THE DEVELOPMENT OF AN INTERVENTION PROGRAM TO OPTIMIZE PSYCHOSOCIAL SUPPORT IN PROSTATE CANCER PATIENTS UNDERGOING ACTIVE SURVEILLANCE



Kim Maria Donachie

Stellingen

Behorende bij het proefschrift

The development of an intervention program to optimize psychosocial support in prostate cancer patients undergoing active surveillance.

Van Kim Maria Donachie

1. Choosing not to treat the cancer during Active Surveillance should never mean choosing not to treat the patient. *(this dissertation, Chapter 1)*

2. Sustained reduction of the psychosocial burden in Active Surveillance requires a combined approach of education, coping support, and lifestyle interventions; isolated measures offer only transient relief. *(this dissertation, Chapter 3)*

3. Optimal psychosocial care in Active Surveillance requires structured, proactive screening of both physical and mental needs, rather than relying on patients to spontaneously express their concerns. *(this dissertation, Chapter 4)*

4. A digital self-management intervention in Active Surveillance is only viable when fully integrated into the broader clinical care ecosystem. *(this dissertation, Chapter 6)*

5. Active self-management is the primary antidote to the loss of control and uncertainty in Active Surveillance, transforming the patient from a passive observer into an active manager of his own health.

6. Although extensive co-creation with patients ensures high initial acceptability of eHealth, it does not guarantee sustained usage.

7. The future sustainability of Active Surveillance relies on a hybrid care model centered around the patient and his social network, empowered by digital technology that enhances clinical interaction.

8. In Active Surveillance, uncertainty is not a side effect of care; it is part of the care that needs to be addressed.

9. Blended care models in Active Surveillance are only effective when digital tools support, rather than replace, human clinical interaction.

10. Resilience is not built despite vulnerability, but through it.

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Promotor

Prof. Dr. L. Lechner, Open Universiteit

Co-promotores

Dr. E.C. Bakker, Open Universiteit

Dr. M.J.M. Adriaansen, HAN University of Applied Sciences

Dr. E.B. Cornel, Andros Kliniek

Leden beoordelingscommissie

Prof. Dr. J.P.M. Sedelaar, Radboudumc

Prof. Dr. J.M.L. Hendriks, Maastricht UMC

Prof. Dr. C.A.W. Bolman, Open Universiteit

Prof. Dr. N.E. Jacobs, Open Universiteit

Dr. M.J.C.M. Magnée, HAN University of Applied Sciences

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PREFACE

Personal and professional motivation

My professional journey leading to this dissertation began in 2008, when I obtained my bachelor's degree in nursing and joined the urology department at Radboudumc. During this period, I frequently encountered men with prostate cancer. Witnessing the profound impact of the disease on patients' lives, coupled with the societal stigma surrounding it, left a lasting impression on me. These experiences provided early insight into the multifaceted challenges faced by patients and highlighted the importance of empathetic, patient-centered care.

Over time, I specialized in uro-oncology, performing prostate biopsies, conducting outpatient clinics for men presenting with urological symptoms, and participating in research aimed at improving diagnostic approaches. Through these clinical engagements, I realized that many patients carried a significant emotional and psychosocial burden, often silently. Observing their resilience alongside vulnerability profoundly shaped my perspective on holistic care and reinforced my desire to address both clinical and psychosocial needs.

In 2010, I transitioned from direct clinical practice to scientific research, focusing on coordinating clinical trials exploring non-invasive diagnostic strategies using biomarkers. While this work advanced scientific understanding and contributed valuable knowledge, it created a distance from patients lived experiences. This reinforced my motivation to reconnect with the human dimensions of care and translate scientific insights into meaningful improvements for patients' well-being.

In 2015, I enrolled in the Clinical Health Sciences program at Utrecht University, which offered the opportunity to conduct independent, clinically informed research. A 2016 case study examining psychosocial challenges among men with prostate cancer crystallized the focus of my PhD research: to develop knowledge and interventions that address the unmet emotional and psychosocial needs of patients, particularly during active surveillance.

This project would not have been possible without the support and guidance of a dedicated, multidisciplinary team. Their collaboration, encouragement, and expertise have been instrumental in shaping and advancing this PhD research.

CHAPTER 1

Introduction

INTRODUCTION

This dissertation focuses on the systematic development and optimization of a nurse-led intervention program designed to address the unmet psychosocial support needs of men with prostate cancer (PCa) undergoing Active Surveillance (AS). While AS is an evidence-based and preferred strategy to avoid the morbidity associated with immediate curative treatment, the psychological paradox of living with an untreated malignancy often triggers significant distress, necessitating tailored supportive care to improve both well-being and protocol adherence. Utilizing a stakeholder-driven co-creation approach, this dissertation seeks to bridge the gap between clinical monitoring and the patient's lived experience, situating this research within the broader transformation toward patient-centered healthcare.

Developments in healthcare

Over the past decade, healthcare systems in many countries have undergone profound changes driven by demographic, technological, and societal developments.[1,2] These developments are strongly interconnected and collectively place increasing pressure on healthcare systems.[1] At the same time, they stimulate new approaches to the organization and delivery of care.[3,4]

One of the most important drivers of change is demographic development.[2,5] Many western countries are experiencing significant population ageing as a result of increased life expectancy and declining birth rates.[1] As people live longer, the prevalence of chronic diseases such as cardiovascular disease, diabetes, cancer, and neurodegenerative disorders increases.[1] Moreover, older adults often experience multimorbidity, meaning they live with multiple chronic conditions simultaneously. This leads to more complex care needs and a greater demand for long-term care, monitoring, and multidisciplinary treatment.[4,6]

Parallel to these demographic changes, rapid technological and medical advancements have transformed healthcare practice.[7] Innovations in diagnostic technologies, such as advanced imaging techniques, molecular diagnostics, and genetic testing, allow diseases to be detected earlier and more accurately than before.[8] Screening programs have expanded, and predictive tools increasingly enable the identification of individuals at risk of developing certain diseases.[9,10] While these developments have greatly improved the ability to diagnose and treat medical conditions, they also contribute to a rise in healthcare utilization.[1] Earlier detection means that more individuals are diagnosed and may receive treatment, and many patients now live longer with chronic conditions that require ongoing management. As a result, technological progress, although beneficial for patient outcomes, also contributes to increasing healthcare demand and costs.[1,11]

Alongside these developments, perspectives on health and healthcare have evolved from a purely biomedical model toward a patient-centered, integrative approach.[12-14] Traditional models that primarily focus on diagnosing and treating disease have gradually been complemented by broader, more holistic

concepts of health. This evolution aligns with the World Health Organization's perspective on health promotion, which is defined as the process of enabling individuals to increase control over and improve their health and well-being.[15] A prominent example of this development is the concept of positive health, which redefines health not as the mere absence of illness, but as the ability to adapt and self-manage in the face of social, physical, and emotional challenges.[16] In clinical practice, this model is often operationalized through tools such as the positive health spider web (see figure 1), which allows patients and healthcare providers to identify real-time concerns across multiple dimensions such as mental well-being, social participation, and daily functioning to facilitate more tailored and comprehensive support.

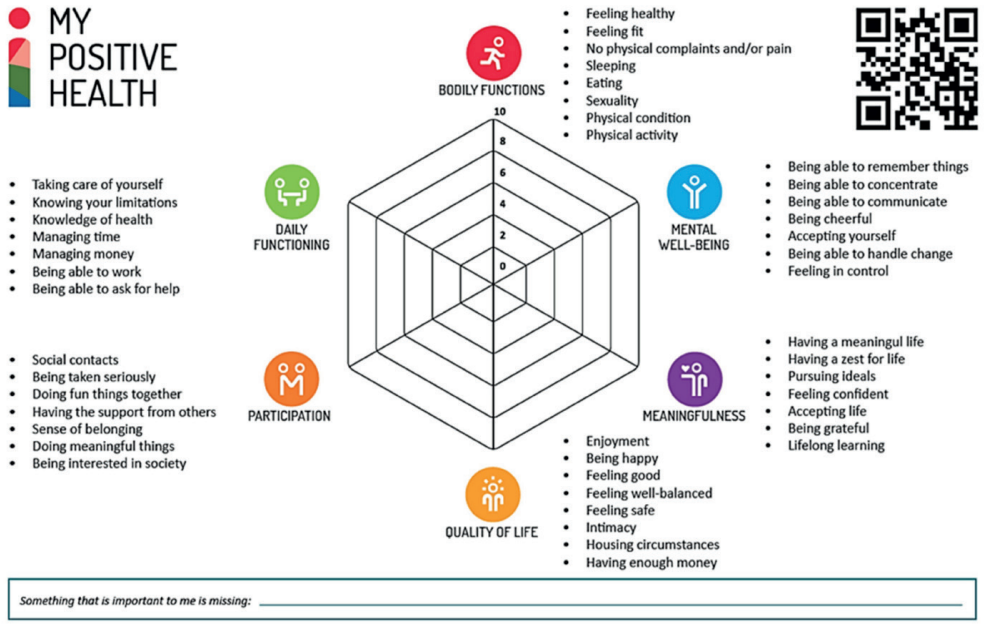

FIGURE 1. Positive health spider web[17]

Consequently, approaches such as patient-centered care, shared decision-making, and patient engagement have gained increasing attention.[18,19] Patients are no longer viewed merely as passive recipients of care but as active participants in managing their own health journey. This shift has also stimulated the development of more personalized and integrated care approaches.[20] Personalized care aims to tailor prevention, diagnosis, and treatment strategies to the specific characteristics, preferences, and needs of individual patients, thereby fostering self-efficacy and empowerment.[8,21] At the same time, integrated care emphasizes seamless collaboration between different healthcare professionals and sectors, recognizing that complex health problems often require coordinated multidisciplinary care to maintain the quality, accessibility, and sustainability of healthcare systems.[4,22]

Despite these promising developments, the combined effects of demographic ageing, technological progress, and changing expectations of care place substantial pressure on healthcare systems.[1] At the same time, demographic changes affect the healthcare workforce.[2] The proportion of older individuals who require care is increasing, while the relative number of younger people entering the labor market is declining. Consequently, healthcare systems face a growing imbalance between the demand for care and the availability of healthcare professionals.[1,23] Healthcare expenditures have risen steadily in many countries, and workforce shortages have become a major concern.[2,11] Healthcare professionals often face increasing workloads, administrative burdens, and complex patient populations.[24] In addition, healthcare systems that were historically organized around acute, hospital-based care must increasingly adapt to the management of chronic diseases and long-term health conditions.[4]

In response to these challenges, policymakers and healthcare organizations are exploring new strategies to ensure the sustainability of healthcare systems.[1,2] A cornerstone of this transformation is a comprehensive focus on prevention and health promotion, which has evolved into a continuum encompassing primary, secondary, and tertiary strategies.[25,26] Whilst primary prevention aims to reduce the initial incidence of chronic diseases by addressing modifiable lifestyle-related risk factors such as physical inactivity, unhealthy diets, smoking, and obesity, secondary prevention leverages early detection through screening programs and timely intervention to halt disease progression and improve long-term outcomes. Increasingly, these efforts are also directed at individuals who have already been diagnosed, shifting the focus toward lifestyle medicine and tertiary prevention. In this domain, the objective is not to prevent the onset of illness, but to optimize quality of life and how patients function with their condition by fostering disease self-management and preventing further clinical deterioration or complications.[21,27]

Another important development, digital health technologies are playing an increasingly important role in addressing current challenges.[7,28] Innovations such as eHealth, remote monitoring and artificial intelligence have the potential to support healthcare professionals, improve decision-making, and enhance patient self-management.[29,30] These technologies may also help reduce the burden on healthcare systems by enabling more efficient use of resources and by shifting certain aspects of care from hospitals to patients' homes.[1,31]

In summary, the developments in healthcare over the past decade cannot be understood in isolation. Demographic ageing increases the demand for care, technological advancements expand diagnostic and treatment possibilities, and evolving perspectives on health emphasize patient-centered and integrated care. Together, these trends place considerable pressure on healthcare systems, particularly with regard to costs and workforce capacity. As a result, healthcare systems are increasingly focusing on prevention, innovative care models, and digital technologies in an effort to maintain accessibility, quality, and sustainability of care in the future.

Developments in oncological care

The developments described above have profound implications for oncological care. As a result of advances in early detection, screening programs, and diagnostic technologies, substantial progress has been made in improving cancer survival over the past decade.[32,33] Tumors are increasingly diagnosed at earlier stages, allowing for more effective and often less invasive interventions.[34,35] Consequently, a growing number of individuals now live with and beyond cancer, which has shifted attention from solely achieving survival toward also optimizing quality of life throughout and after treatment.[36]

In accordance, cancer care is undergoing a fundamental shift from a paternalistic, disease-focused model toward a patient-centered paradigm.[12,13] As part of this evolution, treatment options for cancer patients have expanded and diversified, with therapeutic strategies becoming increasingly personalized by accounting for tumor biology, genetic profiles, and patient preferences.[8,37] As a result, patients today are often presented with choices regarding their care, such as selecting between different surgical, radio-therapeutical, or systemic approaches.[38,39]

The impact of cancer and treatment options extends beyond physical health, affecting psychological, social, and functional well-being.[40,41] Therefore, the concept of quality of life has become increasingly important in oncological care. Quality of life (QoL) is defined as a multidimensional and subjective concept encompassing physical, psychological, and social well-being, reflecting an individual's perception of their health status and their ability to function and adapt within their environment.[42] Given the inherently subjective nature of QoL, it becomes essential to actively involve patients in decisions about their care, ensuring that treatment choices align with what matters most to them.[43]

This necessitates the systematic application of shared decision-making (SDM), which can be defined as a collaborative process where healthcare providers and patients jointly reach care decisions by weighing the best available clinical evidence against the patient's unique values and priorities.[18,38] SDM is increasingly viewed as a central pillar of positive health.[16,17] By fostering patient activation and providing tools such as decision aids, clinicians aim to empower patients to make informed choices that align with their personal goals.[44]

While patient-centered principles and shared decision-making (SDM) are central to contemporary oncology guidelines, their integration into routine clinical practice remains suboptimal. Research suggests that genuine SDM is frequently hindered by factors such as physician bias, inconsistent information provision, and the significant emotional distress patients experience at the time of diagnosis.[45-47] Although the ideal of the patient as a "leading actor" in shaping treatment goals is widely promoted, many patients continue to feel disempowered, overwhelmed by information, or insufficiently supported to take on such an active role.[48,49] At the same time, ongoing advances in oncology, such as increasing survival and the availability of multiple therapeutic options, create important opportunities for more nuanced and individualized decision-making.[8,37] These developments require clinicians and

patients to navigate rising costs while carefully balancing benefits and harms in light of individual values and preferences. Particularly as not every diagnosed tumor necessitates aggressive treatment and some interventions may carry risks that outweigh potential gains.[50] In this context, SDM may offer not only an ethical framework but also a practical opportunity to tailor care appropriately. This highlights the potential to further translate patient-centered ideals into routine clinical practice, with particular attention to patient education, decision aids, and active engagement.

Clinicians are therefore tasked not only with guiding treatment choices, but also with fostering patient agency.[21] They must clearly outline which aspects of disease control remain the responsibility of the healthcare team and which can be meaningfully influenced by patients. Importantly, many patients express a need to actively contribute to their own health and outcomes, engaging with modifiable factors as a way to regain a sense of control and cope with the uncertainty of their disease.[51,52] Such engagement can be understood within the broader frameworks of empowerment and positive health, where patients are supported to develop self-management skills that enable them to influence aspects of their well-being beyond immediate treatment outcomes.[16,27,53] By fostering self-management through education, tailored advice, and practical support, oncological care can not only enhance disease control but also strengthen patients' confidence, resilience, and overall quality of life.[51]

In this context, prevention and lifestyle interventions are increasingly recognized as essential components of oncological care.[54,55] Integrating these elements into patient care not only contributes to disease control but also supports patients' overall well-being, fostering empowerment and the development of self-management skills.[52,54] By engaging in modifiable behaviors such as nutrition, physical activity, and other lifestyle factors, patients can take an active role in shaping outcomes that lie within their sphere of influence.[52,55] Growing evidence indicates that these interventions not only aid in cancer prevention but can also enhance treatment outcomes, reinforcing patients' sense of agency and contributing to a more positive health experience.[56,57]

Overall, contemporary oncological care is in the process of evolving from a purely biomedical model toward a more patient-centered, integrative approach. While radical interventions historically dominated curative treatment, current practice increasingly seeks to balance survival with the long-term needs of patients, including psychosocial well-being, functional recovery, and quality of life. Integrative oncology combines conventional therapies with lifestyle modification, mind-body interventions, and self-management support. It offers a promising framework to enhance symptom management, patient empowerment, and multidimensional outcomes. In this evolving context, concepts such as SDM, patient agency, disease control, and positive health are becoming central pillars of modern oncology, reflecting the ongoing shift toward more personalized and patient-centered models of care.

Developments in prostate cancer care

While offering new opportunities for patient-centered care and empowerment, these advances in oncology also present complex clinical challenges that require careful balancing of treatment benefits and harms. These challenges are particularly evident in prostate cancer (PCa), which is the second most prevalent malignancy among men worldwide and the most common cancer among men in the Netherlands.[58] In 2020 alone, an estimated 1.4 million new cases were diagnosed globally with approximately 16.000 new cases diagnosed annually in the Netherlands.[33,58] PCa displays highly heterogeneous clinical presentations, ranging from indolent, low-risk tumors to aggressive, high-risk disease.[59] Since the introduction of Prostate Specific Antigen (PSA) testing in the 1990s, the early detection of localized, low-risk PCa has increased substantially.[60,61] While widespread PSA screening has contributed to significant reductions in prostate cancer mortality, it has also led to substantial overdiagnosis.[9,60] This poses a fundamental challenge for clinicians: accurately identifying life-threatening tumors while avoiding unnecessary diagnosis and treatment of lesions that would remain clinically insignificant during a patient's lifetime.[9,50] Current efforts in PCa management focus on improving diagnostic validity and specificity through innovations such as multiparametric magnetic resonance imaging, advanced biomarker panels, and genomic profiling.[59,62,63] These tools enhance the ability to distinguish aggressive tumors from low-risk lesions, minimizing unnecessary interventions while ensuring timely curative treatment for those who need it.

In the Netherlands, approximately 35% of men diagnosed with PCa are classified as low-risk.[58] In this population radical interventions, such as radical prostatectomy and radiotherapy are offered as treatment options as well as Active Surveillance (AS) as a management strategy.[59,63] AS involves the systematic monitoring of low-risk tumors through regular Prostate-Specific Antigen (PSA) testing, digital rectal examination, periodic multiparametric MRI, and repeat biopsies, with curative treatment initiated only if clinically significant disease progression occurs.[64] Evidence from large-scale randomized controlled trials, indicates that immediate radical treatment of low-risk tumors does not improve overall survival compared to monitoring strategies, even after long-term follow-up.[65]

A significant and clinically relevant distinction between AS and radical treatment groups is the prevalence of urinary incontinence and erectile dysfunction. Radical prostatectomy, in particular, significantly increases the risk of these complications.[66-68] Long-term patient-reported outcomes show that men on AS maintain relatively stable urinary and sexual function over time, while those undergoing radical treatments often experience a significant functional decline within the first year.[68,69] Specifically, radical prostatectomy is associated with approximately 10-20% higher rates of incontinence and substantial increases in erectile dysfunction compared to surveillance. Although some recovery occurs, men undergoing active treatment continue to report higher rates of urinary incontinence and erectile dysfunction than those managed with active surveillance during long-term follow-up.[65,67]

Efforts to minimize the treatment complications have led to the development of minimally invasive, focal therapies that eradicate the tumor while minimizing collateral damage. Techniques such as cryotherapy, high-intensity focused ultrasound (HIFU), and targeted thermal ablation (e.g., TULSA) offer the potential to control localized tumors with a reduced risk of long-term side effects.[70,71] However, despite these advances, these approaches remain active treatment modalities and are still associated with procedural risks, follow-up burden, and the potential for overtreatment in men with indolent low-risk disease. Because many low-risk prostate cancers have a favorable natural course and may never progress to clinically significant disease, AS remains the preferred management strategy.

