment of self-esteem). For all other items, a four-point Likert scale (range 1–4) was used, with higher levels indicating higher expressions of the specific characteristic.

Previous studies have demonstrated that erectile dysfunction is not necessarily associated with decreased sexual satisfaction. [9] Therefore, satisfaction with sexual life was assessed as a control variable. The item (“Overall, how satisfied are you with your current sex-life?”) was adapted from van den Bergh and colleagues. [26] A five-point Likert scale was used for the item on satisfaction with sexual life (range 1–5, higher levels indicating higher expressions of satisfaction).

Statistical analysis

The RP and AS patients were compared regarding relevant sociodemographic variables and cancer characteristics. Chi²-tests were run for categorical variables and independent t-tests were conducted for continuous variables to compare (a) changes in erectile functioning, (b) impairment of self-esteem (c) the importance of sexuality and (d) satisfaction with sexual life between the two groups. Cohen’s *d* as a measure of effect size was calculated for group comparisons. Bivariate correlations between variables were calculated. A sequential multiple regression analysis was conducted to evaluate the relationship between sociodemographic characteristics, clinical variables, the importance of

sexuality and changes in erectile functioning with the criterion self-esteem. Covariates were entered first, followed by the importance of sexuality, changes in erectile functioning and finally the interaction term. Within all regression models, collinearity diagnostics indicated no multicollinearity among the independent variables. For moderation analyses, [27] predictor variables and the constituents of the respective interaction terms were centered around their grand means. In moderation models, covariates were entered first, followed by the importance of sexuality as moderator and changes in erectile functioning as predictor, and finally by the interaction term. To display and test the interaction effects, simple slopes were tested. [28] Low and high values of the continuous moderators were generated by adding or subtracting one standard deviation from the centered mean of the respective moderator. Moderation analyses were conducted using the PROCESS macro for SPSS (model 1). [29] An alpha level of $p < 0.05$ was considered significant for all analyses.

Results

Of the 292 men with PCa included in this study, 150 (51.4%) had chosen RP as the initial treatment and 142 (48.6%) were still under AS. Table 1 presents the sociodemographic data, clinical characteristics and descriptive statistics based on the two different treatment groups. Table 2 displays correlations between the variables under study. Fewer men after RP (69%) were classified as low-risk compared with men under AS (88%). The two groups differed in age, marital status, occupation, and initial cancer risk classification (Table 1). The RP patients reported significantly more changes in erectile functioning ($t(246.8) = -10.11, p < .001; d = 1.2$), and greater impairment of self-esteem ($t(269) = -4.19, p < .001, d = .51$) than men under AS. On average, men under AS considered sexuality as being less important

Table 1 Sample characteristics and sexuality

	Total (n = 292)	RP (n = 150)	AS (n = 142)	P
Age, yrs., M (SD)	70 (7.2)	67.9 (6.8)	72.2 (7.1)	< .001
Living with partner, n (%)	268 (92.4)	140 (94)	128 (90.8)	.031
Higher education, n (%)	116 (40)	61 (40.9)	54 (38.3)	.737
Still working vs. retired, n (%)	40 (13.8)	28 (18.8)	12 (8.5)	.04
Time since treatment decision (months), M (SD)	42 (16.6)	41.7 (16.3)	42.3 (17.1)	.774
Risk classification ¹				< .001
Gleason-Score (low), n (%)	221 (76.7)	85 (57.8)	136 (96.5)	< .001
PSA, M (SD)	6.2 (3.2)	6.9 (2.8)	5.5 (3.3)	< .001
Number of comorbidities, M (SD)	1.8 (1.5)	1.8 (1.5)	1.8 (1.5)	.713
Importance of sexuality, M (SD)	2.8 (0.8)	2.9 (0.8)	2.6 (0.85)	< .001
Changes in erectile functioning, M (SD)	3 (0.99)	3.5 (0.7)	2.5 (0.99)	< .001
Impairment of self-esteem, M (SD)	1.8 (1.15)	2.1 (1.1)	1.5 (1.1)	< .001
Satisfaction with sexual life, M (SD)	2.8 (1)	2.7 (1.1)	3 (0.9)	.002

AS, active surveillance, RP, radical prostatectomy; ¹ Risk classification based on D’Amico and colleagues [23]

Table 2 Correlations between study variables

Variables	2	3	4	5	6	7	8	9	10	11	12	13
1. Impairment of self-esteem	.55**	.26**	.20**	-.08	-.07	.01	.11	.04	-.04	.08	.09	-.56**
2. Changes in erectile functioning	-											
3. Importance of sexuality	.23**	-										
4. Importance* changes EF	-.12	-.14*	-									
5. Age	-.16**	-.34**	.19**	-								
6. Living with partner	.04	.13*	-.05	-.03	-							
7. Higher education	.58	.03	-.04	-.03	.10	-						
8. Still working	.09	.23**	<-.01	-.59**	.08	.06	-					
9. Time since treatment decision	-.01	-.01	.03	.21**	-.08	.06	-.13*	-				
10. Gleason-Score (low)	-.27**	-.13*	.04	.09	.01	-.01	-.03	.02	-			
11. PSA	.17**	<.01	-.04	.06	-.07	-.02	-.10	-.03	-.13*	-		
12. Number of comorbidities	.11	-.07	.01	.07	-.04	-.05	<.01	.05	-.04	-.11	-	
13. Satisfaction with sexual life	-.42**	-.09	-.20**	-.01	-.01	.01	-.01	.04	.04	-.16**	-.06	-

* $p < .05$; ** $p < .01$

compared to the RP patients ($t(278.4) = -3.54, p < .001; d = .42$). Across both groups, 66.5% of men rated sexuality as “rather or very important” (59% of the AS patients, 73.5% of the RP patients). The AS patients reported being more satisfied with their sexual life compared to RP patients ($t(277.4) = 3.17, p = .002, d = .38$). The correlation between satisfaction with sexual life and changes in erectile functioning was $r = -.42 (p < .001, \text{Table 2})$.

Table 3 Multiple regression of impairment of self-esteem on the importance of sexuality and changes in erectile functioning: final model ($n = 277$)

Variables	B	S.E.	β	ΔR^2 (ad. R^2)
Sociodemographic characteristics				
Age	.002	.011	.009	
Living with a partner	-.511	.216	-.117	
Higher education	-.05	.115	-.021	
Still working vs. retired	.137	.204	.042	.033
Group: RP vs. AS	.016	.143	.007	.06
Tumor risk category				
Gleason-Score (4–6)	.305	.141	.116	
PSA	.004	.019	.012	.002
Time since treatment decision (months)	.004	.004	.056	.004
Number of comorbidities	.039	.039	.051	.01
Importance of sexuality	.252	.074	.184	.048**
Changes in erectile functioning	.668	.069	.567	.207***
Importance of sexuality*changes in erectile functioning	.318	.062	.257	.062***

$R^2 = .426$ Adjusted $R^2 = .398$ $F = 14.93$ ***

B, unstandardized regression coefficient, S.E., standard error; β , standardized regression coefficient, AS, active surveillance, RP, radical prostatectomy; ** $p < .01$; *** $p < .001$

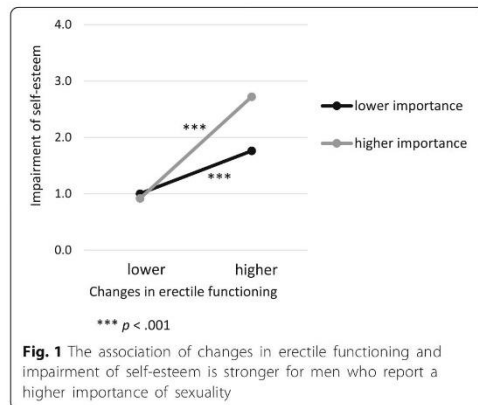
Multiple regression analysis

Sequential multiple regression was used to determine whether the importance of sexuality and changes in erectile functioning predicted impairment of self-esteem (Table 3). ΔR^2 refers to the amount of variance in the criterion (*impairment of self-esteem*), which is explained by the respective variables entered into the regression model at each step. Sociodemographic variables were entered in the first step and did not explain the variance of impairment of self-esteem significantly ($p = .08$). R^2 was significantly different from zero in the second step including *treatment group* ($\Delta R^2 = .06, p < .001$), but not in the third to fifth step including *PSA* and *Gleason-Score* ($\Delta R^2 = .002, p = .725$), *time since treatment decision* ($\Delta R^2 = .004, p = .271$) and *number of comorbidities* ($\Delta R^2 = .01, p = .1$). Again, R^2 was significantly different from zero when including *importance of sexuality* ($\Delta R^2 = .048, p < .001$) and *changes in erectile functioning* ($\Delta R^2 = .207, p < .001$). After the inclusion of *changes in erectile functioning*, the control variable *treatment group* was no longer significant. The interaction term of *importance of sexuality*changes in erectile functioning* also contributed significantly to an explanation of the variance ($\Delta R^2 = .062, p < .001$).

The final model explained 42.6% of variance ($R^2 = .426$; adjusted $R^2 = .398$), meaning that more than a third of the variability in impairment of self-esteem is predicted by our model. The pattern of results suggests that changes in erectile functioning predicted more than a fifth (20.7%) of the variability in impairment of self-esteem, whereas the contribution of the importance of sexuality was small (4.8%).

Moderation analysis

Moderation analysis revealed that the importance of sexuality moderated effects of changes in erectile



functioning on impairment of self-esteem (Table 3). Simple slope analyses showed that for both individuals with higher ($B = .93, t = 10.43, p < .001$) and lower importance of sexuality ($B = .40, t = 4.78, p < .001$) changes in sexual functioning more strongly affect their self-esteem, however this effect was weakened with lower importance of sexuality (Fig. 1). We additionally tested the conditional effect of changes in erectile functioning on impairment of self-esteem if participants reported that sexuality was “not at all” important to them. Then the effect was not significant ($B = .11, t = .85, p = .4$), i.e. if sexuality is of no importance changes in erectile functioning and self-esteem are not associated.

Discussion

Our study aimed at evaluating the importance of sexuality and the relationship of erectile functioning and self-esteem among older men with localized PCa under different treatment strategies. We have identified three key findings: Firstly, age and, even more so, an invasive treatment for PCa are predictive of changes in erectile functioning. Secondly, even after adjustment for socio-demographic and clinical variables, changes in erectile functioning prove to be a strong predictor of self-esteem. Thirdly, the existing relationship between erectile functioning and self-esteem seems to be stronger in those men, for whom sexuality is more important.

Our finding that RP is associated with poorer erectile functioning is supported by findings of RCTs that provide evidence for the invasive procedure being a causal factor. [6, 30] In addition, the results of our study show that men after AS consider sexuality as being less important compared to men after RP. This finding may appear counterintuitive at first sight as one could assume that AS is predominantly chosen by those men who value sexuality as more important. However, due to the cross-sectional

design of our study we cannot identify the time at which sexuality became more important for RP patients. We suggest that the higher importance of sexuality for men after RP manifested after surgery: erectile dysfunction is a common side-effect of RP and men and their partners have to cope with this problem in the long-term. In this process, sexuality may become a present, yet sensitive topic in men’s everyday-life, which vice versa might change men’s attitude towards sexuality.

Erectile functioning is a strong predictor for self-esteem

Erectile functioning explains more than a fifth of the variance in self-esteem across both groups, after adjusting for sociodemographic variables, group assignment and the importance of sexuality. We challenged the common stereotype portraying older people as “asexual” by integrating the importance of sexuality in our study. [18] It is often assumed that older people may no longer consider sexuality an important aspect of their life and would, therefore, see a worsening of their sexual functioning as irrelevant. Our results contradict this stereotype: two thirds of the men, who were on average 70 years of age, rated sexuality as being “rather or very important”. However, even after adjusting for the importance of sexuality, there was a stable association between worsened sexual functioning and impaired self-esteem. This means that even men who consider sexuality as less important could experience an impairment of their self-esteem due to changes in erectile functioning. This finding corresponds with the results from a qualitative study by Gannon and colleagues, who supposed that the ability to perform penetrative sex may be essential for male identity, independent of a man’s actual sexual activity. [31] Only in the small group of men (7% of our sample), who reported that sexuality was of *no* importance to them, there was no association between erectile functioning and self-esteem.

Changes in erectile functioning may have different consequences for men with localized PCa

Our results show a strong association of erectile functioning and self-esteem for men with localized PCa. Moreover, altered erectile functioning and satisfaction with sexual life are negatively correlated in our sample. In a study with men from the general population Braun and colleagues demonstrated that only 14% of men aged 60 to 69 years report having ED and being dissatisfied with their sex life. [9] In our study, however, almost 40% of men who report at least some changes in erectile functioning state that they are “dissatisfied or very dissatisfied” with their sex life. Thus, the consequences of erectile dysfunction might be different for men with localized PCa compared to men without PCa. After the diagnosis, men might address actual or anticipated erectile dysfunction as a possible consequence of invasive PCa treatment. The intensive

preoccupation with implications of erectile dysfunction may thus strengthen the association of erectile functioning and self-esteem, whereas for men without PCa a decrease in erectile functioning may be a simple expression of a normal aging process.

Strengths and limitations

The strengths of this study are a high external validity by using a non-interventional, multicenter design, the length of the follow-up and the sample size which represents one of the largest samples for the comparison of RP and AS. Additionally, our study focuses on the psychosocial aspects of sexuality. While most studies addressing sexuality in men with localized PCa focus more on physiological aspects, we aimed to investigate the psychological aspects of an altered sexuality. We selected our items measuring men's sexual life accordingly. However, the study is subject to some limitations. (1) The cross-sectional and observational design does not allow for causal interpretations. For example, it remains speculative whether a change in erectile functioning for the worse leads to an impairment of self-esteem, or whether there are additional confounding variables. To deal with possible selection biases due to the non-randomization, we controlled for several sociodemographic and clinical variables, which did not explain a significant amount of variance. As opposed to a randomized study, strengths of our observational design are a high external validity and an exceptional participant rate. (2) Our data are based on the participants' self-reports of erectile functioning and we did not validate the latter by objective measures (e.g. medical records). However, the focus of the study was on men's subjective experience, which, particularly regarding sexuality, seems more important than objective parameters. [32] (3) Information on the psychometric properties of measurement of sexuality used in our study is still lacking. (4) Impairment of self-esteem was assessed in the context of erectile functioning. As 90% of our sample report having experienced at least some degree of changes in erectile functioning it seems reasonable to measure self-esteem in this way. However, the amount of variance in self-esteem explained by erectile functioning in our findings may be artificially inflated as a consequence. Thus, independent measures of (impaired) self-esteem should also be taken into account in future research. (5) We did not assess whether men with impaired sexual functioning made use of erection restoration treatments, which could have had an impact on our results. Therefore, this aspect should be included and analysed in future studies. Moreover, we are well aware that a differentiation between homosexual and heterosexual men's sexuality is desirable. The importance of sexuality and erectile functioning particularly when predicting self-esteem could differ among these subgroups. Therefore, our findings may not generalize regarding homosexual men. Finally, our sample

comprises a cohort that was operated in the years 2008 to 2013. Since then, great progress has been made in the field of nerve-sparing PCa surgery. Hence, compared to the present situation, the differences between AS and RP patients in this study may be more pronounced, and emphasis should be given to the relationship between erectile functioning, the importance of sexuality and self-esteem rather than to the absolute differences.

Implications

Our results have some implications for future research. Firstly, questionnaires on male sexuality in PCa patients to date, focus primarily on the function rather than psychological aspects of sexuality. An effort should be made to develop questionnaires that comply with a broader definition of sexuality as a holistic construct [15] and meet the particularities of older men or PCa patients. Widely accepted and validated questionnaires would also facilitate a comparison of results. Secondly, longitudinal studies in this field are desirable to gain a deeper insight into the interplay of age, sexuality, self-esteem and other psychosocial variables in men with PCa over time. As erectile functioning is only one facet of the sexual response cycle that can be affected by invasive PCa treatment more items assessing sexual functioning should be included. Similarly, self-esteem is only one example for the connection between sexual functioning and psychological well-being. Future research should take this into account.

Other implications refer to clinical practice. Previous studies have shown that psychosocial interventions providing information or emotional support can improve psychological outcomes in men with localized PCa. [33] However, men with localized PCa stated not being in need of psychosocial interventions in a qualitative study. [34] Thus, despite of being potentially beneficial for men with localized PCa the preliminary setting of psychosocial interventions may not meet men's needs. We therefore suggest low-threshold services to counsel men on PCa treatment, possible physiological side-effects and associated psychological consequences. This could be put into practice using online tools or by extending the role of the urologist: For men with localized PCa, the urologist is usually the first and probably the most important specialist contact person. With urologists not only giving medical but also psychological advice PCa patients would receive comprehensive consulting without having to make additional efforts. A specific clinical implication of our study concerning medical practice is to structure the doctor-patient conversation about sexuality. Many men still have difficulties discussing this topic with their physician. However, they feel their physician should address it on his or her own volition. The discussion about adverse effects of an invasive treatment should comprise the psychological impact of an

impairment of erectile functioning to reach a fully informed decision. Furthermore, the physician is crucial for rebutting stereotypes for men who experience an impairment of erectile functioning due to invasive treatment or age. The physician may discuss with the patient that the stereotype of older people being asexual, focusing mainly on the degree of erectile functioning, is based on a “too narrow definition of sexuality.” [18] Professionals could encourage their patients to maintain their sexual life and, when being sexually active, to use “what they have.” [15] Low-threshold services (e.g. online consulting tools) and interventions aiming to improve the communication of sensitive (psychological) topics should be conceptualized and tested in future research.

Conclusions

The effect of erectile dysfunction on men's self-esteem is a neglected topic in PCa research that deserves attention in both clinical practice and research. Changes in erectile functioning may become particularly important if they occur due to a PCa treatment. Our results emphasize the importance of sexuality for men with PCa. Therefore, medical advice on PCa treatment should encompass the strong association of erectile dysfunction and self-esteem in men with PCa. This topic should be addressed as a possible consequence of invasive treatment.

Abbreviations

AS: Active surveillance; E.g: Exempli gratia; I.e: Id est; PCa: Prostate cancer; RP: Radical prostatectomy

Acknowledgements

We thank the study participants who provided their time and showed great interest in this study. We would particularly like to thank Hans-Jörg Fiebrandt and the German Association of Prostate Cancer Self-Help for their encouragement. We would like to thank the Stiftung Männergesundheit Foundation for their cooperation.

Funding

This research was funded by the Stiftung Oskar-Helene-Heim Foundation. The funding source had no role in the design of the study, collection, analysis, and interpretation of data and in writing the manuscript. We acknowledge support from the German Research Foundation (DFG) and the Open Access Publication Fund of Charité – Universitätsmedizin Berlin.

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due participant anonymization but are available from the corresponding author on reasonable request.

Authors' contributions

FK and CH conceptualized the study and developed the research questions. FK and CH were also responsible for the acquisition of data. FK, SH, and CH analyzed and interpreted the data; AM, MS, SN, and TF also contributed to the interpretation of data. FK and CH drafted the article which was then revised by SH, SN, MS, AM, and TH. All authors read and approved the final manuscript.

Ethics approval and consent to participate

Ethics approval was obtained from the Charité – Universitätsmedizin Berlin (EA 1/242/13). All participants had given prior written consent to study participation and data publication.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Received: 1 June 2018 Accepted: 9 January 2019

Published online: 21 January 2019

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Study 3: Hilger C, Schostak M, Otto I, Kendel F (2021) Time pressure predicts decisional regret in men with localized prostate cancer: data from a longitudinal multicenter study. *World Journal of Urology*. 39(10): 3755–3761. DOI:10.1007/s00345-021-03727-0

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21	ADVANCES IN CHRONIC KIDNEY DISEASE	1,921	3.306	0.004040
22	Journal of Sexual Medicine	10,551	3.293	0.012440
23	PROSTATE	7,691	3.279	0.008060
24	WORLD JOURNAL OF UROLOGY	5,887	3.217	0.010120
25	AMERICAN JOURNAL OF PHYSIOLOGY-RENAL PHYSIOLOGY	16,035	3.144	0.017010
26	Kidney Diseases	367	3.111	0.001320
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28	UROLOGIC ONCOLOGY-SEMINARS AND ORIGINAL INVESTIGATIONS	5,614	2.882	0.012450
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31	PEDIATRIC NEPHROLOGY	9,325	2.676	0.009770
32	World Journal of Mens Health	541	2.547	0.001000
33	CURRENT OPINION IN NEPHROLOGY AND HYPERTENSION	3,281	2.539	0.004740
34	Urolithiasis	1,035	2.518	0.002550
35	ASIAN JOURNAL OF ANDROLOGY	4,065	2.448	0.005960
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38	JOURNAL OF ENDOUROLOGY	6,343	2.322	0.007030
39	Current Urology Reports	1,512	2.307	0.003250
40	SEMINARS IN DIALYSIS	2,585	2.164	0.003010
41	CURRENT OPINION IN UROLOGY	1,670	2.152	0.003010
42	BLOOD PURIFICATION	2,062	2.116	0.003080



Time pressure predicts decisional regret in men with localized prostate cancer: data from a longitudinal multicenter study

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Received: 2 March 2021 / Accepted: 4 May 2021
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Abstract

Purpose A substantial proportion of men with localized prostate cancer (IPCa) later regret their treatment decision. We aimed to identify factors contributing to decisional regret.