Initially developed for men with low-risk PCa, AS has become the standard of care in this population and, over the past decade, has increasingly been extended to carefully selected men with favorable intermediate-risk disease, supported by improved risk stratification and accumulating evidence on oncological safety. This reflects a gradual broadening of inclusion criteria in contemporary guidelines and clinical practice.[66]

AS for low-risk PCa effectively balances oncological safety, with 10-year cancer-specific survival rates reported as high as 99%, with the preservation of QoL.[64,69] In addition it offers a cost-effective approach for healthcare systems by ensuring that medical resources are directed toward life-threatening disease while sparing patients from the morbidity of overtreatment.[72] By avoiding or delaying invasive interventions such as radical prostatectomy or radiotherapy, AS effectively protects the patient's QoL, specifically by preserving urinary and sexual functions.[68,69]

Despite the growing evidence and expanding indications, the adoption of AS remains highly heterogeneous. While up to 85% of men in certain Dutch very-low-risk cohorts are managed with surveillance, broader European studies have reported substantially lower utilization rates.[73,74]

This wide variability in clinical practice, where AS uptake for low-risk disease fluctuates significantly between regions and institutions, underscores the necessity of a meticulous and transparent decision-making process. A fundamental component of this process is the mitigation of physician bias, as clinicians' personal treatment preferences can often override patient values in the absence of a structured approach.[45,75,76] Consequently, empowering patients through targeted education and reliable information is essential to transition them from passive recipients of care into "leading actors" who possess the agency to manage their surveillance trajectory. In this context, SDM serves as a vital collaborative tool where clinicians and patients jointly weigh the clinical characteristics of the tumor against the individual's specific priorities regarding the risk of treatment-induced urinary incontinence and erectile dysfunction.[18,38,44] This deliberative process must also account for the impact of regular monitoring, such as "PSA anxiety" and the burden of repeat biopsies, on the patient's psychological well-being and overall QoL.[77-79] Evidence suggests that a thoroughly executed SDM process fosters higher levels of trust and patient engagement, which are critical drivers of protocol adherence.[45,49]

Consistent adherence is the primary safety mechanism in AS, ensuring that any disease progression is identified within the window of curability. Therefore, ensuring that the management strategy remains aligned with the patient's personal values and long-term well-being is of paramount importance for the sustainable and successful adoption of AS in contemporary oncology.[80,81]

In summary, contemporary prostate cancer care exemplifies a complex interaction between improved diagnostic precision, treatment personalization, and patient empowerment. The transition from a reflexive "treat all" approach to a nuanced, surveillance-based model for low-risk disease reflects a broader shift toward the principles of positive health, redefining health as the patient's ability to function and adapt while living with their condition.[16,17] However, the long-term success and safety of Active Surveillance (AS) are contingent upon strict protocol adherence, which is essential to ensure that any disease progression is identified within the window of curability. Achieving this requires a meticulous shared decision-making (SDM) process that mitigates physician bias and fosters patient agency by empowering men as "leading actors" in their surveillance trajectory. Ultimately, this paradigm addresses disease control, patient well-being, and system sustainability simultaneously, positioning the patient as an active participant in maintaining their health through enhanced self-management and psychological adaptability.[21,27]

Psychosocial aspects and supportive care needs during Active Surveillance

The AS pathway requires substantial psychological adaptability, as men must reconcile the clinical knowledge of harboring a malignant tumor with a management strategy that avoids immediate intervention. Although AS is medically safe, the psychological burden of living with an "untreated" tumor remains significant. Research indicates that up to 81% of men with prostate cancer report unmet supportive care needs.[82] While the majority of patients maintain a stable quality of life, a significant minority, estimated between 25-30%, experience clinically relevant anxiety and illness uncertainty.[83] This psychological distress is often characterized by a "latent fear of disease progression" and "PSA anxiety," which typically peaks during the recurring medical examinations.[79,83] Crucially, when these psychosocial needs remain unaddressed, they can directly undermine protocol safety. Evidence indicates that approximately 5% to 13% of men on AS eventually discontinue the protocol and pursue radical treatment without clinical evidence of disease progression, a decision primarily driven by unmanaged fear, uncertainty, and pressure from the social support network.[84-86]

These psychological responses are deeply influenced by broader societal and gender norms that shape coping behaviors. Masculine identity often reinforces ideals of stoicism, independence, and an "action-oriented" approach, which can impede emotional help-seeking and make the observational nature of AS more challenging.[87] Men who perceive themselves as proactive and decisive may view surveillance as "doing nothing" or "inaction," leading to a preference for radical treatment framed as "getting it out", to regain a sense of control.[88] While many men rely on strength-based, problem-focused coping strategies, these can be ineffective or lead to premature discontinuation if not accompanied by

emotional validation and psychological processing.[89] When men struggle with these demands, they are more likely to experience decreased trust in the surveillance strategy and reduced adherence to the monitoring protocol.[80,89] Adherence is a critical safety factor, yet research shows it often declines over time. For instance, compliance with repeat biopsies has been shown to drop from 81% at one year to only 33% at ten years.[86] Consequently, strict adherence is essential to ensure the timely detection of disease progression.

Addressing the underlying psychological barriers is vital to maintain the sustainability and oncological safety of the AS approach. Providing tailored psychosocial support is essential.[90] Evidence demonstrates that such structured support can effectively bridge the gap between clinical safety and the patient's lived experience, potentially reducing off-criteria discontinuation rates from 25% to as low as 11%.[91] Psychosocial support should address emotional appraisals of risk, enhance trust in the treating team, and provide personalized, "just-in-time" information regarding the rationale for surveillance and signs of progression.[91,92] Furthermore, interventions must involve partners and family members, whose understanding and acceptance are primary drivers of the patient's commitment to remain on the protocol.[86,89] By providing a psychological safety net through standardized monitoring and peer-to-peer interaction, healthcare providers can ensure that treatment decisions remain grounded in clinical indicators rather than unmanaged fear.[93]

The diagnosis of localized prostate cancer and the subsequent entry into an Active Surveillance (AS) protocol can also represent a significant "teachable moment", a unique window of opportunity where men are highly motivated to adopt health-promoting behaviors.[94] Within the context of AS, where the medical recommendation is often perceived as "inaction" or "doing nothing," lifestyle modifications such as dietary changes and increased physical activity act as a catalyst for patient agency.[80,92] For many men, these behaviors serve as an action-oriented coping strategy that aligns with masculine values of self-reliance and proactivity, allowing them to feel they are constructively "fighting" the tumor rather than merely waiting for it to progress.[95] Research indicates that men who engage in these self-health practices report a greater sense of control over their condition, leading to significantly higher QoL and reduced levels of illness uncertainty.[81,94]

Integrating psychosocial and lifestyle support is not merely a complementary addition but a fundamental safety mechanism for the AS trajectory. The clinical viability of surveillance is entirely dependent on protocol adherence, yet the distress caused by AS and the associated recurring medical examinations causes clinically relevant anxiety in approximately 24% to 30% of men.[79,83] When the psychological burden during AS remains unmanaged, it leads to a direct clinical failure of the management strategy with estimated rates of 5-13% of men discontinuing surveillance and undergoing invasive surgery or radiation without any medical evidence of disease progression.[84-86,96] Furthermore, from a medical perspective, health-promoting behaviors serve as a form of prehabilitation. Patients who are physically fit and trained have been shown to achieve superior functional outcome.[97] By fostering self-management

and enhancing patient agency through this integrated approach, healthcare providers can better safeguard both clinical outcomes and the long-term QoL for men living with a prostate cancer diagnosis and fewer complications if they eventually require radical treatment.

In the context of an increasingly overburdened healthcare system, digital health interventions or eHealth offer promising opportunities to provide supportive care efficiently and sustainably.[28,98,99] Secure, user-friendly digital platforms can deliver just-in-time, personalized information and psychoeducational content, which are essential for helping men navigate the uncertainties and emotional challenges of active surveillance.[100,101] While digital tools provide the necessary infrastructure for efficient care, their clinical success is contingent upon their integration into a care pathway and the adoption by the multidisciplinary clinical team, typically composed of urologists, radiation oncologists, and oncology nurses.[80,90,92,102] Within this team, the specialized nurse's role is fundamental for driving patient-centered care and bridging the gap between the patient and the medical specialists. Specialized oncology nurses act as patient advocates, combining clinical expertise with personalized communication skills to reinforce the rationale for AS as a safe strategy while supporting the patient's psychological adaptation.[80,81,99] Given their patient-centered focus, nurses are uniquely suited to guide and coordinate these digital interventions, ensuring that technical efficiency is balanced with tailored human guidance.

In conclusion, while AS is clinically safe, cost-effective and the preferred management strategy for low-risk prostate cancer, its long-term success depends on both strict protocol adherence and the patient's effective psychological adaptation to the paradox of living with an untreated tumor. To address the psychosocial challenges, tailored supportive care should be coordinated by specialized oncology or urology nurses who serve as fundamental drivers of patient-centered care. Given the constraints of modern healthcare, the potential of digital health technologies should be leveraged to provide just-in-time, personalized information and scalable psychosocial support without increasing clinician workload. Integrating such support into the AS trajectory can effectively re-establish patient agency, enhance resilience, and reinforce the confidence of both the patient and their family in the safety of the surveillance protocol. By systematically addressing the often-overlooked psychosocial needs, healthcare providers ensure that AS remains a sustainable, safe, and truly patient-centered option for current and future prostate cancer populations.

Purpose of this dissertation and research question

AS is a clinically safe and evidence-based strategy. However, the persistent psychological challenges of living with an untreated malignancy remain a significant and often unaddressed burden for many men. The unmanaged distress not only impairs well-being but also serves as a primary driver for premature protocol discontinuation, thereby undermining the long-term sustainability and oncological safety of the surveillance paradigm. To bridge this gap, it is essential to implement tailored supportive care, coordinated by specialized nurses and enhanced by digital health technologies. The purpose of this dissertation is to identify the unmet psychosocial support needs of men with low-risk prostate cancer

during AS and to use a systematic, stakeholder-driven approach to develop and evaluate the feasibility of an intervention program designed to optimize their well-being, self-management, and adherence. Ultimately, this work aims to contribute to more person-centered prostate cancer care by supporting men not only in managing the psychological challenges associated with active surveillance but also in maintaining quality of life, resilience, and confidence throughout their care trajectory. Given the challenges in delivering sustainable and accessible supportive care in routine clinical practice, there is a need to explore approaches that are both feasible and efficient, for which nurse-led eHealth-based interventions may offer a promising avenue.

Central Research Question: *How can a nurse-led (digital) psychosocial support program for men with low-risk prostate cancer during Active Surveillance be systematically developed and optimized through stakeholder co-creation to address unmet needs, enhance psychosocial well-being, and improve adherence to monitoring protocols?*

Framework for development

Complex interventions, such as supportive care programs in oncology, are characterized by multiple interacting components, variability in outcomes, and strong dependence on context. As such, their development and evaluation require a structured methodological approach. The Medical Research Council (MRC) Framework for Complex Interventions provides such a structure and is widely used to guide the systematic development, evaluation, and implementation of complex healthcare interventions (see figure 2).[3,103] The framework is grounded in an iterative and theory-informed process in which evidence, theoretical understanding, and stakeholder input are integrated throughout all phases of development. These phases typically include intervention development, feasibility and piloting, evaluation, and implementation, with each phase informing subsequent refinement of the intervention.[3,103]

The development of a nurse-led support program for men on Active Surveillance (AS) can be considered a complex intervention, as it consists of multiple interacting components, including information provision, psychosocial support, and lifestyle guidance, targeting both patient-related and healthcare-related behaviors. Given the complexity of AS follow-up care and the need for sustained patient engagement over time, such interventions require careful alignment with clinical practice and patient needs.

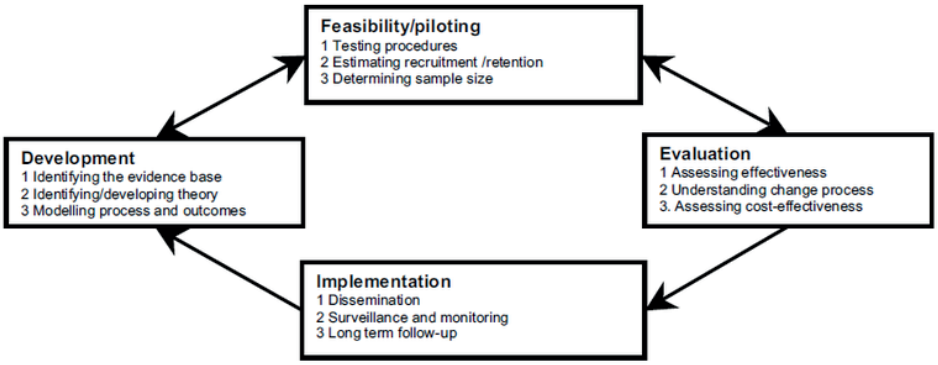

FIGURE 2. MRC Framework[3,103]

This framework emphasizes a phased, systematic approach to move from theoretical development to feasibility testing, evaluation, and eventual implementation. A critical pillar of this approach is the continuous involvement of stakeholders and the target population across all phases of the research process. By utilizing methods such as Design Thinking and co-creation, the perspectives of patients, their partners, and the multidisciplinary clinical team are integrated from the earliest stages of development through iterative refinement of the intervention.[104] This collaborative process ensures that the intervention aligns with the lived experiences of men on AS, thereby increasing the likelihood of clinical relevance, acceptability, and sustainable implementation. This is particularly relevant for digital nurse-led interventions, where usability, contextual fit, and stakeholder engagement strongly influence effectiveness and uptake. Accordingly, stakeholders were actively involved throughout the different phases of this project.

Structure of the dissertation

This dissertation follows the phased approach of the Medical Research Council (MRC) framework, moving from the identification of unmet needs to the development and feasibility testing of a supportive intervention for men on active surveillance. The empirical chapters each correspond to a specific phase of this process and collectively inform the development of the final intervention.

Chapter 2 presents a qualitative study exploring the lived experiences and psychosocial support needs of men on active surveillance.[105] This study provides an in-depth understanding of patient-reported challenges and forms the foundation for intervention development. This study is aligned with the Development phase of the MRC Framework.

Chapter 3 describes a scoping review that maps existing evidence-based interventions for men undergoing active surveillance that address psychosocial needs in prostate cancer care, thereby identifying potential components for inclusion in the support program.[106] This work further contributes to the Development phase by informing the theoretical and evidence base of the intervention.

Chapter 4 reports a modified Delphi study in which consensus was reached among patients, partners, and healthcare professionals regarding the most relevant and acceptable intervention components.[107] This study also forms part of the Development phase, focusing on prioritization and validation of intervention content.

Chapter 5 presents a co-creation and Design Thinking study in which these components were translated into a patient-centered digital prototype through iterative stakeholder involvement.[108] This study represents the final stage of the Development phase, in which the intervention was operationalized into a concrete prototype.

Chapter 6 reports a feasibility study evaluating the usability, acceptability, and potential integration of the developed intervention within routine clinical practice.[109] This chapter corresponds to the Feasibility and Piloting phase of the MRC Framework.

This dissertation concludes with a general discussion presented in **chapter 7**. In this chapter the main findings are synthesized and their implications for clinical practice and future research are discussed.

TABLE OF RESEARCH STUDIES

Chapter	Study Title / Focus	MRC Phase	Design	Population / Respondents
2	Identifying psychosocial support needs	Development	Explorative Qualitative	17 PCa patients on AS
3	Identifying potential interventions	Development	Scoping Review	2,824 articles screened; 12 studies included
4	Stakeholder consensus on interventions	Development	Modified Delphi	31 stakeholders (pts, nurses, urologists, etc.)
5	Systematic development of digital tool	Development	Design Thinking	empathy interviews (n=5); brainstorming sessions (n=9); user tests (n=3); heuristic tests (n=9), implementation interviews (n=18)
6	Feasibility and acceptability in practice	Feasibility / Piloting	Mixed methods	35 PCa patients across 4 clinics, 7 caregivers across 4 clinics

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CHAPTER 2

Optimizing psychosocial support in prostate cancer patients during active surveillance

Donachie K | Cornel E | Adriaansen M | Mennes R | van Oort I | Bakker E | Lechner L.

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ABSTRACT

Introduction

The preferred management strategy for low-risk PCa (LR-PCa) is AS. Patients remain under close surveillance to monitor disease progression. However, living with untreated disease has psychosocial implications. The objective of this study was to investigate the psychosocial support needs in PCa patients undergoing AS. According to a previously conducted study 30% of patients risk developing anxiety during the first year of AS.[9] Additional research suggests approximately 10% of AS-patients request a change to active treatment, often based on anxiety.[7,8] Literature states that psychosocial support can effectively reduce anxiety and uncertainty.[12] Research question: What are the psychosocial support needs of prostate cancer (PCa) patients undergoing active surveillance (AS)?

Methods

A literature-based interview guide was used to conduct 17 semi-structured interviews following an explorative qualitative approach. LR-PCa patients, eligible for AS, were enrolled from two participating Dutch urology clinics experienced with AS. Written informed consent was obtained. Inclusion ended after attaining data saturation. The interviews were transcribed verbatim. NVIVO 10 was used for open coding.

Results

Participants expressed recurring uncertainty and anxiety caused by medical examinations, lower urinary tract symptoms and erectile dysfunction. Various effective and ineffective coping strategies were adopted by participants. The use of specific strategies was associated with patient-physician relationship, locus-of-control and disease-acceptation. Ineffective coping strategies seemed to impede resilience during stressful situations. Satisfactory decision-making and disease acceptation were promoted by immediate availability of relevant, reliable information regarding disease characteristics and treatment options.

Conclusions

Early-stage reliable and relevant information, assessment and encouragement of effective coping strategies appear to be important psychosocial support needs during AS. Most participants in this study had spousal support and completed higher education. Future research should determine the generalizability of these findings in a more heterogeneous population.

INTRODUCTION

Prostate Cancer (PCa) is the fourth most common cancer worldwide and affects 1.3 million men annually.[1] Although incidence of PCa increases, mortality remains constant and low-risk PCa (LR-PCa) is diagnosed more frequently.[2] Possible treatments for PCa include surgery and radiation. These treatments are accompanied by negative side effects and do not improve survival in low-risk disease.[3] Active surveillance (AS) is a conservative treatment approach that involves close monitoring of the disease. During AS patients do not undergo active treatment but remain under close surveillance. Only if disease progression occurs, active curative treatment is initiated. To reduce overtreatment, AS is the preferred treatment option in LR-PCa. AS has the potential to minimize treatment-related toxicity and complications and reduce healthcare costs without compromising survival.[4] This has resulted in an increased AS-adoption in the United States, Australia and Europe during the last decade. In these regions, approximately 40-75% of LR-PCa patients select AS.[5] Despite the obvious advantages, AS is also associated with anxiety and uncertainty caused by living with untreated disease.[6] Although AS is becoming a more popular treatment choice, 2-40% of patients discontinue AS within 5 years. Approximately 10% of AS-patients request to change to active treatment, often based on anxiety.[7,8] Research indicates that approximately 30% of patients risk developing anxiety within the first year of AS.[9] Psychosocial problems, such as anxiety and uncertainty, are not uncommon in cancer patients. One third of the general population of cancer patients express a need for psychosocial support.[10] In PCa patients there is a greater need for psychosocial support during AS compared to the need expressed during active treatment.[11] Psychosocial support aims to reduce the emotional burden associated with cancer by decreasing anxiety and improving effective coping strategies. Psychosocial support can effectively reduce anxiety and uncertainty.[12] Quality of life (QoL) and patient engagement improve during AS when anxiety and uncertainty are reduced.[7] Furthermore, the presence of psychosocial support can improve AS adherence during AS.[13]

Although psychosocial support plays an important role during AS, follow-up visits often focus on physical well-being and early detection of disease progression. Nurses often adopt a more holistic view of care by addressing physical, psychosocial and emotional well-being. However, they are not always involved during AS follow up. If provided with time and opportunity, nurses are well suited to deliver acceptable, accessible and cost-effective psychosocial support during AS.[14] Nurse-led psychosocial support might be a feasible intervention to reduce anxiety and uncertainty and improve adherence.[15]

Various psychosocial support programs exist for the general cancer population. These programs have the potential to positively affect QoL and improve psychosocial symptoms.[16] However, these interventions do not increase QoL or decrease anxiety in PCa patients.[17,18,19] This might be due to the specific characteristics of the AS population. Therefore, it is still unclear what specific psychosocial problems affect anxiety and uncertainty and what interventions effectively reduce the psychosocial burden of AS. The quality of available evidence on psychosocial interventions for PCa patients is limited and most

research does not focus on AS patients specifically. However, factors contributing to AS-adherence have been identified in literature. Since patient engagement improves during AS when anxiety and uncertainty are reduced these factors are important.[7] Contributors to long-term AS-adherence are a realistic survival perception, presence of support groups, online forums, spousal and family support, provision of useful, consistent, reliable information on disease, self-management and effective coping strategies.[20]

Since there are existing unmet psychosocial support needs during AS, this study focuses on these needs. In the general PCa population, the following psychosocial support needs are identified: fear of cancer progression, concerns about relatives, changes in sexual feelings and a demand for disease information. The aim of this study was to identify the psychosocial support needs of prostate cancer patients during AS. This is the first step in developing a psychosocial support program for this specific population.