Methods We conducted a longitudinal study, in which men with IPCa were surveyed at four measurement points: T0 (baseline) = prior to treatment; T1 = 6; T2 = 12; T3 = 18 months after baseline. χ^2 -tests and independent *t*-tests were used to compare men undergoing different treatments [Active Surveillance (AS) vs. local treatment]. Logistic regression models were fitted to investigate the associations between predictors (*time pressure, information provided by the urologist, impairment of erectile functioning, satisfaction with sexual life*) and the criterion *decisional regret*.

Results At baseline, the sample included $N = 176$ men (AS: $n = 100$; local treatment: $n = 76$). At T2 and T3, men after local therapies reported higher regret than men under AS. Decisional regret at T3 was predicted by time pressure at baseline (OR 2.28; CI 1.04–4.99; $p < 0.05$), erectile dysfunction at T2 and T3 (OR 3.40; CI 1.56–7.42; $p < 0.01$), and satisfaction with sexual life at T1–T3 (OR 0.44; CI 0.20–0.96; $p < 0.05$).

Conclusions Time pressure, erectile dysfunction, and satisfaction with sexual life predict decisional regret in men with IPCa. Mitigating time pressure and realistic expectations concerning treatment side effects may help to prevent decisional regret in PCa survivors.

Trial registration number DRKS00009510; date of registration: 2015/10/28.

Keywords Decisional regret · Erectile functioning · Localized prostate cancer · Satisfaction with sexual life · Time pressure

Abbreviations

AS Active surveillance
E.g. Exempli gratia

I.e. Id est
IPCa Localized prostate cancer
PCa Prostate cancer
RP Radical prostatectomy
RT Radiation therapy

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Introduction

With a global incidence of about 1.3 million cases in 2018, prostate cancer (PCa) is the second most common cancer type in men [1]. More than half of the diagnosed prostate carcinomas are localized with a very good prognosis [2]. Various treatment strategies with curative intent are recommended for localized prostate cancer (IPCa) of low and intermediate risk: radical prostatectomy (RP), radiotherapy (RT) and active surveillance (AS). These strategies do not differ in mortality [3], but do differ significantly in side effects [4]. In RP (i.e. surgical removal of the prostate), common side effects are erectile dysfunction and incontinence.

Possible side effects of RT encompass erectile dysfunction, urinary and rectal problems. Over time, the side effects decrease, although baseline levels are often not attained [5]. In AS, local treatment is often delayed until a predefined level of disease progression occurs. In AS, psychological side effects, such as anxiety, may occur [4, 6].

Up to one-third of patients with PCa later regret their initial treatment decision [7, 8]. Several studies with PCa patients have shown that erectile dysfunction after treatment is predictive of later decisional regret [9, 10]. In these studies, erectile dysfunction was assessed with questionnaires focusing on physical sexual functioning (e.g. erection firmness). However, this functional aspect is only one facet of sexuality and does not necessarily reflect how satisfied men are with their sexuality. Although satisfaction with sexual life is likely to play a relevant role in subjective quality of life, research on this topic has been scarce. In addition, an informed treatment decision has been shown to be associated with less regret [11]. As the urologist is still the most important information source [12], the information provided by the urologist may be particularly important for decisional regret.

Informed decision-making that carefully weighs all pros and cons of a treatment strategy takes time [11, 13]. Experimental studies in other contexts have shown that time pressure is associated with less adherence to guidelines [14] and greater decisional regret [15]. Although IPCa often does not require immediate action, the word “cancer” alone may create a desire for rapid local treatment in many patients [16]. Given the resulting time pressure, it is a challenge to carefully discuss the respective side effects of all treatment options. This is volatile because many side effects can permanently affect quality of life.

Surprisingly, the impact of time pressure on decisional regret has not yet been studied in the context of PCa. In addition, most studies concentrated on functional aspects of sexuality. The present study aimed to analyze the association of psychological variables with decisional regret in men with IPCa. We assumed that higher time pressure, less information by the urologist, higher impairment of erectile functioning and lower satisfaction with sexual life were associated with higher levels of regret. As erectile functioning is more frequently impaired after local treatments for IPCa, we further assumed that men after local treatment experience more regret than men under AS.

Methods

Study design and participants

In this prospective, non-interventional, multicentre study (33 urology clinics and practices), men who were ≤ 80 -years old and diagnosed with low-/intermediate-risk PCa (TNM: $\leq T2a$;

PSA: ≤ 10 ng/ml; ISUP Grade ≤ 2) within the last six months were eligible to participate. Data were collected using self-report questionnaires at four measurement points: T0 (baseline) = prior to treatment initiation; T1 = six; T2 = twelve; T3 = 18 months after baseline. Follow-up questionnaires were mailed to participants. Clinical data at baseline (tumor category, ISUP Grade, PSA value, date of diagnosis, comorbidities) were provided by clinicians. Over the course of the study, no further clinical data were collected, such as how the AS strategy was implemented in detail (MRI, re-biopsies). All participants agreed in a written form to take part before enrollment. Ethical approval for this study was obtained from the Charité—Universitätsmedizin Berlin (EA1/242/13).

Materials and main outcome measures

Decisional regret was assessed at T1–T3 using the Decision Regret Scale [17]. A score ranging from 0 to 100 can be calculated with higher values indicating higher regret. There is no validated cutoff value for clinically relevant regret. Due to a right-skewed distribution, we dichotomized the score (0–5: no regret vs. ≥ 6 : at least some amount of regret) *Impairment of erectile functioning* was measured with one item adapted from Johannson et al. [18] and *satisfaction with sexual life* with one item adapted from van den Bergh et al. [19]. Perceived *time pressure* was assessed at baseline using a self-constructed scale consisting of four items (e.g. “When choosing my treatment strategy, I took as much time as I needed”). Subjective *information by the urologist* was captured with a self-constructed single item (“Do you feel that your urologist has provided you with sufficient information?”). For each variable, higher values indicate a higher level in the respective characteristic.

Statistical analysis

Men undergoing local treatment (RP, RT) were compared with men under AS regarding sociodemographic and clinical characteristics using χ^2 -tests and independent *t*-tests/Mann–Whitney *U* tests. To investigate changes in satisfaction with sexual life over time we conducted ANOVA with repeated measures. To analyze how impairment of erectile functioning and decisional regret develop over time, we computed *McNemar* tests. Logistic regression models were fitted to investigate the associations between predictor variables (*time pressure*, *information by the urologist*, *impairment of erectile functioning*, *satisfaction with sexual life*) and *decisional regret*. In a first step, control variables (age, partner status, ISUP Grade, TNM category) and in a second step, the respective predictor were entered into the model. Nominal and ordinal scaled variables were dichotomized. Control and predictor variables were pre-tested for

multicollinearity. All analyses were conducted with IBM SPSS Statistics (Version 25). An alpha level of $p < 0.05$ indicated statistical significance for all analyses.

Results

At baseline, the final sample comprised $N = 176$ men (AS: $n = 100$; local treatment: $n = 76$). Over time, 10.1% of participants dropped out (T1: $N = 167$; T2: $N = 164$; T3: $N = 160$; Figure A1). Sample characteristics and study variables over time are depicted in Table 1. Treatment groups did not differ regarding sociodemographic characteristics and clinical variables, except for ISUP Grade ($p < 0.001$, *Cramér's V* = 0.42).

At T0, men under AS did not differ from men undergoing local treatment in erectile functioning ($p = 0.96$). After local treatment, however, men reported higher impairment compared to men undergoing AS (Table 1). Subgroup analyses showed that men after RP reported the strongest impairment compared to RT and AS (Table A2). Impairment of erectile functioning was lower at T0 compared to all follow-up time points ($p < 0.001$). Impairment of erectile functioning at 18 months was higher compared with T1 ($p = 0.001$) and T2 ($p = 0.04$).

Before treatment (T0) and 18 months later (T3) the two treatment groups did not differ in satisfaction with sexual life. At T1 ($p = 0.01$) and T2 ($p = 0.02$), however, men under local treatment were less satisfied than men under AS (Table 1). Men after RP reported being least satisfied at these measurement times compared with men under AS and RT (Table A2). Satisfaction varied over time ($p < 0.001$, $f = 0.28$): men reported higher satisfaction at baseline compared to all follow-up measurements ($p = 0.001$ – 0.005).

Almost half of participants (40.3–47.7%) reported at least some amount of decisional regret (Table 1). At T2 and T3, men after local therapies reported higher decisional regret than men under AS (Table 1). Men after RP regretted their treatment decision more than men under AS (Table A2).

After controlling for sociodemographic and clinical parameters, time pressure at T0 predicted decisional regret at T3 ($p = 0.039$), a trend was found for T2 ($p = 0.06$). Information by the urologist at T0 did not predict regret. Impairment of erectile functioning at T2 ($p = 0.036$) and T3 ($p = 0.002$) predicted regret at T3. All associations between satisfaction with sexual life and regret were significant, except for satisfaction at T1 predicting regret at T2 (Table A1).

Discussion

The aim of our study was to identify factors explaining decisional regret in men with IPCa. To our knowledge, this is the first study highlighting the role of time pressure in this

context. Our key finding is that time pressure at the time of diagnosis, in addition to impairment of erectile functioning and satisfaction with sexual life, is predictive of later decisional regret. Comparing the three treatment strategies RP, RT, and AS, we found that decisional regret was most pronounced in men after RP.

Our results show that almost half of men with IPCa subsequently regret their treatment decision at least to some amount. This is a higher proportion than in previous studies with between four [7] and 31% [8] of men reporting decisional regret. These large differences could be due to different cut-offs on the Decision Regret Scale. There is no consensus yet which cut-off value for the Decision Regret Scale [17], which ranges from 0 to 100, is considered clinically relevant. While van Stam et al. [20] set a cut-off value at 30, Wilding et al. [9] recommend a more refined classification, distinguishing between milder and stronger regret. In their study, two thirds of men reported at least a mild expression of decisional regret. We also chose a conservative cut-off that includes mild levels of regret. This approach takes into account that many men have difficulties expressing their feelings openly [21]. Another reason for lower levels of regret found in previous studies could be men with IPCa focusing on the benefits of treatment: when weighing the assumed benefit (tumor removal) against the harm (impairment of erectile functioning), the side effects might tend to take a back seat [22]. This effect could be even more pronounced for self-paying patients.

“[I have] decided too quickly” (RP, T3)

Time pressure is omnipresent in clinical practice. Nevertheless, this issue has not gained much attention in research yet. We showed that time pressure shortly after diagnosis predicted longer-term, but not short-term decisional regret. As mentioned above, side effects of treatment may be initially seen as a temporary problem that may still change. If there is no improvement in the long term, however, this could lead to regretting a decision having been made under time pressure. Another reason is that despite the good prognosis of IPCa, the word “cancer” is still often perceived as a “death sentence” [23]. This perception may increase anxiety and the desire for a rapid local approach. Defined time limits for treatment decision and initiation could amplify time pressure. However, for low/intermediate risk tumors, an oncological deterioration within three to six months after diagnosis is not very likely [24, 25]. Many men may not be aware of this. Experienced urologists therefore emphasize that men with IPCa have time to carefully weigh the pros and cons of each strategy. Nevertheless, individual patient factors (e.g. micturition at diagnosis, inconsistent diagnostic findings of biopsy and MRI) should be taken into account, potentially limiting this time frame. More precise diagnostic procedures

Table 1 Sample characteristics at baseline (T0) and study variables according to treatment group over time (T0–T3)

	Total (n = 176)	AS (n = 100)	Local (n = 76)	p
Sociodemographic data				
Age, years, <i>M</i> (SD)	65.5 (7.4)	66.2 (7.0)	65.0 (7.7)	0.13
Living with partner, <i>n</i> (%)	154 (88.0)	90 (90.9)	64 (84.2)	0.18
Higher education, <i>n</i> (%)	93 (53.8)	56 (56.6)	37 (50.0)	0.39
Still working vs. retired, <i>n</i> (%)	58 (33.1)	29 (29.3)	29 (38.2)	0.22
Time since treatment decision (weeks), <i>M</i> (SD)	9.0 (8.6)	9.1 (8.9)	9.0 (8.3)	0.96
Risk classification				
ISUP Grade (low = 1), <i>n</i> (%)	135 (77.1)	91 (91.0)	44 (58.7)	<0.001
PSA, <i>M</i> (SD)	5.9 (2.6)	5.9 (2.3)	5.9 (3.0)	0.95
TNM, (T1a–c), <i>n</i> (%)	163 (93.1)	94 (94.0)	69 (92.0)	0.60
Number of comorbidities, <i>M</i> (SD)	0.3 (0.9)	0.2 (0.5)	0.4 (1.2)	0.26
Time pressure, <i>M</i> (SD)	2.0 (0.6)	1.9 (0.5)	2.0 (0.6)	0.08
Moderate to high, <i>n</i> (%)	48 (31.4)	22 (25.6)	26 (38.8)	
Information provided by urologist, <i>Mdn</i> (IQR)	4 (1)	4 (1)	4 (1)	0.20
Rather to completely sufficient, <i>n</i> (%)	161 (91.5)	90 (90)	71 (93.4)	
Impairment of erectile functioning				
T0				
<i>Mdn</i> (IQR)	2 (1)	2 (1)	2 (2)	0.96
Moderate to severe, <i>n</i> (%)	39 (23.6)	22 (22.7)	17 (25)	
T1				
<i>Mdn</i> (IQR)	2 (2)	2 (2)	3 (2)	<0.001
Moderate to severe, <i>n</i> (%)	78 (47.9)	21 (26.3)	57 (68.7)	
T2				
<i>Mdn</i> (IQR)	3 (2)	2 (2)	3 (2)	<0.001
Moderate to severe, <i>n</i> (%)	83 (52.2)	20 (30.8)	63 (67.0)	
T3				
<i>Mdn</i> (IQR)	3 (2)	2 (1)	3 (2)	<0.001
Moderate to severe, <i>n</i> (%)	96 (60.8)	25 (43.1)	71 (71.0)	
Satisfaction with sexual life				
T0				
<i>Mdn</i> (IQR)	4 (1)	3 (1)	4 (1)	0.69
Moderate to high, <i>n</i> (%)	137 (80.1)	81 (81.8)	56 (77.8)	
T1				
<i>Mdn</i> (IQR)	3 (2)	3 (2)	3 (2)	0.01
Moderate to high, <i>n</i> (%)	104 (63.0)	58 (71.6)	46 (54.8)	
T2				
<i>Mdn</i> (IQR)	3 (2)	4 (2)	3 (2)	0.02
Moderate to high, <i>n</i> (%)	104 (65.4)	48 (72.7)	56 (60.2)	
T3				
<i>Mdn</i> (IQR)	3 (2)	3 (2)	3 (2)	0.91
Moderate to high, <i>n</i> (%)	96 (62.3)	38 (66.7)	58 (59.8)	
Decisional regret (0–100)				
T1				
<i>M</i> (SD)	12.5 (17.5)	9.0 (12.2)	14.1 (19.4)	0.27
Mild to severe, <i>n</i> (%)	51 (47.7)	14 (41.2)	37 (50.7)	
T2				
<i>M</i> (SD)	9.6 (14.4)	5.6 (11.5)	11.6 (15.3)	0.001
Mild to severe, <i>n</i> (%)	52 (40.3)	10 (23.8)	42 (48.3)	
T3				
<i>M</i> (SD)	11.7 (14.0)	8.3 (11.9)	13.5 (14.7)	0.03
Mild to severe, <i>n</i> (%)	62 (47.0)	15 (31.9)	47 (55.3)	

T0: *N* = 176, AS, *n* = 100, local, *n* = 76; T1: *N* = 167, AS, *n* = 81, local, *n* = 86; T2: *N* = 164, AS, *n* = 68, local, *n* = 96; T3: *N* = 160, AS, *n* = 58, local, *n* = 102; Time pressure, range: 1–4; Information provided by urologist, range: 1–4; Impairment of erectile functioning, range: 1–4; Satisfaction with sexual life, range: 1–5; Decisional regret, range: 0–100

AS surveillance, RP radical prostatectomy, RT radiation therapy, *M* arithmetic mean, *SD* standard deviation, *Mdn* median, *IQR* interquartile range

(such as MRI-assisted biopsy) will provide patients with more certainty in future.

“If I had known how this would affect me after surgery, I would have decided against therapy” (RP, T3)

Our finding, that erectile functioning predicts regret in the longer term, is consistent with other studies [9, 11, 13]. Speer et al. [23] showed that in the face of diagnostic shock, “hard outcomes” like survival and cancer eradication have the highest priority. Sexuality, as one aspect of quality of life, may often be of secondary importance in this phase, but regains importance over time. In addition, the relevance of sexuality is often overlooked because erectile dysfunction becomes more likely with age: in the general population more than 40% of men over 76 years report limitations in this regard [26]. However, since treatment groups did not differ at baseline, our findings show that a substantial proportion of the deterioration in erectile functioning is attributable to local treatment.

Satisfaction with sexual life, which captures psychological aspects of sexuality [27], is an important predictor for decisional regret. Sexual satisfaction may be more modifiable than erectile dysfunction and could thus be a starting point for interventions that aim at reducing regret. Our findings align with those of other studies [27, 28] highlighting the importance of satisfaction with sexual life as a patient-centered outcome for quality of life in cancer survivors. In future, patient-reported experience measures (PREMs), like satisfaction with sexual life, will become increasingly important. Interestingly, the satisfaction of men under AS decreased in the longer-term and approached the levels of men with RP/RT. The strain of living with a persistent cancer disease, affecting different areas of life, could add to this decrease.

“Not enough information [was provided about] sparing methods” (RP, T2)

It has been well-documented that an informed decision can contribute to preventing decisional regret [e.g. 11]. In our study, however, the information by the urologist played a minor role. A possible reason for this may be a ceiling effect, since the large majority of men in our sample felt adequately informed by their urologist. Another explanation could be that the item we used rather reflects the trust in the urologist than the information itself. Objective measures (e.g. knowledge questions) could be helpful to assess how the amount and quality of medical information correspond to decisional regret. Furthermore, the grade of interdisciplinarity could

depict the consultation quality. Finally, there are currently mixed findings on whether online tools can support informed decision-making and prevent regret [e.g. 29]. Further studies are needed to clarify these questions.

Strengths and limitations

Strengths of the present study are one of the largest samples of AS patients with a longitudinal design and the low drop-out rate. Furthermore, we analyzed treatment received at every measuring point instead of using intention-to-treat analyses. This approach provides a realistic representation of different treatments and their respective side effects. There are also some limitations: (1) As this is an observational study, no causal conclusions can be drawn. However, since clinical experience shows that men have strong preferences for a particular treatment, it can be assumed that the high external validity of our study design outweighs the advantages of randomized assignment. (2) We cannot completely rule out the possibility of sampling effects, for example that men who are satisfied with their treatment could be more likely to participate. This could contribute to underestimating actual levels of decisional regret. (3) Since the sub-sample of men with RT is relatively small, the findings for this population should be interpreted with caution. However, the results offer valuable insights that can be used to generate hypotheses. Future studies should also be powered to differentiate different methods of RT. (4) We cannot generalize our results for men under focal therapies. A study by Westhoff and colleagues [30] identified a number of initial factors associated with regret in this patient population. Future studies should analyze the associations between regret, time pressure, and satisfaction with sexual life in men undergoing focal therapies. (5) We are aware that other treatment side-effects, such as urinary incontinence, are also predictive of decisional regret [9, 30]. However, since we focused on different aspects of sexuality, other side-effects were outside the scope of this paper. (6) We also did not assess why patients chose or changed to a particular treatment. This should be subject to future studies.

Implications

The effects of time pressure have been neglected in cancer research so far. A first step would be the development of a standardized measurement instrument for assessing time pressure. Furthermore, standardized cut-off values for decisional regret are needed to facilitate interpretation of results.