METHODS

Design

The researcher (KD) conducted 17 semi-structured interviews from March to May 2018. To acquire new insights on patient perspectives regarding this sensitive topic, a qualitative research design is justified.[21] The impact of AS on mental well-being cannot be measured adequately with quantitative instruments.[22] Talking about psychosocial needs is presumably a sensitive topic. Therefore, semi-structured qualitative interviews were suitable for this study. Qualitative interviews provide the opportunity to gain rich insights in patient perspectives and experiences. The generic explorative qualitative design selected for this study was appropriate to identify the needs in this population.

Sample

Participants were eligible to participate if diagnosed with LR-PCa and undergoing AS. Participants were selected from a population of patients diagnosed with LR-PCa undergoing AS at two participating hospitals situated in the Netherlands.

This study aimed to achieve theoretical data saturation. Literature indicated that data collection from approximately 15-17 participants would establish data saturation.[23] A maximum variation purposive sample of 15 patients diagnosed with LR-PCa undergoing AS were included. Participants varied in age, time since diagnosis and educational level. In addition, two deviant cases were included to obtain valuable information on unmet needs and challenge emerging patterns. Deviant cases do not meet eligibility criteria and help to develop a rich, more in-depth understanding. They act as a control case during data-analysis, adding rigor to this study. The first deviant case (age 69, 13 days since diagnosis) concerned a participant opting for either AS, surgery or radiation after a recent LR-PCa diagnosis.

The second case concerned a participant that discontinued AS and underwent active treatment for non-medical reasons (age 65, 27 months since diagnosis).

Inclusion criteria:

- Diagnosed with LR-PCa and eligible for/currently undergoing AS
- Follow up occurred at the participating urology departments.
- Proficiency in Dutch or English language
- Understanding of the interview questions
- Adequate expression of feelings and reactions during the interview

Exclusion criteria:

- Previously diagnosed with an anxiety disorder
- Mentally incompetent or legally incapacitated

Procedures

This study was conducted at two Dutch clinics during a three-month period. Urologists applied the in- and exclusion criteria on the study population. Verbal and written information regarding aim and design of this study was provided to eligible patients by an oncology nurse. Patients willing to participate were approached by KD for further detailed information. A 1,5-hour appointment at the participant's home or in hospital was scheduled after 1 week. During this appointment remaining questions were discussed and informed consents were obtained. Subsequently, KD conducted a semi-structured interview.

Interviews were executed according to a Dutch literature-based interview guide and audiotaped (see table 1). The researcher used detailed field notes to capture occurring thoughts and observations. After completion of each interview, audiotapes were transcribed verbatim.

TABLE 1. Literature based topic list

Emotional support	**Practical support**
supportive counseling	medical support
psychological services	education
coping	disease education
masculinity	urinary incontinence
sexuality	ED therapy
relationship	disease support
communication techniques	lifestyle training
peer support / peer engagement	exercise
	diet
	financial support
	social services
Preferred method	
Delivered by nurse/ general practitioner/ dietician, physical therapist/medical specialist (psychologist, sexologist, urologist)	
Couples-based interventions versus individual or peer group interventions	
Medium: internet, face-to-face, forum, brochure/leaflet	

During the analytical phase attention was paid to rigor, reliability, validity and objectivity. Rigor was increased by adding two deviant cases. The researcher used memos to provide a decision trail. Investigator triangulation took place during the coding process. A sample of 4 transcripts were independently analyzed by a second investigator (RM) using open coding. Results were discussed and initial consensus was reached. Prior to and during this study peer reviews and expert consultations took place to discuss methodology and emerging themes. Interview transcripts were returned to participants for a member check. Frequent peer debriefing was used to achieve reflexivity and critical reflection on own preconceptions.

Data collection

The 17 semi-structured interviews took place according to a literature-based topic list and interview guide.[24-30] Sensitizing concepts were identified in the literature and shaped the topic list and interview guide (see box 1).

Demographic data and participants characteristics were collected. This included the following variables: age, ethnicity, occupation, education, sexual orientation, marital status, family size, tumor characteristics and time since diagnosis.

BOX 1. Interview guide

Could you tell me what you felt when you were told you had prostate cancer?
You were asked to choose a treatment, how did you come to your decision?
What is it like for you to make this decision?
Why did you choose AS?
What advantages or benefits did you expect from AS?
What disadvantages did you expect from AS?
What is your experience with AS up until this moment?
In what way has AS affected your physical well-being?
In what way has AS affected your mental well-being?
In what way has AS affected your social well-being?
What is your experience with the support from your partner?
What is your experience with support from your network?
What is your experience with the support from your GP and the hospital?
Some men experience a loss-of-control over their bodies, lives and disease during AS. What is your experience?
What negative consequences has AS caused?
How did you handle this?
In what could we (professionals) have supported you better during AS?
What emotional support should, or could we offer?
What practical support should, or could we offer?
Who would be most suitable to offer this support?
Should this support be offered to you individually, to you and your partner or to a group of peers?
Should this support be offered during face-to-face meetings, via the internet or using a different medium (i.e. apps, leaflets).

Data analysis

The analytical process commenced by transcription of the audiotapes. Two interviews were not audiotaped due to equipment failure. However, extensive minutes and field notes were used for further analysis. The transcripts were read and re-read to immerse in the data. NVivo 10 (QRS International, Virginia, USA) software facilitated the coding process. Although sensitizing concepts were present prior to analysis, the coding process used an inductive approach. Open coding generated analytical categories by indexing particular phrases and text fragments. Constant comparison was used to check and compare data in one category to other data. Deviant cases were important in this phase to prevent tunnel vision. Sequential analysis used data gathered and analyzed after 4 and 8 interviews to shape ongoing data collection by refining the interview guide and developing additional categories (see table 2).

TABLE 2. Alterations to interview guide based on sequential data analysis.

Phase 1 Questions	Phase 2 Questions	Phase 3 Questions
Impact diagnosis	Impact diagnosis	Physician reliability
AS selection	Role physician in AS selection	Influence of AS on emotional, social and physical well-being
Expected (dis)advantages of AS	Experienced (dis)advantages of AS	Experienced anxiety and uncertainty
Experienced (dis)advantages of AS	Experience with peer support	AS associated problems
Influence of AS on emotional, social and physical well-being	Disease and PSA control	Coping strategies
Experienced support from partners, peers and professionals	AS associated problems	Disease and PSA control
Masculinity and disease control	Coping strategies	PSA rituals

After completion of the coding phase, similar or complementing codes were grouped into themes. Data collection was completed when new cases did not generate new codes or insights (data saturation) and reached after 14 interviews. To understand the larger meaning of the data associations, themes were examined, and findings were related to the available scientific literature and research objectives.

Participant quotations that reflect themes and findings were selected. Memos on analytical decisions were written to provide a decision trail. The consolidated criteria for reporting qualitative research checklist (COREQ) were used to report the results.

Ethical considerations

This study was conducted according to the principles of the Declaration of Helsinki. This study was conducted in compliance with the Data Protection Act and the European Code of Good Administrative Behavior. The study protocol, patient information and informed consent form were provided to the Medical Research Ethics committee (MREC) of both clinics. The MREC provided ethical approval for this study (number 2017-4008) and indicated it is not subject to the Medical Research Involving Human Subjects Act (WMO). During the interviews the researcher paid continuous attention to the psychological well-being of participants. Aftercare was offered to two participants, both declined.

RESULTS

Participants and demographic data

Table 3 shows the demographics and characteristics of all 17 participants. The majority of participants (n=12) were enrolled from clinic 2. Approximately half of the interviews took place at home, the other half at the urology clinic. 1 Interview took place at a university close to clinic 1 upon the patient's request. The average interview duration was 0:59 min. All participants were involved in a heterosexual relationship and most (n=16) participants were married.

All participants had post-high school education. The majority had a master's or bachelor's degree (58%). During 11 interviews a spouse was present. All participants were Caucasian and from Dutch descent. Ages varied between 54-76 with an average of 67 years. Average time since diagnoses was 47 months.

TABLE 3. Characteristics participants

Participant	Clinic	Location interview	Duration interview	Partner present	Time since diagnosis	Age	Education
P1	1	Hospital	1:10	No	36 months	76	MSc
P2	1	Hospital	1:09	Yes	48 months	68	BSc
P3	1	Home	0:47	No	12 months	55	Some college
P4	1	Home	0:57	Yes	48 months	65	BSc
P5†	1	University	0:37	No	< 1 month (13 days)	69	MSc
P6	2	Home	1:01	Yes	7 months	66	MSc
P7	2	Hospital	0:59	No	114 months	71	Some college
P8†	2	Hospital	0:50	No	27 months	65	BSc
P9	2	Home	1:08	No	120 months	68	BSc
P10	2	Hospital	1:13	No	24 months	67	Associates degree
P11	2	Hospital	1:15	Yes	20 months	73	Associates degree
P12	2	Home	0:23	Yes	48 months	68	Associates degree
P13	2	Home	0:44	No	117 months	73	Associates degree
P14	2	Home	1:01	No	12 months	69	MSc
P15	2	Home	0:54	Yes	50 months	54	BSc
P16	2	Hospital	1:30	No	84 months	63	Associates degree
P17	2	Hospital	1:05	No	36 months	64	MSc

† Deviant case(s)

Impact of diagnosis

Most participants stated that PCa diagnosis had a transient big impact. Participants described experiencing fear and feeling confronted with their own vulnerability and mortality immediately after the diagnosis. In most cases, this initial fear was mostly related to associations with the word 'cancer'.

P11: 'But that one word, that one word, it is prostate…. cancer.'

Reliable information by physician or nurse on disease heterogeneity, mortality risk, morbidity and treatment options enabled participants to process the diagnosis and eliminate the immediate life-threat primarily experienced.

P10: 'Well uh... then he explained it to me, he said... Maybe you will die with prostate cancer, but not because of prostate cancer. That last sentence did it for me…'

Participants elaborated on the long-term impact of LR-PCa. Participants that seemed to have accepted their disease often addressed end-of-life preparations and adoption of lifestyle changes such as healthy eating and frequent moderate exercise.

P7: '[..] It is not just the technical stuff, it is also the insurance, the bank details. Who is our accountant? I have written everything down, 8 sheets of paper, everything is on there.'

Overall, the impact of LR-PCa was acceptable. AS was valued positively by all participants. Some discomfort was caused by lower urinary tract symptoms (LUTS) or erectile dysfunction (ED).

P13: 'Well uh… when I think about it, I think about urinating, which has become more difficult, and all the little problems surrounding that. [..]'

Relationship with physician

Participants reported that AS selection was often advised by their physician. Confidence in the expertise and experience of their physician and an emotional connection seemed to play an important role. Almost all participants emphasized that trust in their physician was an absolute condition for AS selection.

P2: 'With this urologist, I thought if I google, I probably know as much as you do...[..] I had to get out of there as soon as possible.'

An empathic approach and genuine consideration of the participants' interests was highly appreciated. AS seemed less attractive to participants that described having a strong internal locus-of-control since the disease is primarily managed by the physician. In these participants AS generated an uncomfortable feeling of dependency.

P10: 'Everyone can tell me... you will live to be 95 with this disease. [..] That cancer is still in my body. '

Coping strategies

Effective coping strategies reduced the psychosocial burden associated with AS. It seemed to be associated with better disease acceptance and more effective long-term coping. Participants described the use of various effective and ineffective coping strategies. Early-stage effective coping seemed to consist of information seeking behavior, discussing the news with family, friends and peers, seeking support from family/friends to face anger, fear or grief and preparations for end-of-life scenarios.

> *P10: 'Yes, it was very difficult. There is something in your body. [..] I needed about 14 days to get to a certain point.'*

Coping strategies that appeared less beneficial to disease acceptance and effective long-term coping were avoidance, denial, excessive smoking and use of alcohol. Participants with these coping strategies did not appear to completely process or accept their diagnosis. Some preferred to avoid confrontations with their disease. Peer meetings, hospital visits or discussing the subject with acquaintances was avoided. On some occasions the diagnosis was not shared with others, for instance close relatives, children or siblings were not informed. Denial occurred in some instances where participants described not being sick.

> *P11: 'I haven't told family or acquaintances; I didn't share it. [..]I haven't told my brothers or sisters.'*

Challenges during AS

A considerable negative impact was related to repeat prostate biopsies and blood tumor markers monitoring. These medical procedures caused anxiety and uncertainty in a great number of participants. The majority of participants described a latent fear of disease progression, especially the presence of undetected metastases.

> *P2: 'It is such an ambiguous feeling. Anything can happen. [..] What if you do have metastases in your bones, well that means the end.'*

> *P13: 'Yeah, it is the anxiety again... what are the results going to be.'*

PSA (prostate specific antigen) is used as a tumor blood marker and determined every 3-6 months to monitor PCa progression. Awaiting the result of this test was also challenging and stressful according to the majority of participants. Some participants described the presence of self-determined and indistinct PSA margins. Exceeding these PSA margins generated uncertainty and anxiety. Sensing loss-of-control was expressed by some participants. This loss-of-control was compensated by varying PSA rituals.

Two participants mentioned the use of cannabis oil to reduce anxiety and decrease PSA-levels. At least three participants avoided cycling or ejaculating up to one week prior to PSA testing. Six participants claimed there was a relation between nutritional adjustments and PSA fluctuation.

P4: 'It went up. I used my diet and close attention to doing all sorts of things to bring it down. But it still went up. That disappointed me.'

P12: 'Since this spring my PSA went up 1 point. [..] that makes me think. It concerns me.'

Practical support needs

Most participants acknowledged spending a great deal of time in search of new or relevant information regarding their disease. Participants expressed a strong need for information in the first two weeks up to four months after diagnosis. The majority of participants consulted the internet. Some participants conferred with multiple physicians for advice. Several participants contacted peers for additional insights and experiences. The information available online and obtained from peers was often a cause for uncertainty or anxiety. A large disadvantage was the subjectivity of this information.

P2: 'We looked up a lot of information. [..] You find all sorts of information about prostate cancer. [..] In that uncertainty you start looking, as a patient you shouldn't.'

Availability of reliable, disease specific information was explicitly mentioned as a potential opportunity for improvement. In addition, participants indicated that immersing in information during this first period was helpful in processing and accepting their diagnosis.

P16: 'I talked about it a lot. I looked up a lot of information that first week. I had to 'ruminate'. It helped me to process [..]'

Further examination of this practical support need revealed that participants experienced insufficient or inadequate information regarding scientific developments and innovations, available treatment options for PCa, LUTS and ED, recommended lifestyle changes and self-management strategies to influence PSA fluctuation. An enclosed website or digital application provided by the hospital or recurring theme meetings was the preferred method of information delivery.

P4: 'Just tips, point me in the right direction. What should you do, what shouldn't...[..] Food, lifestyle, that stuff. '

P10: 'Especially in the first six months. You want to know everything. You want to become your own expert'

Emotional support needs

Although participants did not describe specific emotional support needs, recurring anxiety and uncertainty occurred in the majority of participants. This resulted in behavioral change, such as social withdrawal and increased agitation. Quality of life also decreased according to participants.

P10: 'It is never away; it never leaves my mind. You know it is there...'

P12: 'If it happens to you, it is uncomfortable. Yeah, well, you are relieved but always scared'

Some participants appeared to have passed through various stages of mourning and reached disease acceptance. These participants expressed more effective coping strategies. Although uncertainty and anxiety were still experienced occasionally, the emotional discomfort this caused was openly discussed and the participants allowed the presence of these emotions.

P4: 'Yes, that... exchanging experiences, which helped me.'

At least five participants did not reach the point of disease acceptance. Two participants appeared to have stagnated in the denial phase. Ineffective coping strategies, such as excessive drinking, smoking and avoiding confrontation, were observed by participants, their partners or the researcher. Increased anxiety and uncertainty were experienced by these participants when scheduled medical examinations took place to monitor disease progression. An effective approach to handle these emotions was absent resulting in avoidance, agitation or substance abuse.

P8: 'During that time I faced a lot of problems, it caused me to drink a lot'

P16: 'I'm scared that, if I start with interventions, I will become more aware of my cancer, be more anxious.'

DISCUSSION

This study aimed to generate some insight into the psychosocial support needs of PCa patients during AS. The results of this study provide insight into these needs during various stages of AS. The diagnosis appeared to have a transitory but significant emotional impact. Obtaining and interpreting relevant and reliable information appeared to be a major focus immediately after diagnosis for the participants. This contributed to a realistic perception of disease risk and survival chances. Confidence in the physician, appraisal of their experience and expertise, presence of an emotional connection and personal locus-of-control were crucial for AS-selection in this population. Participants experienced the overall emotional burden of AS as acceptable. However, LUTS and ED decreased the perceived QoL.

Recurring medical examinations appear to temporarily increase anxiety and uncertainty. A latent fear of disease progression or undetected metastases was often present. The ability to cope with these emotions seemed dependent on adopted coping strategies. The selected strategy appeared reliant on three factors: the physician-patient relationship, internal or external locus-of-control and the ability to accept their disease. Ineffective coping strategies were observed more in participants with a strong internal locus-of-control, insufficient trust in the physician or absence of disease acceptation. Participants described that information seeking, family or peer support and practical preparations seemed to promote effective coping and disease acceptation. Avoidance, denial and substance abuse were not associated with a reduction in the experienced emotional burden. Participants indicated the presence of self-defined PSA margins. Various self-management strategies to influence PSA-levels were employed. Specifically presented were dietary changes, nutritional supplements, adaptations in sexual behavior and changes in the nature and frequency of physical exercise.

Anxiety and uncertainty affect AS-selection and patient engagement negatively.[7,8] Furthermore anxiety and uncertainty affect emotional and physical well-being.[31] Effective interventions to reduce AS-associated anxiety and uncertainty are not yet available.[17,18] This study not only demonstrated the emotional burden experienced by PCa patients undergoing AS. It also provides an insight into the psychosocial support needs of this population during various stages of AS. These findings could be used to develop an effective psychosocial support program specifically designed for PCa patients undergoing AS.

The findings of this study have been compared to previously conducted studies. Mastris and Denis also described the transient big impact of PCa diagnosis.[32] PCa patients' initial relief of avoiding invasive treatment by selecting AS is soon replaced by uncertainty and anxiety during follow-up. Kim et al confirm the importance of the patient-caregiver relationship.[33] They indicate that a positive relationship was an absolute condition for AS-selection and adherence. Kinsella et al suggest that AS should come across as well-organized, transparent and supportive to oppose the experienced loss-of-control.[20] Davison and Goldenberg state the importance of Shared Decision Making (SDM) to facilitate a deliberate and informed decision.[34] Kim et al and Loeb et al suggest that patients who have not received sufficient information on AS report higher stress-rates.[33,35] Caregivers should provide transparent information on AS impact. This includes sharing monitoring protocols and patient experiences with AS. Kinsella et al and Yanez et al affirm the use of information and peer contact as effective coping strategies.[20,36] The promotion of effective self-management strategies, such as lifestyle adjustments and complimentary therapies, increases a sense of control.[20]

Strengths and limitations

An important limitation to the validity of this study is that investigator triangulation was only conducted on a sample of 4 transcripts. However, initial consensus was reached. Peer-review of emerging themes did take place. A second limitation could be the characteristics of the study sample. A bachelor's or master's degree was obtained by 58% of participants. This might influence the external validity of this

study since this is not consistent with the general population. Lang et al suggest that educational level affects AS adherence in LR-PCa.[37] The importance of spousal support was expressed during this study. All participants were currently in a heterosexual relationship. It is unclear if this affects external validity. Furthermore, it is possible that a selection bias was introduced into this study. Participants with an ineffective coping strategy tend to avoid confrontation with their disease. Therefore, their willingness to participate in this study might be limited. An important strength was the enrolment of two diverse clinics and the inclusion of deviant cases. Tunnel vision was limited by conducting investigator triangulation, member checks and peer debriefing. In addition, extensive field noted, and memos provide a decision trail.