Especially considering the good prognosis of IPCa and similar mortality rates between treatments [3], educating

patients about side effects and sexuality in particular is key. However, the patient may have difficulties bringing up the subject of sexuality. Doctors may assume the patient has no need. The resulting collusion can be overcome through a routine of open questions. To alleviate time pressure, doctors can encourage patients to take enough time for treatment decision-making. In addition, a culture of shared decision making may contribute to reducing regret.

Conclusions

Our study adds to the understanding of decisional regret in men with IPCa. While time pressure and impairment of erectile function increased the probability of regret in the longer-term, satisfaction with sexual life decreased the probability of regret in the short- and long-term. Enough time in the decision-making process and realistic expectations regarding treatment side effects may help to prevent regret.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00345-021-03727-0>.

Acknowledgements We thank Else Kröner-Fresenius-Stiftung for funding our study. We thank the study participants who provided their time and showed great interest in this study. Our thanks to all participating study centers who supported the recruitment. We particularly thank Hans-Jörg Fiebrandt and the German Association of Prostate Cancer Self-Help for their encouragement. Our thanks to Jamie Smith, who proofread the article and improved it with his comments.

Author contributions FK, IO, MS and CH contributed to the study conception and design. Material preparation and data collection were performed by FK, IO and CH. The analyses were performed by CH. The first draft of the manuscript was written by CH, supervised by FK. FK, IO, and MS commented on previous versions of the manuscript, CH incorporated the comments. All authors read and approved the final manuscript.

Funding We acknowledge support from the Open Access funding provided by Charité - Universitätsmedizin Berlin enabled and organized by Projekt DEAL. This study was funded by the Else Kröner-Fresenius-Stiftung (Grant no. 2013_A282). The funding source had no role in the design of the study, collection, analysis, and interpretation of data and in writing the manuscript.

Availability of data and materials The datasets generated during and/or analyzed during the current study are not publicly available due to participant anonymization but are available from the corresponding author on reasonable request.

Code availability IBM SPSS Statistics—Version 25.

Declarations

Conflict of interest The authors have no conflicts of interest to declare that are relevant to the content of this article.

Ethical approval This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of Charité—Universitätsmedizin Berlin (EA1/242/13).

Consent to participate Written informed consent was obtained from all individual participants included in the study.

Consent for publication Participants signed informed consent regarding publishing their data.

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Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Study 4: Otto I, Hilger C, Magheli A, Stadler G, Kendel F (2021) Illness representations, coping and anxiety among men with localized prostate cancer over an 18-months period: A parallel vs. level-contrast mediation approach. *Psycho-Oncology*. DOI:10.1002/pon.5798

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4	Annual Review of Clinical Psychology	6,126	13.692	0.009570
5	JOURNAL OF CHILD PSYCHOLOGY AND PSYCHIATRY	19,837	7.035	0.021080
6	PSYCHOLOGICAL REVIEW	29,567	6.857	0.009080
7	PSYCHOLOGICAL MEDICINE	26,702	5.813	0.039350
8	DEPRESSION AND ANXIETY	9,355	4.702	0.013860
9	JOURNAL OF MEMORY AND LANGUAGE	9,767	3.893	0.007610
10	PSYCHOSOMATIC MEDICINE	12,560	3.702	0.009890
11	PSYCHOPHYSIOLOGY	14,586	3.692	0.012670
12	INTERNATIONAL JOURNAL OF EATING DISORDERS	9,613	3.668	0.010750
13	Social Cognitive and Affective Neuroscience	7,347	3.571	0.019570
14	JOURNALS OF GERONTOLOGY SERIES B- PSYCHOLOGICAL SCIENCES AND SOCIAL SCIENCES	9,435	3.502	0.009930
15	HUMAN FACTORS	6,763	3.165	0.005330
16	HEALTH PSYCHOLOGY	11,888	3.056	0.015480
17	COGNITIVE PSYCHOLOGY	7,784	3.029	0.004590
18	PSYCHO-ONCOLOGY	11,286	3.006	0.016340
19	INTERNATIONAL PSYCHOGERIATRICS	7,341	2.940	0.009920

Illness representations, coping and anxiety among men with localized prostate cancer over an 18-months period: A parallel vs. level-contrast mediation approach

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Funding information

Else Kröner-Fresenius-Stiftung, Grant/Award Number: 2013_A282

Abstract

Objective: Men diagnosed with localized prostate cancer (IPCa) are confronted with the decision for a treatment strategy, potentially experiencing treatment side effects and psychological distress. The Common Sense Model proposes that coping with such challenges is related to illness representations: Beliefs regarding consequences, coherence, timeline, and controllability of the illness. We analyzed the interplay of illness representations, coping and anxiety over an 18-month period among men with IPCa undergoing different treatment options (Active Surveillance, curative treatment).

Methods: In this longitudinal study, 183 men (age $M = 66.83$) answered a questionnaire before starting treatment, and 6, 12, and 18 months later. We analyzed time trajectories with growth curve modeling and conducted mediation analyses to evaluate the influence of coping on the association of illness representations and anxiety. Using a novel methodological approach, we compared a classic parallel mediation model with a level-contrast approach for the correlated mediators problem- and emotion-focused coping.

Results: Independent of treatment ($b = 1.31, p = 0.200$) men reported an elevated level of anxiety after diagnosis which declined considerably within the following 6 months ($b = -1.87, p = 0.009$). The perceived seriousness of consequences was significantly associated with greater anxiety, at baseline ($\beta = 0.471$) and over time (all $\beta \geq 0.204$). This association was mediated by coping: Using more emotion-than problem-focused coping was associated with higher anxiety.

Conclusions: Receiving a IPCa diagnosis is associated with a phase of increased anxiety. In order to reduce anxiety, information provision should be accompanied by developing concrete action plans to enable problem-focused coping strategies.

Gertraud Stadler and Friederike Kendel should be considered joint senior authors.

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KEYWORDS

active surveillance, anxiety, common sense model, consequences, coping, curative treatment, illness representations, mediation, oncology, prostate cancer

1 | BACKGROUND

Prostate cancer is the second most common cancer among men, accounting for 13.5% of all cancer diagnoses worldwide.¹ Over the past decades, this number has continuously increased, as a result of an aging population and amplified early detection using prostate-specific antigen (PSA) testing. PSA testing has led to the diagnosis of more early-stage, localized prostate cancer (IPCa). IPCa is characterized by a good prognosis with more than 95 out of every 100 men surviving more than 10 years.² The European Association of Urology Guideline³ recommends three treatment strategies for patients with IPCa, including two curative therapies, Radical Prostatectomy (RP) and Radiotherapy (RT), and one observational strategy, Active Surveillance (AS). AS is a treatment option in which definite therapy is only conducted following defined disease progression, which occurs in about one in three patients. The question of the best treatment strategy has been the subject of much controversy in recent years.⁴ Because RP, RT, and AS do not differ in mortality,^{5,6} interest has increasingly shifted to different aspects of health related quality of life. While after curative treatments physical side effects, such as erectile dysfunction, urinary incontinence, and bowel problems, are frequently observed,^{7,8} psychological side effects may be more common under AS due to uncertainty regarding possible disease progression.

Receiving a cancer diagnosis is accompanied by anxiety^{9–11} and psychological consequences can persist for years.^{12,13} The ProtecT study,¹⁴ a RCT with about 1500 men, as well as the PRIAS study,¹⁵ found no significant long-term differences in anxiety levels between men under AS and men after curative treatments, whereas in other studies curative treatment was associated with poorer psychological trajectories.¹⁶ Most studies report that anxiety decreases over time, consistent with an initial elevation effect.¹⁷ Nevertheless, ProtecT and PRIAS showed that 15.2% and 13% of men reported clinically relevant anxiety levels up to 6 and 7 years post-diagnosis, respectively.

However, why do some cancer patients have clinically relevant anxiety levels years after diagnosis, while others report elevated anxiety only around the time of diagnosis? The Common Sense Model of Self-Regulation (CSM) by Leventhal et al.¹⁸ offers an explanation for the variation in patients' perception of and response to illnesses. It proposes that individuals develop cognitive representations of their disease, divided into six dimensions: *identity* (symptoms), *cause*, *timeline* (duration & chronicity), *consequences*, *personal control*, and *treatment control*.

Several meta-analyses and systematic reviews elucidate the relationship of illness representations and psychological outcomes.^{19–22} The more *consequences* patients assume, the higher their anxiety levels are,²¹ the more distress they report, and the lower their well-being is.¹⁹ By contrast, assuming a greater sense of *control*

over the illness, is accompanied by less anxiety,²¹ less distress and better well-being.¹⁹

Illness representations motivate self-regulation processes to cope with the threat of an illness.¹⁸ Whereas the CSM does not distinguish between specific coping strategies, the Transactional Model of Stress and Coping by Lazarus et al.²³ differentiates problem- and emotion-focused coping. Problem-focused coping strategies center on changing the stressful situation itself, while emotion-focused strategies focus on regulating the negative emotional state accompanying the situation. So far, research¹⁹ has confirmed that a higher sense of *control* over the illness is associated with more problem-focused coping, while assuming greater *consequences* is associated with both emotion- and problem-focused coping. Furthermore, emotion-focused coping is associated with elevated distress levels whereas problem-focused coping is associated with lowered distress levels.

To our knowledge, no longitudinal study to date has examined the relationships between illness representations, coping strategies, and anxiety in men with IPCa. The little PCa-specific evidence^{24,25} on the CSM is in line with the described above meta-analyses.

This article has two aims: First, we examine anxiety levels of men with IPCa under different treatment strategies. Applying the framework of the CSM we explore how illness representations, coping strategies, and anxiety associate and develop over time. In particular, we hypothesize that (1) anxiety is elevated at baseline and declines over time, that (2) the illness representation *consequences* is positively associated with anxiety, whereas *personal control* is negatively associated with anxiety, and that (3) the association of illness representations and anxiety is mediated by coping. The second aim is to introduce a new methodological approach: In addition to classic parallel mediation models in which each mediator represents one coping strategy (Model 1a, 1b, 1c), we explore with a level-contrast approach whether the mean level and predominance of one coping strategy over the other has an influence on anxiety (Models 2a, 2b, 2c) (Figure 1).

2 | MATERIALS AND METHODS

2.1 | Design and participants

We adopted a longitudinal design including patients across 33 centers from October 2015 to June 2017.⁴¹ At four measurement points (T0 = baseline; T1 = 6 months; T2 = 12 months; T3 = 18 months) participants filled out paper & pencil questionnaires. Clinical information was obtained through physicians at baseline. Inclusion criteria follow the German Association of Urology²⁶: 0–12 months after diagnosis, age <80 years, diagnosis of low/early intermediate risk (tumor category: ≤T2a; PSA value: ≤10 ng/ml; Gleason Score ≤ 7a).

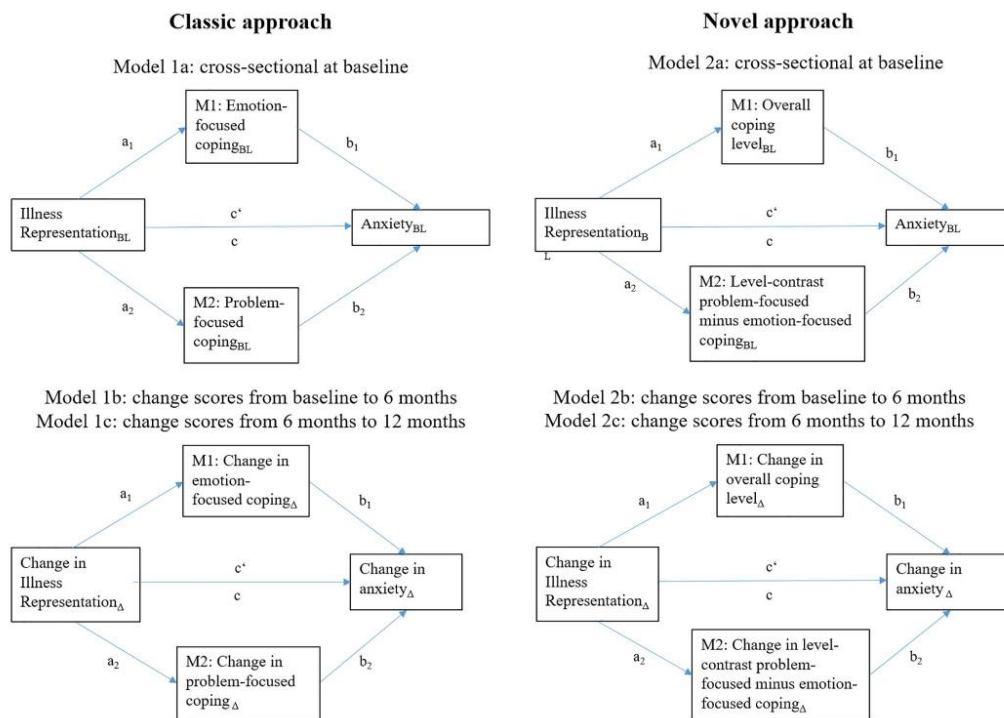


FIGURE 1 Hypothesized mediation models (a , b , and c' = standardized regression coefficients): indirect effect = $a*b$; direct effect = c' ; total effect c = sum of indirect and direct effect = $a*b + c'$. Models 1a and 2a include baseline scores. Models 1b and 2b include change scores from baseline to 6 months and models 1c and 2c include change scores from 6 to 12 months. Models differ in their mediators: model 1 includes both coping strategies, each as one mediator (problem- & emotion-focused), and model 2 includes one overall coping level mediator and one mediator representing a level-contrast of problem-minus emotion-focused coping

The first questionnaire had to be answered before treatment initiation. All patients provided written informed consent. The local ethical review board at the Charité - Universitätsmedizin Berlin approved the study (number: EA1/003/14).

2.2 | Measures

Illness representations were measured using the Brief Illness Perception Questionnaire (B-IPQ) with PCa specific adaptations.²⁷ Since men with IPCa usually do not experience symptoms until treatment, the dimension *identity* was omitted. We further excluded the emotional illness representations dimensions *concern* and *emotion* to avoid an overlap with the outcome anxiety. Results regarding *causes* are not reported as they are outside the scope of this paper. Each illness representation was assessed by one item, for example, *consequences*: "How much does prostate cancer affect your life?". The B-IPQ has shown good psychometric properties in previous studies.²¹

Coping was assessed via the Brief COPE.^{28,29} Previous meta-analyses^{19,30} on the CSM as well as our own preliminary study³¹ guided us in the selection of coping strategies: distraction coping, active coping, and planning, assessed with two items each. The coping dimensions were significantly correlated at all measurement points (all $r \geq 0.36$). A Principal Component Analysis revealed two factors which we used in further analyses, (a) problem-focused coping based on active coping and planning, and (b) emotion-focused coping based on distraction (Supplement 1). Internal consistencies for baseline and change scores at follow-ups was acceptable to good (emotion-focused: baseline = 0.86, T1 α = 0.71, T2 α = 0.73, problem-focused: baseline α = 0.83, T1 α = 0.79, T2 α = 0.81).

The Memorial Anxiety Scale for Prostate Cancer (MAX-PC),³² including 18 items, was used to assess prostate cancer specific anxiety. A cumulative anxiety score can be calculated (with a cut-off for clinically relevant anxiety ≥ 27 points) (Supplement 5).³³ Internal consistency at baseline was good (α = 0.94), as well as for change scores at follow-ups (T1 α = 0.83, T2 α = 0.80, T3 α = 0.77).

2.3 | Data analysis

Differences in sociodemographic characteristics between treatment groups were tested with *t*-tests for continuous variables or χ^2 tests for categorical data. To analyze the relationship between illness representations as predictor variables and anxiety as outcome variables, we conducted regression analyses.

A detailed description of the statistical methods to assess change over time and mediation models is provided in Supplement 2. Due to nonlinear changes over time, we added a dummy coded variable which modeled the initial elevation to the linear time slope.¹⁷ The resulting growth curve model with two time variables (initial elevation and linear slope) assessed change over time in anxiety, illness representations, and coping. Since 37 men changed treatments over the course of the study, treatment was included as a time varying covariate. With an interaction term, treatment by time, we examined the difference in trajectories between treatment groups. Growth curve modeling was conducted with restricted maximum likelihood estimation using IBM SPSS Statistics, Version 27 (IBM Corporation, 2020).

We compared two mediation models each at baseline (Model 1a and 2a) and four subsequent change scores (Model 1b and 2b: 6 months minus baseline; Model 1c and 2c: 12 minus 6 months). To test Mediation Model 1a, 1b, and 1c, we conducted classic parallel mediation analyses (problem- and emotion-focused coping). As problem- and emotion-focused coping were highly correlated ($r = 0.44$ at baseline, $T1 r = 0.57$, $T2 r = 0.67$), we adapted a novel level-contrast approach as suggested by Iida et al.³⁴: In Mediation Model 2a, 2b, and 2c, we included the overall coping level (i.e., the mean of all coping variables) and the contrast (i.e., the difference of problem-focused minus emotion-focused coping). For all models we followed recommendations by Hayes.³⁵

3 | RESULTS

Of 229 invited men, 183 met the inclusion criteria and agreed to participate in the study. Over time, 9.29% of the participants dropped out (study flowchart in Supplement 3). In terms of sociodemographic and clinical parameters, men under curative treatments differed from men under AS only with regard to Gleason Score (indicating tumor aggressiveness); a higher Gleason Score was associated with curative treatments (Table 1).

Participants reported a moderate level of anxiety at baseline ($M = 16.30$; Table 1). In line with Hypothesis 1, participants showed higher anxiety at baseline and lower levels of anxiety in subsequent measurement points. Men under AS showed initially elevated anxiety at baseline and then significantly lower anxiety at 6 months ($b = 15.82$ and $b = -1.87$, $p < 0.05$) and maintained the same lower level from 6 to 18 months ($b = 0.162$, ns). Men with curative treatments did not significantly differ from men under AS at baseline ($b = 1.31$, ns) and showed an additional decrease from 6 to 18 months ($b = -1.25$, $p < 0.05$; Figure 2, Supplements 4 and 5).

Men with curative treatments reported significantly more emotion-focused coping as well as problem-focused coping at baseline than men under AS ($b = 0.482$ and $b = 0.325$, $p < 0.01$). Over time, coping did not significantly change and treatment did not interact with coping strategies (Supplement 4).

Regarding illness representations, men with curative treatments expected a significantly shorter duration of their illness (*timeline*) ($b = -2.27$, $p < 0.01$) and expected more *consequences* ($b = 0.606$, $p < 0.05$) at baseline than men under AS. With respect to *treatment control*, *personal control* and *coherence* no significant differences between treatment groups occurred. Illness representations did not change significantly over time and no interaction effects of treatment*time were found (Supplement 4).

A series of regression analyses revealed that *consequences* was significantly associated with anxiety at baseline and at follow-ups with change scores (from $\beta = 0.204$ to $\beta = 0.471$, see c paths in Table 2). The other illness representations were not consistently associated with anxiety (Supplement 6). Therefore, in the following mediation analyses we focused on the link between *consequences* and anxiety. We can partly confirm hypothesis 2 for *consequences*, but not for *personal control*.

Parallel mediation models (1a, 1b, 1c, Figure 1) with *consequences* as predictor, problem-focused and emotion-focused coping as parallel mediators, and anxiety as outcome were calculated (Table 2). Mediation Model 1a revealed that the association of *consequences* and anxiety was mediated by emotion- as well as problem-focused coping. Mediation Models 1b (change scores: 6 months minus baseline) and 1c (12 minus 6 months) showed that the associations of change in *consequences* and change in anxiety were not mediated by change in coping.