CONCLUSIONS

This study provided an insight into the psychosocial support needs of AS patients during various stages of AS. It emphasizes the importance of providing reliable, relevant information to the patients on disease characteristics and mortality risk, immediately after diagnosis. A positive patient-caregiver relationship seemed to play an important role in AS adoption during the first months. This study recommends that transparent, unbiased, proactive information on treatment options and procedures is provided consistently, and that information is adjusted to health literacy level and socio-economic status. Participants felt a need for information on disease, treatment, scientific developments, complementary and alternative medicine (CAM), self-management strategies and lifestyle changes. This information need was mostly present during the first months after AS-initiation. The use of an enclosed website or digital application to access this information is recommended. According to the participants in this study, this website or digital application should also facilitate PSA self-monitoring, contact with caregivers and peers. Participants also suggested the organization of expert-hosted meetings on ED, LUTS, lifestyle and CAM. During the first year 30% of AS-patients risk developing anxiety.[9] Regular assessment of coping strategies might be crucial in the detection of ineffective coping strategies. Upon the detection of ineffective coping strategies, psychoeducation should promote adoption of effective coping strategies and disease acceptation. Since anxiety is most present during the first year, comprehensive evaluation of AS within this first year should reaffirm the patient's preference. During long term follow-up more attention should be paid to LUTS and ED. Further research should focus on the development of a psychosocial support program. This program should consist of evidence-based elements, based on the needs of the AS population, designed in collaboration with experts and patients.

This research brings us closer to the development of a program that addresses PCa patient's specific needs during AS: individualized information, decisional support, peer support, promoting effective coping and monitoring the physical, emotional and social well-being during AS.

Although AS is beneficial to both patient and health care system, living with an untreated disease can cause anxiety and uncertainty. Living with untreated disease, frequent medical examinations, LUTS and ED causes anxiety during AS. This seemed especially present during the first years after AS adoption. Therefore, psychosocial support should focus on the first years after initiation. This study provides insight into the psychosocial support needs of patients during various stages of AS. The first months after AS adoption there seems to exist a need for reliable, relevant information on disease, treatment, scientific developments, complementary and alternative medicine (CAM), self-management strategies and lifestyle. It seems transparent, unbiased information on AS delivered consistently by caregivers and adjusted to health literacy level and socio-economic status reduces uncertainty during AS. There appears to be a great need for information on disease characteristics and mortality risk immediately after diagnosis. A website or digital application could be a feasible method to provide information, facilitate PSA self-monitoring and contact with caregivers and peers. In addition, expert-hosted meetings on topics such as ED, LUTS, lifestyle and CAM might also be valuable.

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CHAPTER 3

What interventions affect the psychosocial burden experienced by prostate cancer patients undergoing active surveillance? A scoping review

Donachie K | Cornel E | Pelgrim T | Michielsen L | Langenveld B | Adriaansen M | Bakker E | Lechner L.

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ABSTRACT

Introduction

Living with untreated prostate cancer (PCa) may cause anxiety and uncertainty in men undergoing active surveillance (AS). Developing a psychosocial support program for such patients might promote psychosocial well-being and patient engagement. This review aims to identify interventions with the potential to influence the psychosocial burden of prostate cancer patients undergoing AS.

Methods

A scoping review was conducted in accordance with the PRISMA Extension for Scoping Reviews Checklist. A systematic search was conducted in six databases and included publications dating from 2009. All available and eligible evidence was included in this review.

Results

After screening 2824 articles, 12 studies were included in the review: nine quantitative, one qualitative, and two mixed-method papers. The relative strength of these studies was limited and the quality of most was moderate.

Conclusions

The described interventions can be categorized into three major themes: information and education, coping and (psycho)social support, and lifestyle. Psychosocial support for men undergoing AS should entail involvement of family and spouse during the decision-making process, tailored information about PCa treatments, risks, benefits, protocols, lifestyle adjustments, and complementary and alternative medicine. Assessment and promotion of effective coping and self-management strategies is recommended. Healthcare providers should actively promote physical activity and nutritional improvements. Physical activity programs may also be helpful in facilitating peer support, which is especially important for men with limited social support. Future research should investigate combining interventions to increase efficacy and optimize supportive care during AS.

INTRODUCTION

In 2020, approximately 1.4 million men were diagnosed with prostate cancer (PCa) worldwide.[1] The incidence is still increasing and it is estimated that around 2.3 million men will be diagnosed with PCa annually by 2040.[1] A large proportion of these men are diagnosed with low-risk or insignificant disease, and various studies have suggested that men with insignificant or low-risk PCa (LR-PCa) do not benefit from radical treatment.[2] In this patient population expectant management is warranted.[3] During expectant management, patients do not undergo active treatment but remain under close surveillance. Expectant management can be subdivided into Active Surveillance (AS) and Watchful Waiting (WW).[4]

AS has a curative intent and consists of aggressive observation to detect early disease progression by monitoring several predefined parameters.[4] If disease progression is detected, radical curative treatment is initiated.[5] In contrast, WW is a palliative option that is most often provided to fragile or older patients when curative or invasive treatment is not desirable (e.g., because of limited life expectancy).[4]

AS is a cost-effective treatment option for LR-PCa.[6] Men who choose AS also avoid complications related to radiotherapy or surgery, such as erectile dysfunction and urinary incontinence.[7] As a result, men undergoing AS generally have greater quality-adjusted life-year scores.[8] Despite these advantages, living with untreated cancer and frequent medical examination may cause anxiety and uncertainty in men undergoing AS.[9] The psychosocial burden of AS has been widely discussed in literature.[10] A recent study suggests that approximately 30% of patients are at risk of developing anxiety during the first year of AS.[11] And approximately 5-10% of men initiate radical treatment based on anxiety without disease progression present.[12,13] A decrease in psychosocial well-being may influence patients' adherence to AS and lead them to initiate curative treatment without disease progression.[9,10,14]

It has been suggested that there is a greater need for psychosocial support among PCa patients undergoing AS than among patients in active treatment groups.[15] Psychosocial support can be effective in reducing anxiety and uncertainty, and providing professional psychosocial support during the first year of AS might enhance its appeal and improve adherence.[9,10,11,16,17]

This scoping review aims to identify interventions with the potential to alleviate the psychosocial burden experienced by PCa patients undergoing AS. These interventions include coping strategies, information and psychoeducation, symptom management, lifestyle, complementary and alternative medicine (CAM), self-management, mindfulness, and (peer) support.[18] This research may contribute to developing a psychosocial support program for AS patients that increases psychosocial well-being and patient engagement. This review aimed to answer the following research question: What interventions affect the psychosocial burden experienced by prostate cancer patients undergoing active surveillance?

METHODS

A scoping review was conducted in accordance with the PRISMA Extension for Scoping Reviews Checklist with the aim of being systematic, transparent, and replicable.[19] No ethical approval was required, and no protocol was registered.

In contrast to a systematic review, a scoping review provides a more general overview of evidence regarding a broader subject. Scoping reviews are used to inform healthcare practice and map the available evidence on a relevant topic. Since the aim of this review is to identify evidence about interventions that may alleviate psychosocial burden during AS, a scoping review is a suitable design for a comprehensive and broad exploration of this topic.[20,21]

Search strategy

Between August and October 2020, a systematic scope search was conducted in the following databases with the assistance of a medical librarian: Cinahl plus with full text, Cochrane, Embase (OVID), Psychinfo (Ebsco), PubMed, and Web of Science. Database-specific search strategies are described in Appendices 1 and 2.

The search strings for all databases are provided in Appendix 1. The results of each search were exported into Rayyan, and the de-duplication process described by Bramer was performed.[22,23]

The first reviewer (KD) screened all titles and abstracts for mention of prostate cancer, active management (i.e., active surveillance), and interventions influencing psychosocial burden during AS. Articles were either deemed eligible for full-text screening or excluded. A subset of articles was independently screened by blind reviewers (LM, BL, EC).

Following title and abstract screening, full texts of all remaining articles were obtained and read. A selection was then made, based on the inclusion and exclusion criteria. In accordance with the nature of a scoping review, all study types and research designs were included. This included both original studies and reviews that presented new results or interpretations not described in included individual studies.

A hand search of the reference lists of included studies and a forward reference check was conducted to identify additional eligible articles. When hand searching revealed new titles, the process of screening and application of in and exclusion criteria was repeated.

Selection criteria

In- and exclusion criteria were used to assess eligibility for this review.

Articles were eligible for inclusion if:

- A peer-reviewed full-text article was available (reporting empirical qualitative, quantitative, or mixed-methods studies and literature reviews)
- Articles were published in English or Dutch (for practical reasons)
- Research involved adult male humans (generalizability)
- Publication date was in or after 2009 (when a clear distinction between AS and WW was introduced in clinical practice)[24,25]
- Research on interventions with a potential effect on psychosocial burden during AS
- Research in men with LR-PCa (AS is justified and safe in LR-PCa)

Articles were excluded from this review if:

- Research (primarily/exclusively) on the influence of race, ethnicity, age, socioeconomic status, or health literacy on psychosocial burden (not influenced by a psychosocial support intervention)
- The research population consisted of patients undergoing WW and not AS, or the article made no distinction between WW and AS (WW is a palliative option)
- Research on the influence or effects of focal therapy, i.e., HIFU/ cryotherapy (no expectant management)
- Research on the influence of medication on disease progression, i.e., statins or androgen deprivation therapy (no expectant management)
- Research that compared levels of quality of life, distress, anxiety, or uncertainty between treatment groups (does not investigate the effect of interventions on the psychosocial burden within AS treatment group)
- Research on the decision-making process and considerations before beginning AS

Data extraction

A data extraction sheet was used to derive all relevant data from qualitative and quantitative studies. Hard copy data extraction sheets are stored by the reviewer (KD).

Quality appraisal

Quality appraisal tools were used to assess the quality of the included evidence and assess the level of evidence.[26-29] The quality of included studies was ranked as 'high,' 'moderate,' or 'low.' Two reviewers (KD, BL) discussed various cut-off values until consensus was reached. This corresponds with the scores described in table 1.

TABLE 1. Quality scoring

Quality Appraisal Tool	High	Moderate	Low
Law, et al (McMaster)	≥12	≥9	≤8
Tong, et al (COREQ)	≥26	≥19	≤18
Hong, et al (MMAT)	≥14	≥10	≤9

RESULTS

Search results

The literature search was carried out in six scientific databases and yielded 2808 unique citations. A supplementary hand search identified 16 more citations. A flowchart of the search strategy is provided in Figure 1.

Blind reviewers (LM, BL, EC) independently screened a random subset of 1100 articles. An 82.5% consensus rate on this subset was established. Remaining conflicting results were discussed by the reviewers until consensus was reached.

Characteristics of the studies

After full-text screening, 12 studies met all criteria and were included in the review.[30-41] This included nine quantitative[30-33,35,39-41], one qualitative[37], and two mixed-method[34,36] papers. All studies involved men with LR-PCa who were under active management. An overview of study characteristics is provided in table 2.

Quality appraisal

The results of the quality appraisal are provided in table 3. None of the 12 studies met all quality criteria, and only three met more than 80% of the quality criteria and were considered to be of high quality.[30,34,40]

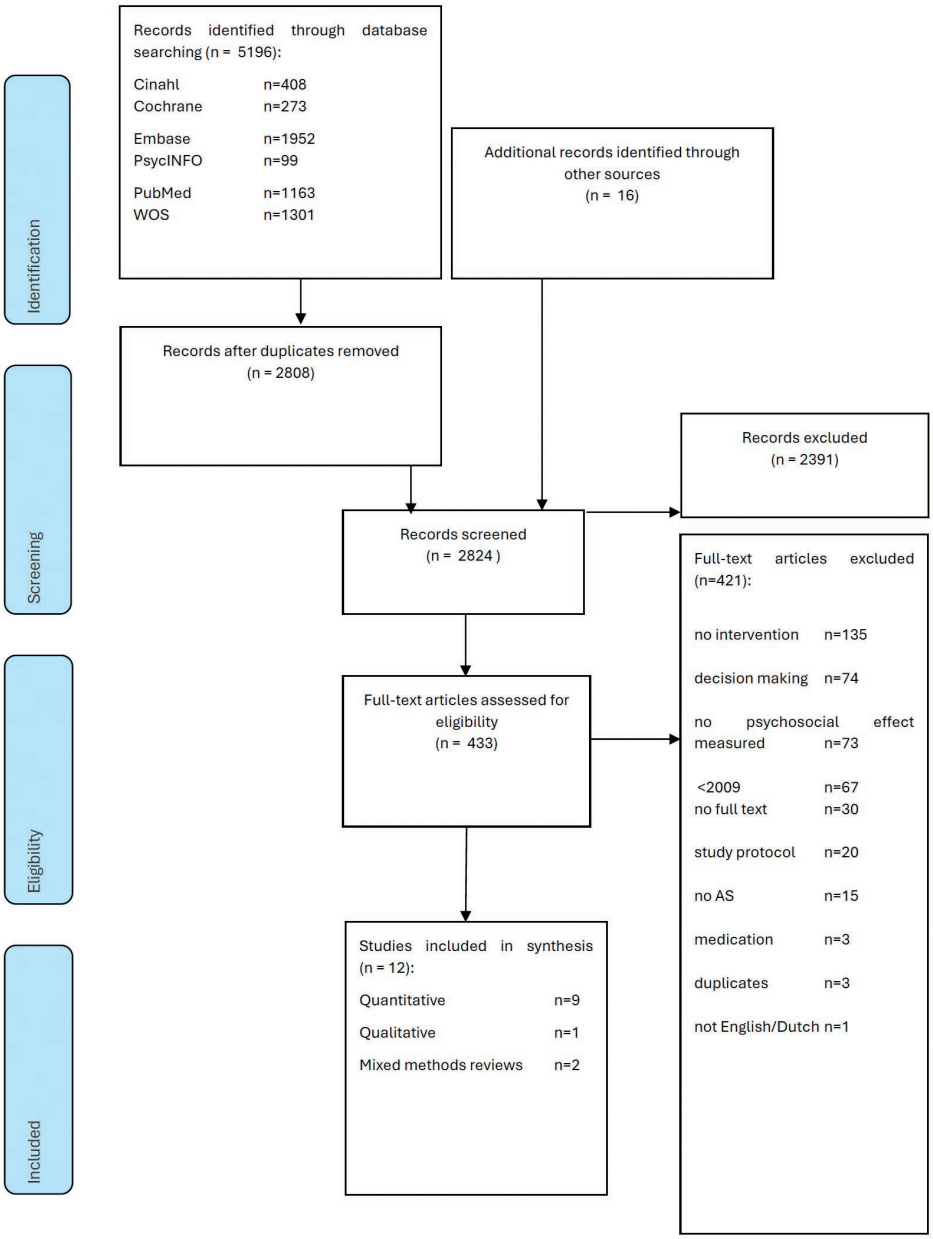

FIGURE 1. PRISMA Flowchart

TABLE 2. Characteristics of included studies[30-41]

Study	Year	Research Design	Sample	Duration	Country	Intervention	Outcome/ Themes	Results/ Findings
Baba et al.	2021	Observational cross-sectional	N=130		Germany	Psychological and social support	Distress, depression and anxiety	33.3% elevated distress. 16.5 % depressive symptoms, 13% anxiety. Psychosocial support increased in distressed patients.
Berg et al.	2016	Cohort study	N=235	Median 42 months	United States of America	Diet and food supplements	Adherence	11.5% AS discontinuation
Hedden et al.	2017	Pre-test post-test	N=71		Canada	Educational session	Anxiety, distress, uncertainty	Reduction in distress (p=0.02)
Kazer et al.	2011	Pre-test post-test	N=9	5 weeks	United States of America	Five-week internet intervention that entails cognitive reframing, lifestyle and education.	Self-efficacy, uncertainty, QoL	Correlation (r=0.88 p0.02) between increased QoL and use internet intervention
Kinsella et al.	2018	Mixed method review	N=64	n/a	United Kingdom	Social support	Adherence	Increased adherence (p=0.001)
Kinsella et al.	2019	Quasi-experiment	N=255	5 years	United Kingdom	Single educational seminar	Adherence	Increased AS adherence in intervention group (p=0.001)
McIntosh et al.	2019	Mixed methods systematic review	N=8	n/a	Australia	Support needs	Adherence	Information, psychological and emotional support, social support
Oliffe et al.	2009	Qualitative semi-structured interviews	N=25	45-90 mins	Canada	Social, peer and spousal support, coping, diet, CAM	Uncertainty	'Living a normal life' coping leads to decreased social support. 'Doing something extra' coping leads to increased uptake of lifestyle modifications.
Papadopoulos et al.	2020	Retrospective cohort study	N=630	2001-2016	Canada	Self-reported physical activity	Quality of life, emotional well-being	High physical activity leads to increased QoL (p=0.002) and increased emotional well-being (p=0.10)

Sumiyoshi et al.	2010	Pre-experiment (time series)	N=74	6 months	Japan	Mushroom Mycelium Extract	Anxiety	Anxiety decreased (P=0.0018 and P=0.0099)
Thomas et al.	2014	Double blind RCT	N=199	6 months	United Kingdom	Polyphenol rich food supplement	Adherence	Increased AS continuation in intervention group (P=0.014)
Victorson et al.	2016	Pilot RCT	N=43	12 months	United States of America	Mindfulness meditation training	Anxiety, uncertainty	Anxiety decreased (p=0.04) QoL increased (p<0.05) within intervention group.

TABLE 3. Quality scores and levels of evidence

Study	Year	Research Design	Quality tool	Quality score	Quality appraisal	Level of evidence
Baba et al.	2021	Observational cross-sectional	Law et al.	11	High	Level VI
Berg et al.	2016	Cohort study	Law et al.	9	Moderate	Level IV
Hedden et al.	2017	Pre-test post-test	Law et al.	11	Moderate	Level III
Kazer et al.	2011	Pre-test post-test	Law et al.	11	Moderate	Level III
Kinsella et al.	2019	Quasi-experiment	Law et al.	9	Moderate	Level III
Kinsella et al.	2018	Mixed method review	Hong et al.	14	High	Level V
McIntosh et al.	2019	Mixed methods systematic review	Hong et al.	13	Moderate	Level V
Oliffe et al.	2009	Qualitative semi-structured interviews	Tong et al.	20	Moderate	Level VI
Papadopoulos et al.	2020	Retrospective cohort study	Law et al.	11	Moderate	Level IV
Sumiyoshi et al.	2010	Pre-experiment (time series)	Law et al.	10	Moderate	Level III
Thomas et al.	2014	Double blind RCT	Law et al.	13	High	Level II
Victorson et al.	2016	Pilot RCT	Law et al.	10	Moderate	Level II

Themes

Three major intervention themes emerged from this review: information and education, coping and (psycho)social support, and lifestyle. A narrative synthesis of the results from the included studies is provided.

Information and education

Five studies investigated the relationship between information, education, and the psychosocial burden of AS.[32-36] These studies confirmed the presence of unmet informational needs among PCa patients eligible for, or currently undergoing, AS.

The systematic review carried out by McIntosh et al. identified unmet informational needs.[36] PCa patients undergoing AS often receive information that is inadequate, confusing, and inconsistent, which causes them distress. They receive inadequate information about PCa, signs of progression, future treatment options, and adjuvant treatment such as diet and exercise.

Ideally, the information should be consistent, unambiguous, concise, and adequately tailored to the individual. This conclusion was supported by the systematic review conducted by Kinsella et al., which identified facilitators and barriers to AS adherence.[34] Their review affirmed the importance of customization and personalization of just-in-time information. It also stressed that information should not only be provided to patients, but education must involve partners and family. Inaccurate risk assessment can cause family and friends to pressure patients to undergo curative treatment.

The importance of educating patients and their partners was affirmed by the results of the quasi-experiment conducted by Hedden et al., which evaluated the effect of an educational intervention on distress and anxiety among men diagnosed with LR-PCa (n=71) and their partners (n=48).[32] The study demonstrated that partners had higher distress levels than patients before attending an educational seminar (p= 0.03) about PCa and treatments. That seminar addressed the informational needs identified by McIntosh et al.[36] Customized and personalized information was also provided during a private meeting between the patient, partner, urologist, and radio-oncologist. Hedden et al. found that attending the seminar and private meeting significantly decreased distress among patients and partners compared to their distress before the seminar (p=<0.001).

Kinsella et al. assessed the long-term effects of a seminar on AS adherence.[35] They conducted a quasi-experiment to assess the effect of a single 1.5-hour educational seminar, after which time was scheduled for questions and peer discussion. During the first year of the study, no one experienced clinical disease progression in the intervention (n=120) or control (n=135) group. However, a significantly smaller proportion of men in the intervention group (11%, p=0.003) dropped out of AS compared to the control group (25%). After five years, the intervention group continued to demonstrate increased adherence

to AS with a significantly smaller dropout rate among patients with no evidence of disease progression ($p<0.001$).

Kazer et al. conducted a quasi-experimental study to investigate the effect of an internet-based information and education intervention on older men undergoing AS (aged 66-79, $\bar{x}=72$).[33] The intervention was combined with tailored information provided via email by a specialized nurse upon request. Cognitive reframing and self-management strategies were also provided. After subjects completed the intervention, researchers observed an overall trend toward an increase in quality of life (QoL). This study suggests that it is feasible to provide information online.

Successful reassurance and education of the patient and family are key facilitators to AS adherence. Health literacy also plays an important role, and provision and access to relevant and understandable information is a consistent theme. Inaccurate risk and survival perceptions by patients and their families may increase distress and decrease AS uptake and adherence. In contrast, distress is decreased and AS uptake and adherence are increased by the provision of transparent, consistent, and understandable information regarding PCa diagnosis, prognosis, treatment options, active surveillance, monitoring protocols, AS-associated risks, and reliable guidelines on complementary options, diet, and lifestyle changes.

Coping and (psycho)social support

Five studies addressed the importance of coping and social support during AS.[30,33,34,36,37] A cross-sectional study conducted by Baba et al. found that distressed patients undergoing AS have an elevated need for psychosocial support.[30] The systematic review conducted by McIntosh et al. found that distress is caused by unmet emotional, psychological, and social support needs.[36] In particular, men who experience AS negatively have more difficulty dealing with AS. That was less complicated for men who felt that AS was "having a positive impact," according to Kinsella et al.[34] They found that such men experience less uncertainty and feel more in control. Baba et al. found something similar in their cross-sectional study of men with PCa (n=130) who were undergoing AS (n=19).[30] They claimed that a "positive attitude" was helpful to promote coping with AS- associated distress.

Oliffe et al. affirmed the importance of adopting coping strategies.[37] Their qualitative interview study identified two self-management strategies for alleviating AS-induced uncertainty in a sample of 25 men: "living a normal life"' and "doing something extra." The study also assessed the implications of these strategies. Although "living a normal life" seemed to be an effective strategy for avoiding worry and distress, it was associated with a limited support network, avoidance, stoicism, and a resistance to lifestyle changes. Thus, this strategy may decrease AS compliance. In contrast, adopting a "doing something extra" strategy seemed to promote positive lifestyle changes. This strategy is characterized by engagement in self-health and education. Oliffe et al. observed an increased use of CAM in this population.

Engagement with their partner, family, and friends seemed to affirm the patients' commitment to AS and increase adherence.

The finding that social support promotes coping with AS corresponds with the results from other studies in this review. The review conducted by Kinsella et al. demonstrated a strong correlation between AS adherence and AS support groups for men and their families.[34] This was confirmed by Baba et al., whose study indicated that peer support from interpersonal relationships with partners, friends, and family helps patients cope with AS.[30] McIntosh et al. recommends referring men to (online anonymous) support groups during AS.[36]

Psycho-therapeutic interventions may help men who are unable to cope with AS. Kazer et al. investigated a cognitive reframing behavioral intervention among men (n=9) and found a positive correlation between intervention usage and QoL, especially in the domains "role function related to emotional health" and "social function" (r=0.88, p=0.02).[33]

In summary, men who have unmet support needs during AS are at increased risk of distress. Adopting helpful coping and self-management strategies, such as a positive attitude and a "doing something extra" strategy, may improve patients' ability to cope with AS. Furthermore, social support promotes coping, AS adherence, and commitment. Social support can be present within personal relationships or facilitated through peer support groups. Professional psycho-therapeutic help may be beneficial to men who feel unable to cope with AS.

Lifestyle

Eight studies examined the uptake and effects of lifestyle adjustments.[30,31,33,34,37-41] Most of them focused on diet and food supplements.[31,33,34,39,40] According to Oliffe et al., engagement in self-health is associated with increased commitment and adherence to AS.[37] The review conducted by Kinsella et al. found that self-management strategies, such as exercise and stress management, help men cope with uncertainty during AS.[34] Baba et al. also stated that physical activity was helpful for men who were dealing with distress.[30]

These findings were confirmed by the retrospective cohort study conducted by Papadopoulos et al., which explored the association between self-reported physical activity, QoL, and emotional well-being in a cohort of 630 men.[38] Highly active participants showed significantly higher (p=0.002) QoL scores. The most active group also demonstrated the highest odds of experiencing high emotional well-being (p=0.010).

Kazer et al. investigated the effect of an internet-based intervention that combined various components, including nutritional recommendations and the promotion of physical activity.[33] This incorporated weight control, exercise, limiting meat, and avoiding alcohol and smoking. Their four-component intervention

resulted in an overall trend toward improved QoL. After patients completed the intervention period, their QoL returned toward baseline, indicating that the intervention had a temporary and transient effect.

Diet and nutritional recommendations were also investigated in the large longitudinal cohort study conducted by Berg et al.[31] They examined the effect of a holistic AS approach on adherence in a sample of 235 men. Holistic AS consisted of AS monitoring complemented with strict dietary recommendations. In this study, with a median follow up of 42 months, only 1.3% of patients discontinued AS because of anxiety or uncertainty. In general, researchers observe a drop-out of 5-10% due to anxiety and uncertainty.[13]

Thomas et al. conducted a double-blind placebo-controlled randomized trial to evaluate the effect of a polyphenol-rich whole food supplement on AS discontinuation.[40] They found that a statistically significant lower proportion of men in the food supplement group (n=134) discontinued AS (p=0.014). Their reasons for discontinuing AS were not disclosed.

Only the study by Sumiyoshi et al. assessed the direct effect of a food supplement on psychosocial well-being.[39] They examined the effect of dietary administration of mushroom mycelium extract (AHCC) on anxiety during a quasi-experiment among 74 men treated with expectant management. Significantly lower State Trait Anxiety Index (STAI) scores were observed in participants with high anxiety levels before the intervention ($p<0.01$).

Anxiety and uncertainty also significantly decreased as a result of participation in an eight-week mindfulness meditation training, according to Victorson et al..[41] Results from their pilot randomized controlled trial demonstrated a significant ($p=0.04$) within-group decrease of anxiety in the intervention group (n=24) between baseline and six months after the intervention. Uncertainty decreased between baseline and 12 months ($p<0.01$), and global mental health increased between baseline and eight weeks ($p<0.05$). A between-group analysis indicated that post-traumatic growth was the outcome that significantly increased in the intervention group ($p=0.01$) compared to the control group (n=19).

Overall, engaging in self-health by making healthy lifestyle adjustments seems to provide men with important self-management strategies during AS, resulting in decreased distress, anxiety, and uncertainty and improved AS adherence. In addition, some lifestyle adjustments seem to directly affect anxiety and uncertainty. For instance, exercise seems to directly benefit emotional well-being, and participation in a mindfulness meditation program decreased anxiety and uncertainty.

DISCUSSION

This scoping review identified interventions that affect the psychosocial burden experienced by PCa patients undergoing AS. Those interventions can be categorized into three major themes: information and education, coping and psychosocial support, and lifestyle.

In the first category, providing information about PCa, treatments, AS protocols, prognosis, mortality, morbidity, and lifestyle via a website or educational seminar seems to assist in risk assessment and decrease uncertainty.[32,36] A positive impact on AS adherence is associated with these interventions. The involvement of the patient's partner and family is critical to the provision of information since they seem to play an important role in reassuring the patient and facilitating AS adherence.[32,36] In addition, the information should be tailored to the needs and health literacy levels of the patient and their family.[34] Individual meetings or tailored contacts could provide opportunities to assess whether patients have obtained all the required information and whether that information was consistent, understandable, and relevant.[33]

Selecting AS should be the result of a thorough consideration of risks, benefits, and coping and self-management strategies. It should not merely be selected to avoid treatment-related complications. Thus, it is recommended that shared decision-making techniques and decision aids be used to support careful deliberation about AS.[44-46]

The second category comprised coping and psychosocial support interventions.[30,33,34,35,37] Adopting a positive attitude toward AS seems to decrease distress and uncertainty.[30,34] Although an avoidant self-management strategy enables patients to temporarily prevent stress, uncertainty, and anxiety associated with AS, this strategy is also associated with a limited support network and a resistance to lifestyle changes.[33,37] These last two features are negatively associated with AS adherence. Adopting a self-management strategy that emphasizes self-health, self-education, and engagement with family and friends seems to improve AS adherence.

It is recommended to assess the adoption of effective coping and self-management strategies. Healthcare providers can use specially designed questionnaires to identify anxiety, uncertainty, or distress, and professional psychological support should be offered to men who are unable to cope with AS.[36,42,47,48] Cognitive behavior therapy, especially cognitive reframing, might help to promote a positive attitude[33] Social support from peers, family, and friends also plays an important role in helping patients deal with the psychosocial burden associated with AS. Some patients may benefit from peer support, especially those who have a limited social support network or who do not wish to discuss their experience with their friends or family.[30,34,36,37]

Lifestyle interventions and adjustments comprise the final category.[30,31,33,34,37,38,39,40,41] Physical activity, exercise, and mindfulness seem to directly affect distress, QoL, and uncertainty.[30,33,34,38,41] In addition, dietary recommendations and nutritional supplements may positively influence AS adherence.[31,33,34,39,40] It is most likely that lifestyle adjustments provide a self-management strategy that helps patients cope with uncertainty during AS.[37] Engaging in self-health practices seems to promote a sense of control over one's disease that directly and indirectly affects the psychosocial burden experienced during AS. Patients and their partners actively seek information about dietary and exercise interventions.[49]. Providing such recommendations may lead some men to make positive lifestyle changes. However, others may need professional support and guidance (e.g., from a nutritional or physical therapist) to facilitate lifestyle improvements. Motivational interviewing might improve the uptake of healthy lifestyle changes.[50,51]

Strengths and limitations

The results of this review are based on a comprehensive and systematic search of multiple databases. The search and selection processes have been described in detail. In addition, the quality of the available evidence was assessed, and a quality appraisal is provided. Despite the strengths of this scoping review, it has some limitations. One is that it was conducted by a single researcher. However, three independent reviewers were involved in selecting the articles to be reviewed. The methodology and process also were extensively discussed within the supervisory team. This decreases the risk of measurement bias.

A second limitation is the quality of the evidence included. None of the included studies met all quality criteria. In addition, the level of evidence of the included studies was predominantly low to medium. Of the two high-level studies included, one was a pilot study that therefore had a small sample size. This may have influenced the validity of the results. However, this review imposed no restrictions on research designs and thus included all available and eligible evidence in this review.

In addition, this review identified interventions that mostly had a short-term, positive effect, and most of the studies investigated stand-alone interventions.[33] Therefore, it is unclear whether combining interventions can have a complementary effect and whether a combination of interventions would generate longer lasting or improved results (e.g., a combination of interventions that have a transitory effect with interventions that demonstrate long-term results).[35]

Conclusions

In conclusion, various psychosocial interventions and lifestyle adjustments seem to affect the psychosocial burden experienced by prostate cancer patients undergoing active surveillance. Based on the findings from this review, various interventions appear to decrease the psychosocial burden during AS. Firstly, this review emphasizes the importance of transparent, understandable, relevant, and reliable information about PCa, treatments, AS risks, benefits, and protocols. In addition, information on lifestyle adjustments and CAM should be provided. Secondly, families and partners should receive adequate information and be involved in the decision-making process. Moreover, assessing the coping

and self-management strategies used by men undergoing AS can identify those who find it difficult to handle. Men who are struggling with AS or have limited coping skills should be encouraged to adopt helpful coping strategies, such as a positive attitude and health-promoting behavior. Professional psychological support should be offered to men unable to deal with AS. Furthermore, healthcare providers (e.g., urologists, nurse specialists, nurses) should actively promote physical activity and nutritional improvements by providing exercise and dietary recommendations or organizing lifestyle support programs. Physical activity programs for men undergoing AS may also be helpful in facilitating peer support.

In regard to the limitations of this review, the included number of studies and their quality it is recommended that future research investigates the feasibility and efficacy of combining various interventions that may potentially decrease psychosocial burden and optimize supportive care during AS.

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CHAPTER 4

Selecting interventions for a psychosocial support program for prostate cancer patients undergoing active surveillance: a modified Delphi study

Donachie K | Adriaansen M | Nieuwboer M | Cornel E | Bakker E | Lechner L.

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ABSTRACT

Introduction

Curative treatment of low-risk prostate cancer (LR-PCa) does not improve cancer specific survival and active surveillance (AS) is recommended. Although AS is cost-effective and reduces treatment-related complications, it requires psychosocial support. Research on psychosocial interventions specifically focused on men undergoing AS is limited. Aim of this study is to reach consensus amongst relevant stakeholders on selecting interventions offering psychosocial support to PCa patients during AS.

Methods

In accordance with the RAND/UCLA method, a modified Delphi approach was used to establish consensus on selecting interventions. During phase one, interventions were identified through a literature review and open survey among all participants. During phase two, three consensus rounds were conducted to rate potential interventions and obtain statistical consensus. The IQ healthcare consensus tool was used to calculate statistical consensus.

Results

After the first consensus round, 31 participants scored individual interventions on relevance using a 9-point Likert scale resulting in the selection of 6 interventions. During the second consensus round 13 discussion items were reviewed during a focus group. After the third consensus round, 7 additional interventions were selected by 23 participants.

Conclusions

In total, 13 interventions were selected for inclusion in a support program. This included four interventions within the domain information and education, three within coping and support, one intervention within physical well-being and four within the domain lifestyle.

INTRODUCTION

Prostate cancer (PCa) incidence increases worldwide. Approximately 1.4 million men are diagnosed with PCa annually of which 375.000 men die.[1] Due to aging and unhealthy lifestyle in the western population, a significant increase in PCa is expected within the next few decades.[22] Low-risk prostate cancer (LR-PCa) entails 28% of all newly diagnosed PCa.[2] Since curative treatment of LR-PCa does not improve cancer specific survival, expectant management is safe and cost-effective. It reduces treatment-related complications such as erectile dysfunction, lower urinary tract symptoms (LUTS) and urinary incontinence.[3,4]

Expectant management is divided into Watchful Waiting (WW) and Active Surveillance (AS). WW is a palliative option offered to men unable to undergo curative treatment due to comorbidity or limited life expectancy.[5] AS is widely adopted as an acceptable management strategy in LR-PCa and entails close monitoring with frequent medical examinations.[6] Curative treatment is initiated upon detection of tumor progression.

During AS, frequent medical examinations and living with untreated disease can cause anxiety and uncertainty.[7,8] During the first year of AS, 30% of men risk developing anxiety.[9] Some men are unable to cope with the psychological burden of AS. Approximately 5-10% of men discontinue AS and pursue active treatment despite a lack of disease progression.[10] Research indicates men undergoing AS need psychosocial support to promote psychological adaptability during AS.[7,11,12] To prevent psychosocial problems, assessment of psychosocial support needs is important amongst all men undergoing AS and not merely those already experiencing problems. Psychosocial support in this study consists of all activities aimed at reducing the emotional burden associated with cancer by decreasing anxiety and improving effective coping strategies.

Within the psycho-oncological research field, ample knowledge is available on the effects of psychosocial interventions on uncertainty, anxiety and distress in cancer patients. Based on findings from a scoping review, psychosocial support can decrease the psychosocial burden of AS and increase adherence.[13] However, research on psychosocial interventions specifically focused on PCa patients undergoing AS is limited and mostly addresses stand-alone interventions with a transitory effect.[13,14,15]

A comprehensive psychosocial support program, combining interventions with complementary characteristics is likely to lead to a broader and more sustainable effect. Such a program has the potential to optimize psychosocial support during AS and contribute to an effective and long-term psychological adaptation, which results in decreased uncertainty, anxiety and increased AS adherence. Effects of such a multicomponent program have not been extensively researched. Components of such a program should be the results of a rigorous development process involving relevant stakeholders.

Therefore, aim of this study is to reach consensus amongst stakeholders on selecting interventions for a psychosocial support program offered to men with PCa undergoing AS.

METHODS

Design

A modified Delphi approach is used to establish consensus on interventions selected for inclusion in a support program. In contrast to the more exploratory character of classical Delphi methods, interventions in this study were previously identified through literature review and stakeholder consultation.[16,17]

This study was conducted according to the RAND/UCLA Appropriateness Method.[18] Ethical approval was obtained from the Open University Ethical Committee (ref.nr. U202104601).

The RAND/UCLA Appropriateness Method distinguishes two phases. During phase one, interventions are identified through a literature review and open survey among all participants. This survey identifies additional relevant interventions based on participants' experience and expertise, resulting in a complete and comprehensive list of potential interventions. During phase two, three consensus rounds are conducted to rate potential interventions and obtain statistical consensus.

Participants

A stakeholder analysis identified relevant stakeholders (e.g. patients, nurses, paramedics, physicians and mental health professionals). Purposive snowball sampling allowed inclusion of participants representing all stakeholders from various parts of the Netherlands. Potential participants were informed about the study and approached via e-mail or telephone. Informed consent was obtained. At least 5 stakeholders per subgroup were enrolled to ensure stability of results.[19]

Phase 1: selection of interventions

Between August and October 2020, a literature review was conducted.[13] In addition to this review, relevant interventions described in a report from the Dutch Society of Psychosocial Oncology (NVPO) were added to the intervention list.[20] All identified interventions were translated into Dutch and a list of potential interventions was presented to participants. Suggestions for additional interventions were discussed within the research team. Relevant interventions were added to the final intervention list. This final list was supplemented with a description, rationale, references and divided into four domains: information and education, coping, physical well-being and lifestyle.

Phase 2: consensus rounds

During consensus round one, participants received the intervention list through LimeSurvey. Participants scored all interventions on relevance using a 9-point Likert scale. Relevance in this study was defined as the extent to which participants found interventions essential for a support program. An open text field was added to each intervention and enabled participants to place remarks or suggestions. Participants were invited to complete the rating process between July 9 - September 20, 2021.

The second consensus round took place on January 12, 2022, and consisted of a two-hour focus group meeting. Due to COVID-19 restrictions the meeting was organized online using Microsoft Teams. In accordance with the RAND/UCLA method the meeting was led by an independent experienced moderator (MN) and at least 9 panel members were invited to participate.[18] Using purposive sampling, a proportional representation of all stakeholders was ensured. Prior to the meeting, all focus group participants received a list of discussion items. After obtaining permission from participants the meeting was recorded. To emphasize the importance of a patient-centered approach, each discussion item was introduced by the moderator after which patient perspectives were explicitly asked. Afterwards, all other participants were asked to comment on the discussion item and more timid participants were actively invited to present their point of view. A researcher (KD) was present as an observant, taking field notes, writing down memos and meeting minutes.

All study participants were briefed on the focus group results. During consensus round three, participants received a modified list of interventions through LimeSurvey. Again, all participants were invited to score interventions on relevance using a 9-point Likert scale. An open text field was available for additional remarks. Participants were invited to complete the rating process between March 3-24, 2022.

Data analysis

The IQ healthcare consensus tool was used to calculate statistical consensus after the first and third round (see table 1).[21] In accordance with the RAND/UCLA method, participants were invited to rate each intervention on relevance using a 9-point Likert scale. Scores ranged from 1 not relevant to 9 very relevant. The RAND/UCLA method provides clear guidelines on execution of a consensus study, and its procedures have been refined since its development in the 1980's resulting in a reliable and rigorous approach.[21] The IQ healthcare consensus tool is based on the RAND/UCLA method and uses median and highest tertile scores.