3.1 | A novel methodological approach to the consequences–anxiety association

Because the two coping strategies were significantly correlated at all measurement points (all $r \geq 0.44$), we reevaluated the mediation models using a novel methodological approach (Models 2a, 2b, 2c) (Table 2). Instead of including both coping strategies individually, we included the overall coping level as Mediator 1 and a level-contrast of problem-minus emotion-focused coping as Mediator 2. At baseline, the association of *consequences* and anxiety was mediated by both mediators, showing that overall coping level was associated with higher anxiety while the contrast between problem-focused and emotion-focused coping was associated with lower levels of anxiety. In Model 2b (6 months minus baseline), the association between *consequences* and anxiety was not mediated by either coping mediator. In Model 2c (12 minus 6 months), the association of *consequences* and anxiety was mediated by the overall coping level but not the contrast between problem- and emotion-focused coping. The comparison of Model 1a and 2a indicates that the contrast between problem- and emotion-focused coping

TABLE 1 Sociodemographic data at baseline

	Range	Total N = 183	AS n = 100	Curative treatment n = 83
Age Mean (SD)		65.8 (7.4)	66.7 (7.0)	64.8 (7.7)
Family status n (%)				
Living with partner		159 (87.4)	89 (88.9)	70 (86.7)
Occupation n (%)				
Retired		120 (65.9)	70 (70.7)	50 (60.3)
Working		58 (31.9)	28 (28.3)	30 (36.1)
Unemployed		4 (2.2)	1 (1.0)	3 (3.6)
School education n (%)				
Low		84 (46.7)	43 (43.4)	41 (50.6)
Clinical parameters				
PSA-value at baseline Mean (SD)		5.9 (2.6)	5.9 (2.3)	5.8 (3.0)
Tumor stadium at baseline n (%)				
T1a–T1c		170 (93.4)	93 (93.9)	77 (92.8)
T2a		12 (6.6)	6 (6.1)	6 (7.2)
Gleason score n (%)				
≤6		138 (75.8)	91 (91.9)	47 (56.6)
7a (3 + 4)		44 (24.2)	8 (8.1)	36 (43.4)
Charleston Comorbidity Index n (%)				
0		138 (78.4)	78 (81.3)	60 (75.0)
≥1		38 (21.6)	18 (18.7)	20 (25.0)
Time since diagnosis in weeks Mean (SD)		9.4 (9.1)	9.0 (8.9)	9.9 (9.4)
Central study variables				
Illness representations Mean (SD)				
Timeline	0–10	6.4 (3.2)	7.7 (2.6)	4.8 (3.0)
Consequences	0–10	3.3 (2.7)	3.0 (2.7)	3.7 (2.6)
Personal control	0–10	4.0 (2.9)	4.1 (3.0)	3.9 (2.9)
Treatment control	0–10	7.8 (1.9)	7.9 (1.9)	7.8 (2.0)
Coherence	0–10	7.4 (2.2)	7.3 (2.1)	7.5 (2.3)
Coping Mean (SD)				
Emotion-focused	1–4	2.1 (0.9)	1.8 (0.8)	2.3 (1.0)
Problem-focused	1–4	2.4 (0.9)	2.2 (0.8)	2.5 (0.9)
Anxiety Mean (SD)	0–54	16.3 (11.2)	15.7 (10.2)	17.0 (12.3)
Clinically relevant anxiety n (%)		29 (16.8)	14 (15.1)	15 (18.8)

Abbreviations: AS, active surveillance; M, mean; PSA, prostate specific antigen; SD, Standard deviation.

matters: Men reported higher anxiety levels when they coped more emotion-than problem-focused compared to men with a balanced use of both coping strategies or a predominant use of problem-focused coping. Thus, the findings partly support Hypothesis 3 that coping mediates the association of illness representations and anxiety.

4 | DISCUSSION

Across all treatment groups men experienced a phase of elevated anxiety immediately after diagnosis, which considerably declined in the following six months. The initial higher anxiety levels were still within a subclinical range for most men. This is consistent with

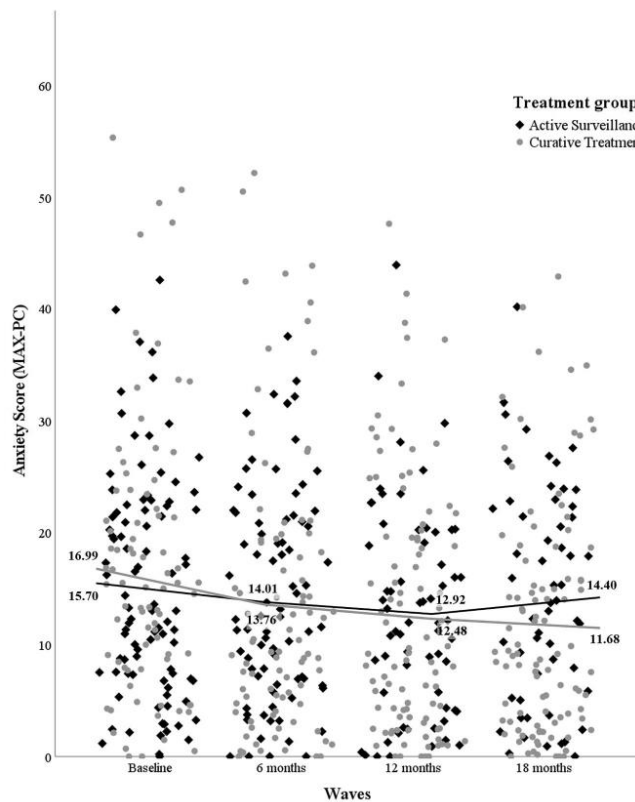


FIGURE 2 Anxiety over time by treatment groups including means for each measurement point

previous research demonstrating that men with PCa have lower anxiety levels than individuals with other cancer diagnoses.³⁶ One reason may be the on-average good prognosis for IPCa. Another reason could be that traditional concepts of masculinity may hinder emotional expression.³⁷ Therefore, even relatively low levels of anxiety deserve attention. Furthermore, we found that one in ten men, independent of the chosen treatment strategy, reported clinically relevant anxiety levels, a finding which is supported by other longitudinal studies.^{14,15}

Illness representations in men were found to be stable, whereas, according to the CSM, they are likely to change over the life span.³⁸ Possibly the time span in our study was too short to show any changes as such processes may take more time. In addition, PCa diagnoses affect men who may already have relatively stable assumptions about their disease, because they often witness PCa illnesses in their social group. Considering the intraindividual changes, perceiving an increase of consequences was associated with an increase in anxiety. This is in line with other studies showing that changes in illness representations can be determinants for changes in psychological and behavioral illness outcomes.^{39,40}

The CSM proposes that severe consequences signal threat and lead individuals to manage negative feelings using coping strategies. In line with a recent meta-analysis,¹⁹ we found that assuming more severe consequences is associated with higher use of both emotion- and problem-focused coping. Another finding from this meta-analysis is that problem-focused coping is related to less distress, whereas emotion-focused coping is related to more distress.¹⁹ Our results support this latter association—but only partially: when analyzed as individual mediators, *both* coping strategies were associated with an increase in anxiety. However, by using a new methodological approach which allows to model the overall level of coping in addition to the contrast between problem- and emotion-focused coping, we were able to get a more nuanced understanding: Participants with higher emotion-than problem-focused coping showed higher anxiety levels, while participants with a balanced combination of emotion- and problem-focused coping or a predominantly problem-focused coping style showed lower anxiety levels. Thus, too much emotion-focused coping in the absence of problem-focused coping seems to be problematic in our population. It remains to be seen

TABLE 2 (Continued)

	Mediation Model 1a Change score 6 months minus baseline	Mediation Model 1c Change score 12 months minus 6 months	Mediation Model 2b Change score 6 months minus baseline	Mediation Model 2c Change score 12 months minus 6 months
b_1	Mediator 1 to anxiety 0.205 (0.090)*	0.198 (0.090)*	0.296 (0.083)**	0.254 (0.092)**
b_2	Mediator 2 to anxiety 0.125 (0.090)	0.060 (0.092)	-0.118 (0.089)	-0.136 (0.087)
Covariate	Treatment ^a on Mediator 1 0.026 (0.083)	-0.098 (0.084)	0.015 (0.084)	-0.143 (0.081)
	Treatment ^a on Mediator 2 0.008 (0.082)	-0.140 (0.082)	-0.015 (0.078)	-0.063 (0.086)
	Treatment ^a on anxiety -0.057 (0.078)	-0.063 (0.080)	-0.057 (0.078)	-0.063 (0.080)
Total indirect effect	0.19 (0.030)	0.042 (0.030)	0.019 (0.030)	0.042 (0.030)
Indirect effect via Mediator 1	0.006 (0.020)	0.031 (0.028)	0.026 (0.032)	0.050 (0.030)*
Indirect effect via Mediator 2	0.042 (0.017)	0.011 (0.020)	-0.008 (0.013)	-0.008 (0.017)

Note: Classic parallel mediation models = Model 1a, 1b, 1c. Novel level-contrast approach = Model 2a, 2b, 2c. All path coefficients, standard errors and mediations are standardized.

Abbreviation: SE, Standard Error.

^aTreatment was included as a covariate, coded as 0 = AS, 1 = curative treatment.

* $p < 0.05$; ** $p < 0.01$.

whether other studies using level-contrast models will replicate this effect.

Longitudinally, an increase in the perception of consequences was associated with an increase in anxiety over time. This effect was not mediated by changes in coping, possibly due to small changes over time in general and in the coping dimensions especially.

Men under AS reported significantly less use of emotion- and problem-focused coping than men with curative treatments. One possible explanation is that men undergoing curative treatment are more embedded in an institutional care system and receive more information from various sources, while men under AS have less contact to health care providers. Another reason could be that men undergoing curative treatments may perceive their treatment itself as an active coping strategy in contrast to men under AS who deliberately decide against quick and immediate action.

4.1 | Study limitations

One limitation is that observational studies do not allow causal inferences. Nevertheless, the longitudinal design with an exceptionally low drop-out rate is appropriate to describe the relationships over time. Further, although this is one of the larger studies with men under AS, the sample sizes of the different treatment groups were still limited. We therefore grouped RT and RP under curative treatments to explore moderation effects.

4.2 | Clinical implications

Because anticipation of severe consequences seems to increase anxiety, physicians need to inform IPCa patients as comprehensively as possible about treatment strategies and possible side effects so that men have a realistic idea of their alternatives without creating too much anxiety. We also demonstrated that the level of anxiety is associated with the balance of emotion- and problem focused coping. A shift towards more problem-focused but, at the same time, less emotion-focused coping may enhance emotional well-being. To explore associations of coping patterns with emotional well-being, methods like the level-contrast approach should be used to obtain a differentiated picture.

5 | CONCLUSION

Our study adds to the growing evidence that men who decide for AS do not suffer from higher anxiety levels than men who opt for curative treatment. Thus, AS is a viable treatment strategy that can postpone or even avoid the physical side effects of curative

treatments without causing too much psychological distress. Nevertheless, on average and independent from the treatment strategy, the time shortly after the diagnosis is a period of increased psychological stress, and for some men this stress persists for a long time.

The perception of severe consequences is associated with increased anxiety. By adapting a novel methodological approach to explore this relation within the Common Sense Model framework, we can show that engaging in more emotion-than problem-focused coping is associated with higher anxiety. Whether a combination of disease-related information and support for developing problem-focused coping strategies improves well-being should be explored with intervention studies.

ACKNOWLEDGMENTS

This research project was funded by the Else Kröner-Fresenius-Stiftung (Grant number: 2013_A282). We are very grateful for their financial support. We further thank the study participants who provided their time and showed great interest in this study. We would like to thank all participating study centers who supported us in the recruitment process. We thank Julia Roseman for her helpful comments on the manuscript.

CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

AUTHOR CONTRIBUTIONS

Friederike Kendel designed the study and acquired the funding. Caren Hilger, Friederike Kendel, Ahmed Magheli, and Isabella Otto implemented the study. Friederike Kendel, Isabella Otto, and Gertraud Stadler conducted the data analysis. Isabella Otto drafted the paper under supervision of Friederike Kendel and Gertraud Stadler. All authors read, revised and approved the final version of the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the Open Science Framework website, without sociodemographic and clinical parameter which could lead to an identification of the participants. URL: https://osf.io/yj5ca/?view_only=8058c916b28c4afc98c15f47aebc9e39.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

How to cite this article: Otto I, Hilger C, Magheli A, Stadler G, Kendel F. Illness representations, coping and anxiety among men with localized prostate cancer over an 18-months period: A parallel vs. level-contrast mediation approach. *Psychooncology*. 2021;1-11. doi:10.1002/pon.5798

Curriculum vitae

Mein Lebenslauf wird aus datenschutzrechtlichen Gründen in der elektronischen Version meiner Arbeit nicht veröffentlicht.

U r k u n d e

Die Arbeitsgemeinschaft für Psychoonkologie in der
Deutschen Krebsgesellschaft e.V. (PSO)

verleiht

CAREN HILGER

Geschlechterforschung in der Medizin,
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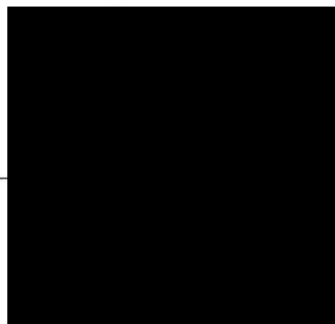
für das Poster

**„Zeitdruck sagt das Bereuen der Therapieentscheidung von
Männern mit lokal begrenztem Prostatakarzinom vorher:
Daten aus einer längsschnittlichen Multicenter-Studie“**

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Psychoonkologie in der Deutschen Krebsgesellschaft e.V. (PSO)



Complete publication list

Original articles

- Hilger, C., Schostak, M., Otto, I., & Kendel, F. (2021). Time pressure predicts decisional regret in men with localized prostate cancer: data from a longitudinal multicenter study. *World Journal of Urology*, 39(10): 3755–3761. **Impact Factor: 4.226**
- Otto, I., Hilger, C., Magheli, A., Stadler, G., & Kendel, F. (2021). Illness representations, coping and anxiety among men with localized prostate cancer over an 18-months period: A parallel vs. level-contrast mediation approach. *Psycho-Oncology*. 31(2): 227-237 **Impact Factor: 3.894**
- Besch, L.*, Hilger, C.*, Speiser, D., Feufel, M., & Kendel, F. (2020). Online-gestützte Beratungstools für *BRCA1/2*-Mutationsträgerinnen. *Journal Onkologie*. * shared first authorship
- Hilger, C. & Kendel, F. (2020). Facetten des Arzt-Patienten-Gesprächs in der Urologischen Praxis – Handlungsempfehlungen aus der Psychoonkologie. *Onkologische Welt*, 11(2), 90-96.
- Hilger, C., Schostak, M., Neubauer, S., Magheli, A., Fydrich, T., Heuse, S. & Kendel, F. (2019). The importance of sexuality, changes in erectile functioning and its association with self-esteem in men with localized prostate cancer: data from an observational study. *BMC Urology*, 19(1): 9. **Impact Factor: 1.592**
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- Hilger, C. & Kendel, F. (2019). Facetten des Arzt-Patienten-Gesprächs in der Urologischen Praxis – Handlungsempfehlungen aus der Psychoonkologie. *Aktuelle Urologie*, 50(02), 172-178. **Impact Factor: 0.405**

Conference contributions

- Hilger, C., Otto, I., Schostak, M. & Kendel, K. (2021). Zeitdruck sagt das Bereuen der Therapieentscheidung von Männern mit lokal begrenztem Prostatakarzinom vorher: Daten aus einer längsschnittlichen Multicenter-Studie. *Poster presentation, 19. Jahrestagung der Arbeitsgemeinschaft für Psychoonkologie in der Deutschen Krebsgesellschaft e.V. (PSO)*, Ulm.
- Hilger, C., Otto, I., Schostak, M. & Kendel, K. (2021). Time Pressure Predicts Decisional Regret in Men With Localized Prostate Cancer: Data From a Longitudinal Multicenter Study. *Oral presentation, gemeinsame Jahrestagung der Deutschen Gesellschaft für Medizinische Soziologie (DGMS) und der Deutschen Gesellschaft für Medizinische Psychologie (DGMP)*, Hamburg.
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- Otto, I.* , **Hilger, C.*** , & Kendel, K. (2018). Information seeking behavior and disease specific anxiety among men with localized prostate cancer. *Poster presentation, 33. Deutscher Krebskongress (DKK)*, Berlin. *first author
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Acknowledgements

Mein erster Dank gilt meiner Betreuerin, PD Dr. Friederike Kendel. Vielen Dank für deine kontinuierliche Unterstützung über die vergangenen Jahre. Danke, dass du nach meiner Master-Arbeit nun auch meine Dissertation betreut hast und dir immer wieder die Zeit genommen hast, meine Projekte mit dir zu besprechen. Vielen Dank für deine konstruktive Kritik, durch die sich nicht nur meine Dissertation verbessert hat, sondern durch die ich auch sehr viel dazu lernen konnte. Danke für die schöne Zusammenarbeit, dein Vertrauen, deine Förderung und deinen wertschätzenden Umgang in all unseren Forschungsprojekten! Ich möchte mich bei meiner Zweitbetreuerin Prof. Dr. Christine Holmberg bedanken. Durch ihre Ideen und Kritikpunkte hat sie die Einordnung und die Implikation meiner Befunde geschärft. Mein weiterer Dank gilt meinem Drittbetreuer Prof. Dr. Martin Schostak. In enger Absprache mit ihm habe ich den medizinischen Hintergrund der Publikationen sowie der Promotionschrift ausgearbeitet und dabei viel von ihm lernen dürfen. Bei der Diskussion der Ergebnisse und vor allem auch bei den Implikationen für die klinische Praxis hat er mit seiner medizinischen Expertise neue Aspekte eingebracht und direkte Bezüge zum klinischen Alltag hergestellt.

Vielen Dank an Hans-Jörg Fiebrandt und den Bundesverband Prostata Selbsthilfe e.V., die die Wichtigkeit unseres Forschungsvorhabens betont und unterstützt haben. Vielen Dank an alle Studienteilnehmer, die sich die Zeit genommen haben, unsere Fragebögen auszufüllen und damit einen maßgeblichen Teil zu unserer Forschung und meiner Promotion beigetragen haben.

Ich bedanke mich bei Prof. Dr. Gertraud Stadler und alle Kolleg:innen aus der Geschlechterforschung in der Medizin an der Charité. Danke für die Gelegenheit, meinen Arbeitsstand mehrfach in unseren Besprechungen vorzustellen und für eure wertvollen Anmerkungen zu meiner Arbeit. Danke, dass ihr euch mit mir gefreut habt als ich die Dissertation abschließen konnte. Danke, liebe Turu, für deine Art, das Institut zu leiten, die von Kommunikation auf Augenhöhe und Wertschätzung geprägt ist. Danke für die positive Arbeitsatmosphäre, die du dadurch schaffst.

Weiterhin bedanke ich mich bei meiner Kollegin Isabella Otto, die in einem ähnlichen Themengebiet wie ich promoviert hat und die mich in den vergangenen Jahren begleitet hat und ein Büro mit mir geteilt hat. Danke, dass ich meinen Zwischenstand immer mit dir besprechen und mich mit offenen Fragen an dich wenden konnte! Bei Julia Roseman möchte ich mich für das Korrekturlesen meiner Arbeit bedanken. Danke, dass du dir neben deinen zahlreichen anderen Projekten und Aufgaben die Zeit genommen hast, meinen Manteltext zu lesen und sprachliche Korrekturen vorzunehmen. Auch bei Jamie Smith möchte ich mich für das Korrekturlesen und die sprachliche Überarbeitung meiner Publikation zum Bereuen der Therapieentscheidung bedanken. Euch beiden bin ich besonders dankbar dafür, dass ihr so positiv auf meine Anfragen reagiert und Interesse an dem Thema gezeigt habt, obwohl es zeitintensive Aufgaben waren. Weiterer Dank gilt PD Dr. Dorothee Speiser und Prof. Dr. Markus Feufel sowie dem gesamten iKNOW-Team. Danke für die interessante und konstruktive Zusammenarbeit in den letzten Jahren. Ich habe unglaublich viel von euch gelernt und bin euch sehr dankbar, dass ihr mir die Gelegenheit dazu gegeben habt!

Ich möchte mich bei der „Berlin School of Integrative Oncology“ dafür bedanken, dass sie mir die Chance gegeben haben, an dem strukturierten Promotionsstudiengang „Integrative Oncology“ teilzunehmen. Vielen Dank an Antonia Schwarz und Dr. Franziska Schwarz für die Illustrationen, die noch viel schöner geworden sind als ich es mir hätte vorstellen können. Danke für eure (völlig überzogene) Großzügigkeit und eure Kreativität! Ich bedanke mich bei meinen Eltern, die mich in meiner Ausbildung immer unterstützt und gefördert haben. Ich bin mir sehr bewusst, dass ich diesen Schritt ohne euch nicht hätte machen können. Mein Dank gilt meinen Großeltern, die diesen Tag leider nicht mehr miterleben können. Ich weiß, dass ihr mich unterstützt hättet und wahnsinnig stolz auf mich gewesen wärt. Ich möchte mich bei Sunna Becker, Antonia Schwarz und Danny Vogel bedanken, nicht nur für das Korrekturlesen meiner Arbeit, sondern auch für euren Rückhalt und eure Unterstützung. Danke, dass ihr Teil meines Lebens seid.