TABLE 1. Consensus labels IQ healthcare consensus tool

	≥70% in the highest tertile	**≥30% in the lowest tertile and ≥30% in tte highest tertile**	**<70% in the highest tertile**
Median ≤ 3	Discussion	Discussion	No selection
Median 4 ≤ 7	Discussion	Discussion	No selection
Median ≥ 8	Selection	Discussion	Discussion

After analyzing data from round one, a selection, discussion or no selection label was appointed to each intervention (see table 2). A subgroup analysis was conducted to calculate consensus scores for specific subgroups and identify between-group differences. In addition, remarks and suggestions placed in open text fields were collected and thematically analyzed. This provided insight into the rating process, existing concerns and motives. Results from the data analysis were discussed during a research team meeting. Interventions with a discussion or no selection label, substantial between-group differences and important remarks and suggestions were selected by the research team as discussion item for the focus group meeting. Important results and findings from round one were presented to all study participants via e-mail.

During the second round, discussion items were presented to panel members. Interventions were adjusted if focus group participants deemed it necessary or otherwise removed. The moderator checked for consensus on adjustment or removal. Consensus was established if >75% of participants agreed on adjustment or removal. During the focus group meeting, notes were collected by a researcher (KD) and discussed within the research team. Meeting notes and suggested adjustments were returned to all focus group participants for a member check. After approval, the list of interventions was modified in accordance with suggestions and findings from the first two rounds. After collection of data during the third consensus round, data were analyzed and a final consensus label was appointed to each intervention: selection, discussion or no selection.

Incomplete data handling

To prevent loss of valuable data, both complete and incomplete surveys were included in the analysis.

RESULTS

Selection of interventions

A total of 39 interventions were selected for the first consensus round. Interventions were divided into four domains (see table 2). A literature review identified 13 interventions, 12 interventions were derived from the NVPO report and 14 resulted from the open survey amongst experts (see box 1).

BOX 1. Selected interventions overview box

Information and education

- (online) educational videos about prostate cancer, various treatment options, monitoring protocols, mortality, morbidity during AS, lifestyle advice
- use of a prostate cancer decision aid
- treatment decision in accordance with shared decision-making (SDM) principles
- provision of standard or individualized AS monitoring protocols

Coping and support

- application of Memorial Anxiety Scale for Prostate Cancer
- application of State Trait Anxiety Index
- structural assessment of psychosocial burden during consultations with stepped care provision of psychosocial support interventions

Physical well-being

- structural assessment of LUTS, ED, problems with intimacy and sexuality during consultations

Lifestyle

- use of motivational interviewing to promote health behavior
- standard provision of healthy dietary recommendations and guidelines
- provision of reliable information regarding food supplements
- standard provision of healthy exercise and physical activity recommendations and guidelines
- consultation with oncological physical therapist or nutritionist to promote health behavior upon request

Participants

A total of 43 subjects were invited to participate in this study. This included 11 patients, 9 nurses/nurse practitioners, 10 urologists, 5 paramedical and 8 mental health professionals. Participation was declined by 4 subjects (1 patient, 2 urologists and 1 nurse) due to practical reasons: time, personal circumstances. Approximately 80% (31/39) of subjects returned the survey. Three patients did not complete the entire survey. The primary reason provided was their self-described inability to rate specific interventions.

First consensus round

After analyzing data from the first consensus round, statistical consensus on selection, no selection or discussion on all 39 interventions was established. Consensus on selection of 6 interventions was reached (see table 2).

TABLE 2. Selected interventions first round

Intervention	Whole group (n=31)	Patients (n=7)	Nurses (n=7)	Urologists (n=6)	Paramedics (n=4)	Mental health professionals (n=7)
Information and education						
PCa decision aid†	●	●	●	●	●	●
Shared Decision-Making (SDM)†	●	●	●	●	●	●
Single 1,5-2h educational seminar on disease, treatment, risks and lifestyle†	●	●	●	●	●	●
Multidisciplinary consultation†	●	●	●	●	●	●
Provision of standard or individualized AS monitoring protocols†	●	●	●	●	●	●
Coping en support						
Buddy program‡	●	●	●	●	●	●
Mentor program§	●	●	●	●	●	●
Shared Medical Appointments§	●	●	●	●	●	●
Face-to-face peersupport†	●	●	●	●	●	●
Online peersupport†	●	●	●	●	●	●
Memorial Anxiety Scale for PCa§	●	●	●	●	●	●
State Trait Anxiety Index§	●	●	●	●	●	●
Distress thermometer§	●	●	●	●	●	●
Mishel Uncertainty in Illness Scale Community Form§	●	●	●	●	●	●
Mini-Mental Adjustment to Cancer Scale§	●	●	●	●	●	●
Masculinity in Chronic Disease Inventory§	●	●	●	●	●	●
GSE Self-efficacy questionnaire§	●	●	●	●	●	●
Group Mindfulness Based Cognitive Behavioral Therapy (MBCT)‡	●	●	●	●	●	●
Individual-MBCT‡	●	●	●	●	●	●
Group psycho-education‡	●	●	●	●	●	●
Problem solving skills training‡	●	●	●	●	●	●
Cognitive Behavioral Therapy‡	●	●	●	●	●	●
Acceptance and Commitment Therapy§	●	●	●	●	●	●
Online partners selfhelp ‡	●	●	●	●	●	●
Partner peersupport‡	●	●	●	●	●	●

Guided individual or partner program on cancer, intimacy and sexuality‡	●	●	●	●	●	●
Geriatric navigator§	●	●	●	●	●	●
Physical well-being						
International prostate symptom score (IPSS) and uroflowmetry§	●	●	●	●	●	●
Sexual Health Inventory for Men score§	●	●	●	●	●	●
Single sexologist consultation <12 months after AS initiation§	●	●	●	●	●	●
Lifestyle						
Dietary guidelines†	●	●	●	●	●	●
Food supplements†	●	●	●	●	●	●
Guided individual exercise program†	●	●	●	●	●	●
Guided group exercise program†	●	●	●	●	●	●
Individual exercise guidelines†	●	●	●	●	●	●
Individual relaxation and yoga guidelines‡	●	●	●	●	●	●
Group relaxation and meditation training‡	●	●	●	●	●	●
Individual mindfulness and relaxation guidelines‡	●	●	●	●	●	●
Motivational interviewing to promote health behavior†§	●	●	●	●	●	●

Subgroup analysis displayed important between-group differences. Particularly in the domain coping and support, and lifestyle. For instance, various questionnaires were rated differently between subgroups. In addition, the importance of peer support is valued conflictingly. Within the lifestyle domain there are large between and within-group differences regarding relevance of exercise, relaxation and diet resulting in the labels discussion and no selection for the majority of interventions.

Thematic analysis of open text fields

Analysis of open text fields demonstrated three recurring themes: intervention feasibility, suggestions for adaptation and tailored care. Feasibility concerns were often expressed in regard to sexological interventions. Especially costs and reimbursement possibilities were questioned. In addition, availability of certified sexologists was a major concern.

Q1: "Costs! This is not reimbursed by health insurance companies and in a lot of hospitals sexologists are not present."

Time was also often addressed as a limiting factor. For instance, in regard to multidisciplinary consultations.

Q2: " Difficult, expensive and time-consuming to get everyone together."

Often participants provided suggestions for adaptation of interventions. For instance, provision of information through an educational seminar can be replaced by online information, complemented by individual consultations. With regard to facilitation of peer support, it was suggested to combine peer support with an activity to promote accessibility.

Q3: " ..link this to something active, this makes talking easier. "

Tailored or stepped care was also frequently recommended. Information and education should be adjusted to needs and characteristics of patients and involve partners. Emphasizing on understandable and just-in-time information. Interventions focusing on mindfulness, relaxation, and stress reduction should be provided to patients expressing unmet needs and should not be standard care.

Q4: "Might be relevant for a subgroup of patients, good to have the possibility and offer it to particular men."

Although anonymous, analysis of open field texts also provided possible explanations for observed between-group differences. Notable was a statement from a participant in relation to the use of mindfulness and stress-reduction interventions.

Q5: "Are you suitable for AS if you need support in coping with anxiety, uncertainty, or distress during AS? …. they should opt for active treatment."

The relationship between anxiety, uncertainty, and exercise was questioned by some participants. The importance of food and diet as a self-management strategy to cope with the psychosocial burden of AS was recognized by some participants and doubted by others. Presence of sexological or urological problems in the AS population was not acknowledged by some participants. They linked these problems to patients in active treatment groups.

Second consensus round

The second consensus round consisted of an online focus group meeting. Out of the 12 invited focus group members, 11 participated. This included 3 patients, 2 nurse practitioners, 2 urologists, 3 paramedical caregivers and 1 mental health professional. One mental health professional was unable to attend. During the meeting, all 13 predetermined items were discussed. Based on group consensus, 4 interventions were removed, and 9 interventions were adjusted (see table 3).

TABLE 3. Discussion items focus group

Intervention	Discussion	Results
	Information and education	
Single educational seminar	Feasibility, suggestions for adjustment, subgroup differences	Suggestions for adjustment
Multidisciplinary consultations	Suggestions for adjustment, subgroup differences	Suggestions for adjustment and separation into multidisciplinary medical and paramedical consultations
	Coping en support	
Participation buddy/mentor program	Relevance, desirability, subgroup differences	Removal
Shared Medical Appointments	Feasibility, suggestions for adjustment	Removal
Peer support for patients and/or partners	Suggestions for adjustment, subgroup differences	Suggestion for adjustment and separation into peer support online, face-to-face and involving partners
Anxiety, uncertainty, distress, masculinity, coping, self-image, self-efficacy questionnaires	Feasibility, suggestions for adjustment, subgroup differences	Suggestion for adjustment
Mindfulness	Relevance, subgroup differences	Removal
Psychoeducation	Relevance, subgroup differences	Removal
Sexological screening and/or consultation	Feasibility, suggestions for adjustment	Suggestion for adjustment
	Physical well-being	
LUTS and ED screening	Feasibility, suggestions for adjustment	Suggestion for adjustment
	Lifestyle	
Dietary recommendations and food supplements	Relevance, subgroup differences	Suggestion for adjustment and additional educational intervention
Exercise/physical activity guidelines	Suggestions for adjustment, subgroup differences	Suggestions for adjustment and additional supportive intervention
Relaxation, yoga and meditation	Suggestions for adjustment	Suggestion for adjustment

Third consensus round

Based on results from the previous two rounds, an adapted list containing 14 interventions was returned to study participants (see table 4). Out of the 39 participants, 3 declined participation due to practical reasons. The rating process was completed by 23/36 participants through LimeSurvey resulting in a 64% response. This included 5 patients, 4 nurse practitioners, 5 urologists, 3 paramedics, and 5 mental health professionals. After data-analysis, statistical consensus on all 14 interventions was established. All 23 participants completed the survey. Consensus on additional selection of 7 interventions was reached (see table 3). After the third consensus round, 7 remaining interventions were rejected based on their discussion or no selection label. Due to the small subgroup sizes a subgroup analysis was not performed.

TABLE 4. Selected interventions third round

Interventions	Whole group (n=23)
Information and education	
Educational and informational videos (PCa, treatments, AS, prognosis and lifestyle)	●
Multidisciplinary consultation upon patients' request	●
Coping en support	
Face-to-face peer support	●
Face-to-face partner peer support	●
Online peer support (patients and/or partners)	●
Distress thermometer	●
Structural assessment of psychosocial burden during consultations. Steppedcare provision of psychosocial support interventions	●
Physical well-being	
Structural assessment of LUTS, ED and sexual functioning	●
Lifestyle	
Standard provision of dietary/nutritional guidelines	●
Provision of reliable information regarding food supplements	●
Standard provision of exercise and physical activity guidelines	●
Guided group exercise program facilitating peer support	●
Consultation with oncological physical therapist or nutritionist to promote health behavior upon request	●
Composition health promotion plan during (paramedical) multidisciplinary consultation	●

DISCUSSION

Aim of this study was to reach consensus amongst relevant stakeholders on selecting interventions for a psychosocial support program offered to PCa patients undergoing AS. Findings from this study suggest that this support program should include 13 interventions.

After round one, immediate consensus was reached on application of decision aids, SDM and provision of monitoring protocols. This demonstrates the widely shared desire to improve information and education during treatment decision making in LR-PCa. The need for transparent, unambiguous, tailored information and education involving both patients, partners and family members has been underlined in previous literature.[24,25] This is becoming more important since AS is increasingly applied and also extends to patients with favorable intermediate-risk PCa.[26] However, merely implementing informational and educational interventions is not enough to actively involve and empower patients. Research suggests patient-centered decision making also requires a behavior change in caregivers.[27] A support program should therefore also include communication training for caregivers to break long-standing interaction patterns.[28]

Both the Memorial Anxiety Scale for PCa and State Trait Anxiety Index were selected during the first consensus round. This illustrates the perceived importance of adequately detecting anxiety in men undergoing AS. An important trigger for anxiety and uncertainty during AS are recurring medical examinations.[29] Presence thereof negatively impacts physical and psychosocial well-being.[30] Standardized screening and adequate support upon detection need improvement.[8-11] Distress is often not expressed by PCa patients.[31] Open communication and empathy, especially from male caregivers, helps men to openly address distress.[31] During the second consensus round this topic was discussed extensively. A more structural and proactive approach to detecting mental or physical problems is required. Issues regarding masculinity, sexuality, intimacy and urinary function are not necessarily addressed by patients during routine consultations. Especially not, when initiative lies with the patient. This may be caused by stigmatization, which plays an important role in the lives of men with PCa.[32] Adequate screening of physical and mental health needs and stepped individualized care were suggested during the focus group. This resulted in adjustment and selection of two interventions during the third consensus round: structural assessment of psychosocial and physical well-being (LUTS, ED, intimacy, and sexuality) during consultations. Upon detection of unmet needs, supportive interventions are provided by a caregiver, or patients are referred to a specialist.

Additionally, prevention of mental and physical problems by supporting self-management was perceived relevant. Although interventions directly aiming at lifestyle improvements were not selected during round one, supporting men expressing the need to improve health behavior was perceived important. Application of motivational interviewing to promote health behavior was selected during round one. Recently, there has been an increased interest in the relationship between PCa progression

and health behavior during AS.[33-36] Research suggests men diagnosed with PCa frequently have a desire to adopt a healthier lifestyle.[37] However, caregivers generally provide inadequate information and support. Healthy lifestyle modifications positively influence physical and mental well-being.[38] It is suggested caregiver education is necessary to improve information delivery and overcome barriers, such as a perceived lack of evidence.[38] Providing information regarding exercise and dietary guidelines, food supplements, relaxation techniques and health promotion was discussed during the focus group meeting. This resulted in adjustment and selection of the following interventions during consensus round three: standard provision of healthy dietary recommendations and guidelines, provision of reliable information regarding food supplements, standard provision of healthy exercise and physical activity recommendations and guidelines and consultation with oncological physical therapist or nutritionist to promote health behavior upon request.

Strengths and limitations

Despite carefully designing this study, several limitations should be addressed. First, participants in this study were recruited using snowball sampling. Therefore, selection bias cannot be ruled out. Yet, a large and conscientious representation of all subgroups was purposively selected. This included participants from varying parts of the country and enrolment of health care professionals from larger and smaller institutions. The large response rates improved reliability of the results. However, a larger proportion of healthcare providers than patients were included. As a result, conclusions of this study may represent to a greater extent the perspectives of healthcare providers.

Patients also addressed an important limitation by declaring they felt incapable of adequately scoring the relevance of certain interventions. This resulted in 3 incomplete surveys during round one. Although results from consensus round one may underrepresent patient perspectives, a conscious emphasis was placed on patient perspectives throughout this study. First, by including incomplete data from patients collected during the first round. Since consensus is calculated for each intervention separately, inclusion of incomplete surveys does not affect the calculated consensus scores. However, it does increase the risk of non-response or participation bias. Second, emphasis on patient perspectives was ensured during the focus group meeting. A patient-centered approach was used to actively engage and empower patients.

An additional important limitation was caused by COVID-19 restrictions. Online focus groups impede live interaction between participants. However, the independent moderator focused on equal contribution of all participants and invited participants to speak freely, share thoughts and emotions expressed non-verbally.

CONCLUSIONS

Increased AS adoption, even within the intermediate-risk population, is observed globally. AS is recommended as the preferred treatment option in low-risk prostate cancer. The importance of AS, as part of the urological treatment palette, is growing. Resulting in a larger AS population. Establishing important preconditions for successful selection and adherence to AS is becoming progressively important. This emphasizes the need for a psychosocial support program in men undergoing AS. Assessment and identification of psychosocial problems and needs should be conducted amongst all men undergoing AS and not merely those already experiencing problems. Findings from this study suggest that such a support program should integrate the key elements comprising the 13 interventions as chosen. These interventions originate from research conducted in Germany, the United States of America, Canada, the United Kingdom, Australia and Japan, improving the generalizability of these findings.[13] Future research should focus on the composition and operationalization of such a support program. Moreover, this study underlines the importance of a more patient-centered approach to AS combining the implementation of patient-orientated interventions as well as a change in caregiver attitudes and behaviors to promote open communication and patient empowerment.

Based on this modified Delphi study, a total of 13 interventions were selected for inclusion in a support program for men with low-risk prostate cancer (LR-PCa) undergoing active surveillance. This included four interventions within the domain information and education, three interventions within the domain coping and support, one intervention within the domain physical well-being and four interventions within the domain lifestyle. Interventions originate from a literature review, the NVPO report and an open survey amongst experts.[13,20]

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CHAPTER 5

Developing a digital psychosocial support program for men with low-risk prostate cancer during active surveillance

Donachie K | Hansma M | Adriaansen M | Cornel E | Bakker E | Lechner L.

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ABSTRACT

Introduction

Active surveillance (AS) is a preferred treatment for men with low- to intermediate-risk prostate cancer, but its psychosocial impact presents challenges. This study used design thinking to develop a digital psychosocial support program aimed at improving quality of life and health outcomes for men on AS.

Methods

The design process followed five phases: Empathy, Define, Ideate, Prototype, and Test. Stakeholder interviews generated a problem statement. Brainstorming in the ideation phase conceptualized a self-management application. A framework of the application's features and prototype was developed in close collaboration with end-users and experts. The testing phase included heuristic evaluations and feedback from patients and healthcare providers.

Results

Interviews highlighted the need for personalized care, timely information, and holistic tailored support. The process aimed at reducing the psychosocial burden and improving coping during the first year. Multidisciplinary brainstorming resulted in the concept of a self-management application with features such as information, appointment preparation, self-reporting of medical results, lifestyle guidance, relaxation exercises, and communication tools. A prototype application was developed. Testing showed strengths in navigation and design, with recommendations for improving error handling and help documentation. Feedback led to refinements enhancing usability and clinical integration.

Conclusion

This study developed a patient-centered self-management application to address psychosocial challenges in AS. By fostering engagement, self-efficacy, and communication, the tool aims to improve outcomes in prostate cancer management. Future clinical studies will evaluate its effectiveness.

INTRODUCTION

Cancer care has evolved over recent decades from focusing solely on overall survival to prioritizing the quality of life and positive health outcomes.[1] This change necessitates that healthcare providers address the long-term needs of cancer patients, emphasizing patient-centered care that enhances overall well-being while considering cost-effectiveness.

Prostate cancer (PCa) is the second most prevalent malignancy globally and exemplifies the challenges of this transition. In 2020, there were an estimated 1.4 million new PCa cases, making it the most frequently diagnosed cancer in 112 countries.[2] With an aging global population, PCa incidence is expected to increase. PCa is categorized into low-risk, intermediate-risk, and high-risk groups, with low-risk prostate cancer (LR-PCa) comprising a third of all new cases.[3]

Active surveillance (AS) is the preferred management strategy for LR-PCa. This approach involves regular monitoring of tumor progression through Prostate Specific Antigen (PSA) testing, digital rectal exams, MRI, and periodic biopsies, with curative treatment being initiated only upon tumor progression. AS is safe, cost-effective, and avoids treatment-related complications such as erectile dysfunction and urinary incontinence.[3-5] AS is also becoming a popular option for men with intermediate-risk PCa.[6] Despite its benefits, the uncertainty associated with AS can significantly impact the mental health and overall quality of life of men, affecting their adherence to AS protocols and potentially leading to disease progression and poorer health outcomes.[7-9]

Research suggests that psychosocial support has been shown to reduce uncertainty, anxiety, and distress among cancer patients.[10] However, research on interventions specifically tailored for PCa patients undergoing AS remains limited.[11] Most studies focus on standalone interventions with temporary effects. A comprehensive psychosocial support program integrating various interventions could provide broader and more sustainable benefits, optimizing support during AS and improving adherence.[12]

However, offering such a program to all AS patients could result in unnecessary interventions, higher healthcare costs, and an increased caregiver workload. Digital health technologies may present a viable solution in providing just-in-time, personalized care without raising costs or burdening caregivers.[13] These tools are scalable, accessible, and cost-effective.[14] Therefore, digital health technologies can play an important role in addressing the uncertainty, anxiety, and distress often experienced by AS patients while improving adherence to AS protocols and promoting health outcomes sustainably.[15]

Successful implementation of digital psychosocial support within healthcare systems depends on usability, effectiveness, and accessibility.[16] Achieving this requires a user-centered, methodical approach to designing and integrating these technologies.[17] Therefore, this study aims to systematically develop

a digital psychosocial support program for men with PCa by applying design thinking principles to improve their quality of life and health outcomes.

METHODS

Study design

A design thinking (DT) approach was used to develop a psychosocial support program for men with PCa during AS. DT is increasingly adopted in healthcare for its human-centered approach to developing patient-centered interventions involving end-users.[18] DT entails five phases in the development process (see fig.1). Patient representatives were engaged throughout this study to ensure the program effectively met their needs and preferences. All participants provided verbal informed consent prior to participation, including permission for audio recording (in the empathy interviews) and use of anonymized data for research purposes. The HAN University of Applied Sciences ethical committee provided ethical approval for this study (No. ECO 584.09/24).

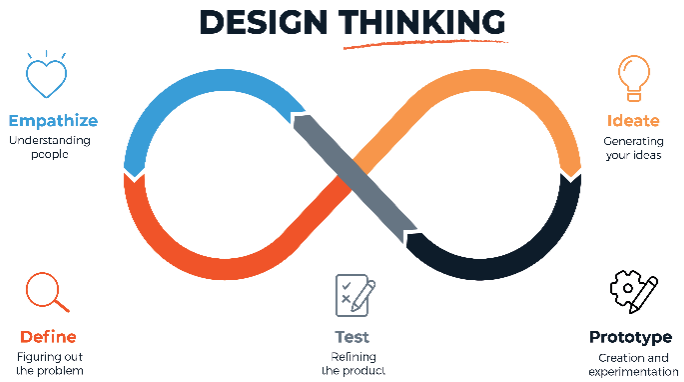


FIGURE 1. Five phases in design thinking[18]

The method section provides a concise overview of activities undertaken during the different phases of the Design Thinking (DT) process. The results section offers a detailed account of the activities and outcomes in each phase, highlighting how they informed subsequent phases.

Phase 1. Empathy

A qualitative interview study provided insight into the experiences and needs of men undergoing AS.[19] Given that the needs of men undergoing AS were already studied extensively in the beforementioned study by Donachie et al. (2020), additional empathy interviews were conducted during this study and gathered broader insights into the challenges faced by men with PCa during AS as experienced

by healthcare professionals. An interview guide was used to execute the interviews (see box 1). The interview guide was developed using the "what, how, why" method, a recommended approach in the empathy phase of design thinking to uncover user needs and experiences

BOX 1. Interview guide

1. How do you experience the current healthcare provided to men with prostate cancer during active surveillance?
- What is currently going well?
- What is currently not going well?
- Can you explain this?

2. When is the care for men with prostate cancer meaningful to you?
- Why?
- Can you provide an example?

3. When do you experience the current care to be inadequate?
- Why?
- How do you notice this?
- Can you provide an example?

4. What would you like to change?
- Why is it important?
- How do you envision this?
- What is needed for this?
- What hindering factors do you foresee?
- What would this change yield for both the patient and the healthcare provider?

Phase 2. Define

The insights from the empathy phase were synthesized to develop a problem statement. The findings from the qualitative study and supplementary interviews were deliberated within the research team, leading to the formulation of a clear problem statement.

Phase 3. Ideate

A stakeholder analysis was conducted to identify individuals or groups with a vested interest in or influence on the program. This helped to better understand and incorporate their perspectives, expectations, and concerns. Three brainstorming sessions with key stakeholders were organized, and various brainstorming techniques were used to facilitate creative ideation: the brain dump method, the Disney method, mind mapping, and the SCAMPER technique.[20,21] The brain dump method enabled participants to quickly capture and share existing thoughts and assumptions, creating a broad starting point for discussion. The Disney method encouraged participants to explore ideas from a more utopian perspective. Mind mapping supported the visual organization and expansion of ideas around central

themes and the existing interconnectivity. The SCAMPER technique provided a structured framework to critically review the current care path and identify opportunities to Substitute, Combine, Adapt, Modify, Put to another use, Eliminate, and Reverse aspects of care delivery.

Phase 4. Prototype

Consultations with end-users, including caregivers, patient representatives, information specialists, and regulatory board advisors, helped define the specifications and criteria for the prototype. These criteria included effectiveness, efficiency, inclusivity, accessibility, and user-friendliness. Experts were involved in developing the prototype based on the ideas generated during the ideation phase, which was then tested with a small group of end-users to gather feedback and refine the design.

Phase 5. Test

The refined prototype was tested within a larger group of stakeholders using a heuristic testing approach to assess usability (see table 1). Eight interviews with end-users and ten interviews with healthcare providers assessed barriers and facilitators for the adoption and implementation of eHealth in general, and this eHealth tool specifically.

TABLE 1. Heuristic test form

	0	1	2	3	4	5	Remarks
1. User control and freedom							
Are there clear and easily accessible ways for users to undo or redo actions?							
Can users easily go back to the previous state or page without losing their work or progress?							
2. Consistency and Navigation Clarity							
Is there a consistent layout and design throughout the application?							
Are navigation menus and buttons clearly labelled and logically organized?							
3. Error Prevention							
Are there mechanisms in place to prevent users from making common errors?							
Is there validation for user input (date, PSA value) to ensure it is in the correct format or range?							
4. Ease of Memory Recognition							

TABLE 1. Continued

	0	1	2	3	4	5	Remarks
Are icons, labels, and symbols used consistently and intuitively throughout the application?							
Is the terminology and language used familiar to the target audience?							
5. Flexibility and Efficiency of Use							
Are there shortcuts or advanced features that experienced users can use for faster interaction?							
Can users customize their settings or interface according to their preferences?							
6. Simplicity and Information Architecture							
Is information presented in a clear and organized manner, without unnecessary complexity?							
Is there a logical hierarchy for content and sections?							
7. Help and Documentation							
Is there accessible documentation or help features for users in need of assistance?							
Are tooltips or contextual help provided for potentially confusing elements?							
8. Progress and Response Notifications							
Do users receive feedback when an action is performed, such as submitting a form or completing a task?							
Are loading indicators or progress bars used when necessary?							
9. Animations and Feedback							
Do animations serve a purpose and provide visual feedback to guide users?							
Do animations enhance the user experience without being distracting?							
10. Affordance for Different States or Properties							

TABLE 1. Continued

	0	1	2	3	4	5	Remarks
Do interactive elements like buttons and input fields visually indicate their current state (e.g., hover, focus, disabled)?							
Are action-oriented items distinguished from static content?							
11. Cursor Affordance for Actions							
Does the cursor change appropriately to indicate interactive elements or actions (e.g., pointing cursor for clickable items)?							

RESULTS

Phase 1. Empathy

Participants (N=5) for the empathy interviews were enrolled using a purposive sampling method and were recruited from the researcher's professional network. To obtain a diverse sample, participants varied in age, gender, region, organization and function (see table 2). The sample included a patient representative, spouse, nurse practitioner, urologist, and researcher on psychosocial support for men with PCa undergoing AS. A semi-structured interview guide was used to facilitate the interviews (see box 1). All interviews were conducted using MS Teams and recorded after obtaining verbal consent from the participants. The average duration of the interviews was 33 minutes (26-40 minutes).

The recorded interviews were reviewed and analyzed using thematic content analysis. Applying an inductive approach, open coding was used to identify recurring patterns, which were grouped into overarching themes. These themes, along with supporting key quotes, were then translated into the components of an empathy map (figure 2), categorizing insights into what users said, did, thought, and felt. Major themes included the need for tailored, personalized care, a more holistic approach with attention to lifestyle, and the importance of just-in-time, reliable information.

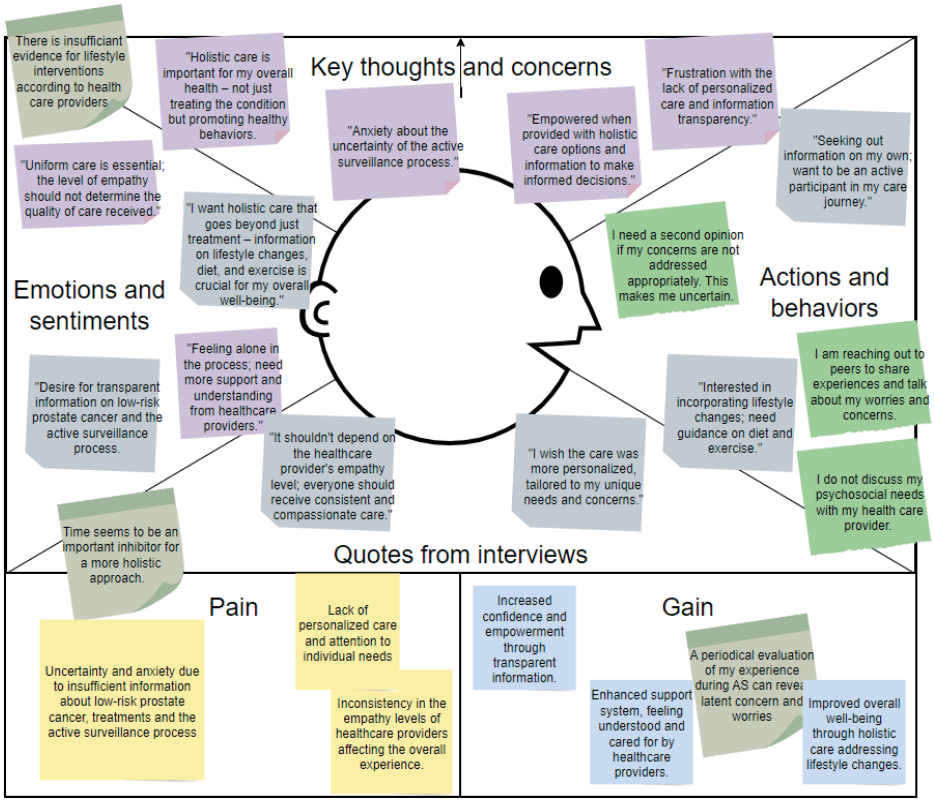


FIGURE 2. Empathy map

TABLE 2. Characteristics of participants

N=5	Function	Gender	Age group	City	Organization	Interview duration (minutes).
Participant 1	Patient representative	M	65+	The Hague	Prostate Cancer Association	35:19
Participant 2	Spouse	F	50+	Gorinchem	Beatrix Hospital	26:02
Participant 3	Nurse practitioner	M	30-50	Nijmegen	CWZ Hospital	32:27
Participant 4	Urologist	M	65+	Tilburg	Andros Clinics	40:11
Participant 5	Researcher	F	30-50	Rotterdam	Erasmus MC	33:02

Phase 2. Define

The researchers collaboratively defined the problem statement using various tools. The '5 WHY' technique was used to identify the root cause of an issue by repeatedly asking 'Why?' until the underlying cause was uncovered.[20] This iterative questioning, typically conducted over five rounds, helps uncover underlying causes and promotes effective solutions. In addition, the collaborative discussions delved into root causes and led to the identification of cohesive themes, offering a comprehensive understanding of challenges faced by men with prostate cancer during active surveillance. This process contributed to the human-centered approach of the study, resulting in the following problem statement:

"The redesign of support for men with PCa during the first year of the AS, aiming to reduce their psychosocial burden and enhance their ability to cope with the consequences of this trajectory."

Phase 3. Ideate

A stakeholder analysis identified key individuals involved in the prostate cancer care process (see figure 3).

Subsequently, three targeted brainstorming sessions were conducted, involving a diverse panel selected based on the findings of the stakeholder analysis. The panel comprised three patient representatives affiliated with the Prostate Cancer Association, an oncology nurse, two uro-oncological nurse specialists, a student pursuing a Bachelor of Nursing Care currently working as a student nurse in the oncology department, a researcher specializing in media and IT with expertise in inclusivity, and a prostate cancer peer group counsellor. The brainstorming sessions, each lasting 90 minutes, were executed between September 2022 and March 2023, fostering a collaborative environment for creative idea generation. Various brainstorming techniques, such as brain dumping, the Disney-method, the SCAMPER method and mind mapping were used.[20,21] This multidisciplinary approach harnessed collective expertise and perspectives of the diverse panel and resulted in the conceptualization of a digital health tool as part of the care path for patients undergoing AS: a self-management application.

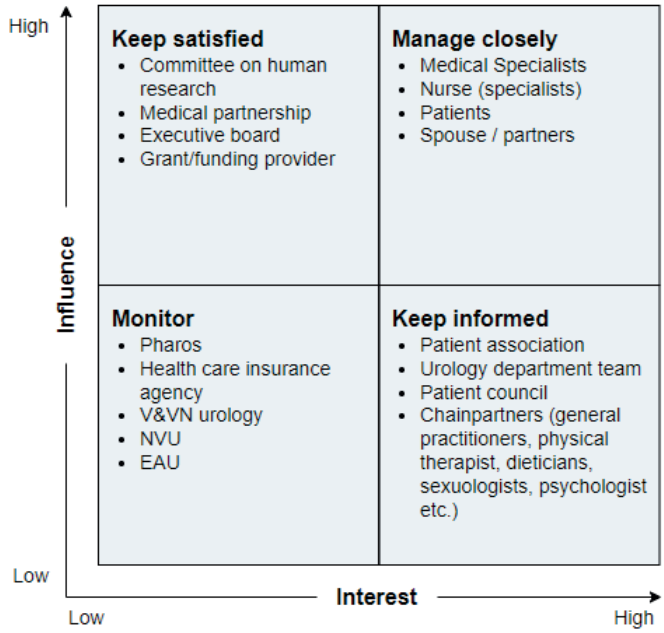


FIGURE 3. Stakeholder analysis

Phase 4. Prototype

In December 2022, a meeting with three healthcare providers addressed the application's integration into the existing care pathway. The previously conducted Delphi study resulted in a consensus on 13 key interventions to be incorporated into a support program for men on AS. All requirements and conditions for the self-management application were formulated based on the scoping review, Delphi study, and ideation phase.[11,12] These were subsequently integrated into the prototype program. Experts on data protection, medical device regulation, and inclusivity were consulted. Strict adherence to privacy regulations and data security was stressed. The criteria to avoid classification as a medical device were extensively discussed. To ensure an inclusive application, guidance on accessibility was provided. This resulted in a framework describing the content and features of the prototype self-management application (see table 3).

TABLE 3. Framework for application content and features

Buttons	Content	Features
My Information	Prostate Cancer Treatment options Active surveillance Decision Aids FAQ	Accessible and usable Low health literacy friendly Link to online tools
My Lifestyle	Food and Diet Exercise Relaxation FAQ	Diet plans Information on food supplements Reliable references Advice, schedules, Exercises
My Appointments	My protocol My appointment schedule Prepare next consultation Questions for health care provider	Interactive Dictaphone function
My Results	PSA values Biopsy results Other medical results FAQ	Interactive Graph and table Medical Device Regulations compliant
My Contacts	Contact information health care provider Peer support contact information	General Data Protection Act compliant with
My Profile	General information Health information	General Data Protection Act compliant

A researcher and web app developer commenced the development of the prototype in April 2023. The first user test with three healthy male volunteers, all aged 65 and older, was conducted in May 2023. None of the three men had been previously involved in the design and development process. During an one-hour test, the participants were asked to evaluate the application's accessibility, layout, navigational ease and functionality of interactive elements. Feedback was discussed within the research team and incorporated into the ongoing development process.

Phase 5. Test

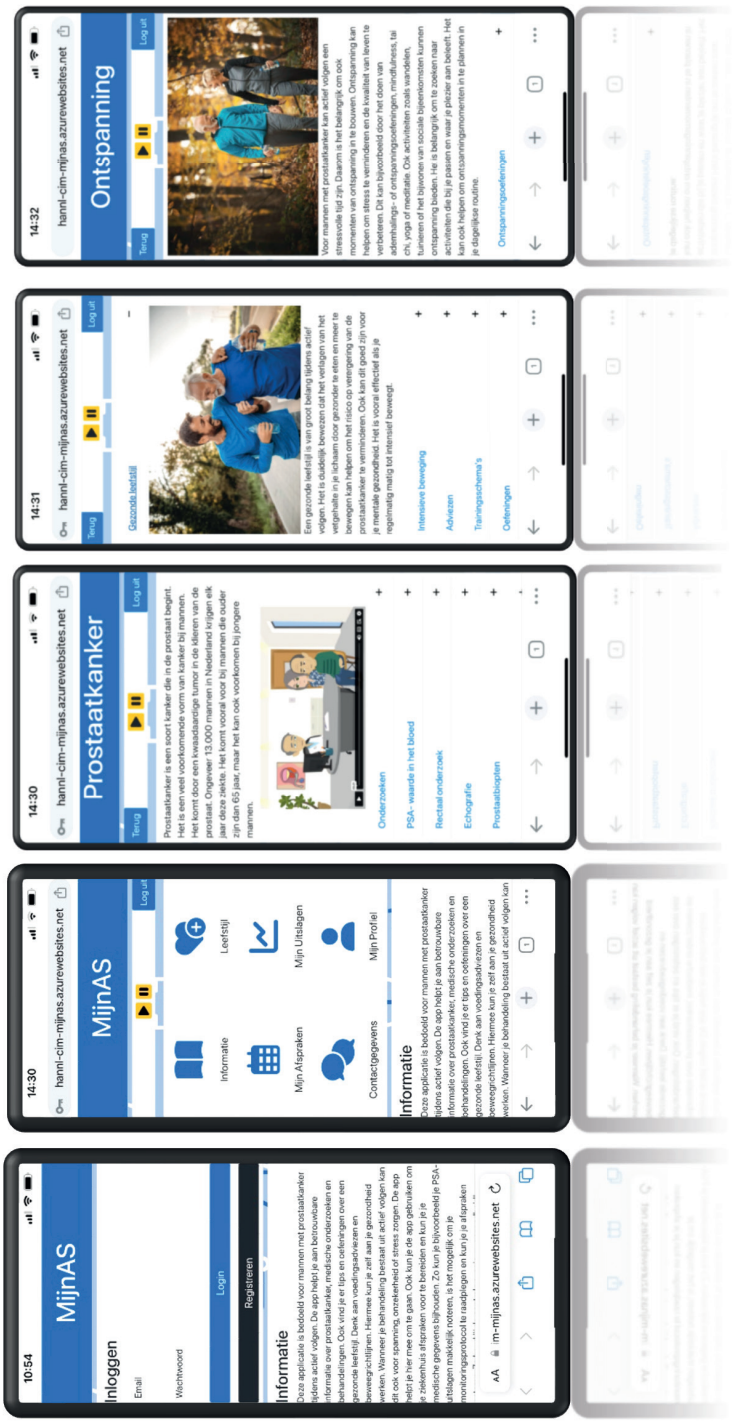
In September 2023, the prototype was subjected to heuristic testing with a panel of nine experts using three test cases. This panel consisted of two health psychologists, three researchers in eHealth applications, two patient representatives, and two nurse practitioners. A simplified heuristic evaluation form was filled out by the participants (see table 1). The heuristic test displayed that user control and freedom, consistency, navigational ease and recognition were scored positively. Both 'error prevention' and 'help and documentation' required immediate and further adjustment (see table 4).

TABLE 4. Results heuristic evaluation

Domain:	Very poor	Poor	Fair	Neutral	Good	Excellent
1. User control and freedom						
Clear and easy to un/redo actions	0,00%	0,00%	16,67%	33,33%	33,33%	16,67%
Go back without losing work or progress	0,00%	14,29%	0,00%	14,29%	42,86%	28,57%
2. Consistency and Navigation Clarity						
Consistent layout and design	0,00%	0,00%	0,00%	12,50%	62,50%	25,00%
Navigation menus and buttons labelled and organized	0,00%	0,00%	0,00%	12,50%	25,00%	62,50%
3. Error Prevention						
Mechanisms to prevent common errors	16,67%	0,00%	0,00%	16,67%	50,00%	16,67%
Validation for user input to ensure correct format or range	16,67%	0,00%	16,67%	33,33%	33,33%	0,00%
4. Ease of Memory Recognition						
Icons, labels, and symbols used consistently and intuitively	0,00%	0,00%	0,00%	0,00%	75,00%	25,00%
Terminology and language familiar to target audience	0,00%	0,00%	0,00%	28,57%	28,57%	42,86%
5. Flexibility and Efficiency of Use						
Shortcuts or advanced features	0,00%	0,00%	14,29%	57,14%	14,29%	14,29%
Customize settings or interface	14,29%	14,29%	0,00%	57,14%	14,29%	0,00%
6. Simplicity and Information Architecture						
Is information presented clear, organized	0,00%	0,00%	14,29%	14,29%	28,57%	42,86%
Logical hierarchy for content and sections	0,00%	12,50%	0,00%	0,00%	62,50%	25,00%
7. Help and Documentation						
Accessible documentation or help features	0,00%	33,33%	50,00%	0,00%	0,00%	16,67%
Tooltips or contextual help provided	16,67%	16,67%	66,67%	0,00%	0,00%	0,00%
8. Progress and Response Notifications						
Feedback performed actions	0,00%	14,29%	28,57%	28,57%	14,29%	14,29%
Loading indicators or progress bars	28,57%	0,00%	14,29%	28,57%	0,00%	28,57%
9. Animations and Feedback						
Purposeful animations and visual feedback	0,00%	0,00%	28,57%	0,00%	57,14%	14,29%
Animations enhance experience	0,00%	0,00%	33,33%	0,00%	50,00%	16,67%
10. Affordance for Different States or Properties						
Interactive elements visually indicate state (e.g., hover, focus, disabled)	16,67%	0,00%	16,67%	33,33%	16,67%	16,67%
Action-oriented items distinguished from static content	0,00%	0,00%	16,67%	33,33%	50,00%	0,00%
11. Cursor Affordance for Actions						
Cursor changes to indicate interactive elements	0,00%	16,67%	0,00%	33,33%	16,67%	33,33%

In addition, the researchers investigated the barriers and facilitators inhibiting or encouraging the uptake of the application. A panel of eight end-users was interviewed to investigate factors influencing the acceptance and user-friendliness of the application. A panel of ten healthcare providers was interviewed to assess the factors influencing the adoption and implementation in clinical practice. The recommendations emphasized the need for clear visual contrasts in the health application, such as black text on a white background or bold colors like red and blue, with an option for users to customize colors. All options and functions should be arranged on the homepage with icons, accompanied by features like a search function and adjustable font size, to enhance accessibility. Simple, non-medical language is preferred, with explanations provided where necessary. Privacy measures, including a login screen and automatic logout upon app closure, are essential, as well as the exclusion of notifications for advertisements and cookies. Practical guidance for patients on how to use the application, along with training and a test environment for healthcare providers, should be incorporated to ensure effective utilization. Regular updates are necessary to keep the app accurate and reliable.

This resulted in the development of a web-based application featuring six primary buttons: information, lifestyle, appointments, medical results, contact information, and personal information. Behind each button, users will find a brief instruction leading to expandable sections. These sections include information, FAQs, animations, images, interactive elements (like a medical results logbook and preparation for caregiver questions and health scores), guidelines, and exercises. Additionally, it includes a text-to-speech feature for all spoken content. This self-management tool enhances personalized care by delivering timely information, encourages positive lifestyle adjustments, and fosters patient empowerment.



FIGURES 4-10. Self-management application



FIGURES 4-10. Continued

DISCUSSION

The study aimed to develop a digital psychosocial support program for men with PCa undergoing AS to help them cope with the emotional and social aspects of their diagnosis and treatment journey using DT principles. While standalone interventions exist, a comprehensive, integrated support program is needed to cater to PCa patients' needs and align with the current care landscape that faces challenges such as demographic changes and staff shortages.[11,22]

The iterative process of DT allowed for continuous feedback and improvement, ensuring the program evolved to meet changing needs.[18] Collaboration with multidisciplinary stakeholders ensured comprehensive consideration of medical, psychological, social, and practical aspects. Creativity and innovation addressed complex challenges that went beyond traditional pathways. The DT process emphasized a human-centered approach, prioritizing understanding of PCa patients' needs and experiences.

The developed self-management application aims to increase personalized care by providing reliable just-in-time information, facilitating positive lifestyle changes, and promoting patient empowerment. The adoption of this eHealth application within the current care path may contribute to reducing the psychosocial burden associated with AS.[23] Despite these potential benefits, there is some apprehension regarding the uptake of eHealth in PCa patients due to their age and digital literacy.[24] However, previous research already underlined the potential benefit that eHealth self-management interventions can provide for this patient population.[9] In addition, the integration of eHealth applications in current care introduces numerous potential benefits for individuals undergoing AS. eHealth interventions have the capacity to enhance self-efficacy by providing PCa patients with accessible and personalized tools to actively participate in their care.[25,26] The application's features, such as self-monitoring functionalities and educational resources, contribute to increased engagement by encouraging a sense of empowerment and involvement in the management of their health.[27] It provides patients with information and practical guidelines to facilitate positive lifestyle changes. The application promotes personalized support, setting it apart from generic online resources by integrating patient data and feedback into tailored interventions. It offers just-in-time support aligned with emerging needs. For example, providing access to relevant FAQs or visualizations when new PSA results become available. The patient-completed positive health "spider web" further supports consultations, helping healthcare providers identify real-time concerns (e.g., anxiety or physical symptoms) and refer patients to appropriate features such as relaxation or lifestyle modules. Additionally, the application serves as a communication tool, bridging gaps in information exchange and promoting a more informed and collaborative patient-provider relationship.[28]

Strengths and limitations

While the user-centered, iterative, and collaborative design approach aligns with contemporary principles of creative problem-solving in healthcare, it is crucial to critically examine both its strengths and limitations. This method can be time-consuming, subjective, and costly. Although DT does not follow a rigid structure or rigid scientific methods, it is important to recognize that its inherent flexibility allows for responsiveness to the complex, dynamic nature of healthcare challenges. This approach allows for the incorporation of diverse perspectives and adapts to user needs through iterative refinement.[29] In addition, it reduces the risk of subjectivity and increases triangulation of data.

Overall, using design thinking to develop a digital psychosocial support program for men with PCa during AS enhances the program's potential to be effective, patient-centered, and sustainable. The clinical usability and acceptability of the self-management application, incorporated in the care path of men with PCa undergoing AS, needs to be determined in a feasibility study prior to the assessment of its effectiveness in a clinical trial.

Conclusions

This study applied DT principles to develop a complex intervention addressing unmet needs and promoting personalized, patient-centered care. The self-management application aims to empower individuals undergoing AS by providing tailored support for their psychosocial challenges. Successful implementation relies on collaboration between healthcare providers, patients, and technology developers to ensure seamless integration into the existing care pathway. A feasibility study should be conducted to assess the potential usefulness and integration of this application in clinical practice, with insights from the feasibility study incorporated into a clinical trial evaluating the application's effectiveness in reducing psychosocial burden.

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CHAPTER 6

Investigating the feasibility of a self-management application for men with prostate cancer undergoing active surveillance: a mixed-methods feasibility study

Donachie K | Cornel E | van Soest R | Elsinga- te Raa B | van Elst M | Adriaansen M | Bakker E | Lechner L

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ABSTRACT

Introduction

Active surveillance (AS) is the preferred management strategy for men with low-risk prostate cancer (PCa) and is also offered to those with favorable intermediate-risk disease. Although oncologically safe, living with an untreated tumor requires significant psychological resilience and agility. Currently, structured support to foster this resilience is often lacking in routine care. This gap can lead to heightened anxiety and uncertainty, particularly surrounding medical examinations, causing a subset of men to discontinue AS in the absence of medical indications for disease progression. Digital self-management tools may address these unmet needs by providing scalable psychosocial support and enhancing patient agency. This study evaluated the feasibility and acceptability of a co-created digital self-management application designed to support patient engagement and clinical navigation for men with PCa undergoing AS in routine care

Methods

A single-arm mixed-methods feasibility study was conducted across four Dutch urology clinics. Primary outcomes included recruitment, retention, and adherence, assessed through self-reported questionnaires and objective application metadata. Acceptability was measured using the Acceptability of Intervention Measure (AIM). Qualitative semi-structured interviews with patients (n=10) and caregivers (n=5) were conducted to explore barriers and facilitators to implementation.

Results

The recruitment rate was high (85%; 35/41), though overall retention declined to approximately 50% by study completion. Attrition was primarily driven by excessive survey burden rather than dissatisfaction with the application. Objective metadata revealed higher levels of functional engagement than self-reported data: 65% of participants registered PSA values, 44% logged appointments, and 32% used consultation preparation features. Acceptability was generally positive, with 73.4% of participants reporting approval, although a substantial proportion remained neutral. Qualitative themes highlighted the application's role as a "psychological anchor" providing reassurance and validation of the AS care path. However, digital fragmentation and a lack of integration with electronic health records (EHR) were identified as significant systemic barriers. The sample consisted predominantly of highly educated men, which may limit generalizability.

Conclusions

A co-created digital self-management application is acceptable and relevant for men on AS, specifically for addressing episodic needs during diagnosis and clinical follow-up moments. To optimize long-term feasibility and adoption, such tools should be integrated into existing clinical pathways and hospital portals to reduce digital burden and avoid standalone "app overload". Future research should focus on a large-scale effectiveness study using streamlined data collection and a more diverse sample to evaluate impacts on patient-reported outcomes.

INTRODUCTION

Prostate cancer (PCa) is the second most commonly diagnosed cancer in men worldwide. In the Netherlands, approximately 35% of newly diagnosed cases are classified as low risk.[1] For these men, active surveillance (AS) is the recommended management strategy.[2,3] Active surveillance is also a considered treatment option in favorable intermediate-risk prostate cancer.[4]

AS involves structured monitoring through serial prostate-specific antigen (PSA) testing, digital rectal examination, imaging, and repeat biopsies, with curative treatment initiated only in the case of clinically significant progression.[5] Long-term evidence indicates that immediate radical treatment does not improve survival in low-risk disease, while it is associated with substantial treatment-related morbidity.[6,7]

Despite its oncological safety, adherence to AS remains suboptimal. Between 13% and 38% of men discontinue surveillance even though there were no indications for disease progression.[8-11] This discontinuation is frequently driven by psychological distress, uncertainty, and anxiety related to repeated monitoring procedures.[12-16] These findings highlight that successful AS requires not only clinical safety but also sustained psychological support and reinforcement of patient confidence in ongoing surveillance.

Recent consensus work has identified unmet needs in information provision, psychosocial support, and self-management among men undergoing AS.[12,17] Digital health interventions may address these needs by offering scalable support for information provision, monitoring, and consultation preparation, while minimizing additional burden on healthcare providers.[18,19] In response to these needs, a co-created self-management web application was developed in collaboration with patients and healthcare professionals.[20]

Before implementation at scale and evaluation of clinical effectiveness, it is essential to assess feasibility and acceptability in real-world clinical settings.[21,22] Therefore, this study aimed to evaluate the feasibility and acceptability of implementing this self-management application for men with PCa on AS in routine care, focusing on recruitment, retention, adherence, patient-reported outcomes, and implementation barriers and facilitators.

METHODS

Study design and setting

This study was designed as a single-arm mixed-methods feasibility study with an embedded qualitative component. The quantitative component was used to assess feasibility outcomes, implementation metrics, and patient satisfaction, whereas the qualitative component explored barriers and facilitators related to intervention uptake and adoption in clinical practice.

The study was conducted across multiple Dutch urology outpatient clinics and hospitals, including Andros Clinics, University Medical Center Utrecht, Franciscus Hospital, and Zorggroep Twente. Participant inclusion took place between March 2025 and May 2026.

Given that psychological distress among men undergoing active surveillance (AS) is frequently associated with upcoming medical examinations and follow-up consultations, the study timeline extended from the moment patients elected AS after prostate cancer diagnosis until two weeks after their first scheduled follow-up consultation, which typically takes place 3–6 months after diagnosis.[14-16,23] This timeframe was chosen to capture both the initial adjustment phase and the period surrounding the first surveillance evaluation.

Participants and recruitment

Participants were recruited as a consecutive convenience sample from participating Dutch urology clinics. Eligible participants were men aged ≥18 years with histologically confirmed low- or intermediate-risk prostate cancer who had elected active surveillance (AS) as their primary management strategy. Men with high-risk prostate cancer or with a history of previous treatment for prostate cancer were excluded. Additional exclusion criteria were severe comorbid medical conditions that could interfere with participation, inability to use digital devices (such as smartphone, tablet, or computer), or inability to provide written informed consent. To participate, patients were required to be able to read and understand Dutch and have access to a digital device to enable use of the intervention.

Recruitment was performed by a designated nurse practitioner or oncology nurse at each participating site. Eligible patients received verbal and written study information during routine clinical care and were asked to sign a data provision consent form. Subsequently, the study coordinator contacted interested patients to provide detailed study information and obtain written informed consent. After enrolment, participants received instructions for installation and registration of the self-management web application. Demographic and clinical diversity was ensured by including multiple centers across the Netherlands, selected to represent different geographic regions, levels of AS use, and heterogeneous patient populations.

Intervention

The intervention consisted of a self-management web-based application specifically developed for men with prostate cancer undergoing AS. The application was developed through an intensive co-creation process using a design thinking methodology, involving active collaboration with patients undergoing AS and relevant healthcare professionals. A detailed description of the development process has been published previously.[20] Before implementation in the current study, a technical pilot study was conducted to optimize functionality, usability, and technical stability. All content was based on previously established consensus-driven psychosocial support priorities for men undergoing AS.[17] For key features of the final intervention see box 1. To enhance accessibility, the application was designed for users with varying health literacy levels and included:

- plain language text
- text-to-speech functionality
- videos
- visual materials
- frequently asked questions

Participants additionally received an instructional video and written instructions. Technical and practical support was available throughout the study from both the study coordinator and the application developer.

BOX 1. Key features intervention[20]

Information
- Reliable, tailored information on PCa, AS, treatment options and decision tools.

Lifestyle
- Guidance on food/diet, exercise, relaxation exercises, (support in smoking, drinking, drug cessation) and reliable references.

Appointments
- Tools for tracking the AS protocol, scheduling appointments, and preparing questions for healthcare providers, including filling in positive health scores prior to consultation.

Medical results
- Interactive features to log and visualize medical results such as PSA values and biopsy outcomes.

Contact Information
- Details for healthcare providers and peer support.

Outcomes and data collection

Data were collected using online questionnaires, system and qualitative interviews. See figure 1.

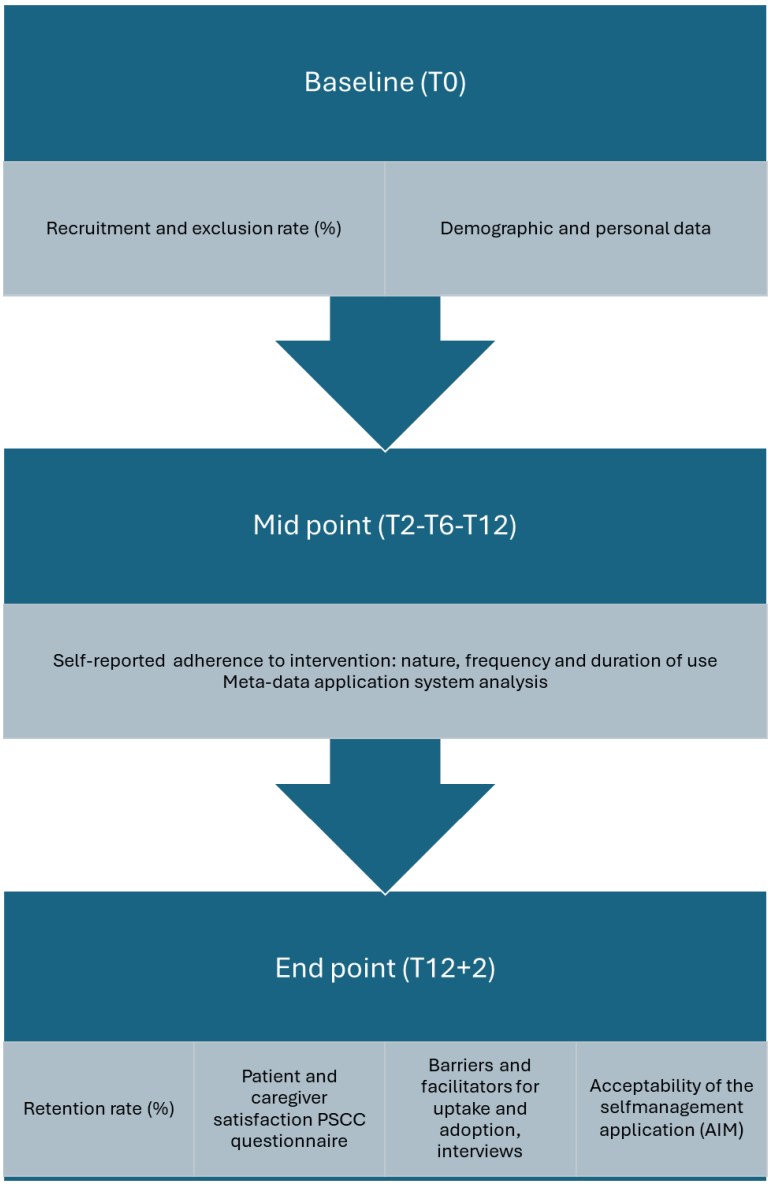

FIGURE 1. Flowchart data collection

Baseline demographic variables were collected at study entry (T0), including age, educational level, partner status, employment status, and AS start date.

Primary Outcomes (Feasibility):

The primary study outcomes were feasibility measures:

- *Recruitment rate:* Proportion of eligible patients enrolled in the study.
- *Retention rate:* Proportion of enrolled participants completing study follow-up.
- *Adherence to the intervention:* Frequency, duration, and type of web application use, assessed using a self-report adherence questionnaire administered through Lime Survey at three timepoints (T2, T6 and T12). In addition, system analytics (app meta-data on registration and use of interactive features) were collected to provide objective information on participants' engagement with the web application.
- *Acceptability:* Measured at endpoint (2 weeks after first follow-up consultation) using the 4-item Acceptability of Intervention Measure (AIM) which assesses the extent to which participants perceive the intervention as agreeable, satisfactory, and acceptable.[24]

Secondary Outcomes (Satisfaction and Insights):

Secondary outcomes included:

- *Patient Satisfaction*: Patient Satisfaction: Measured at endpoint using the Patient Satisfaction with Cancer-Related Care (PSCC) questionnaire, which assesses patients' satisfaction with the quality, coordination, and overall experience of cancer-related care.[25]
- *Barriers and Facilitators for uptake and adoption*: Explored through semi-structured interviews with healthcare providers and semi-structured interviews with patients following study completion. Patients were recruited for interviews using a convenience sample drawn from study participants. Healthcare professionals involved in the study were invited to participate in the interviews.

The interview guide (see box 2) for the interviews was based on existing literature and informed by the Technology Acceptance Model (TAM) and the Unified Theory of Acceptance and Use of Technology (UTAUT), focusing on perceived usefulness, perceived ease of use, facilitating conditions, and informational and psychosocial support needs.[26-31] Field notes were recorded during interviews to capture contextual and non-verbal observations. The interviews were transcribed verbatim using Amber Script software.

BOX 2. Interview guide[26-31]

Part A. Patients (men with prostate cancer)

1. Experiences with the app

- Can you describe how you used the app during the active surveillance process?
- What did you like about using the app?
- What did you find less pleasant or difficult?

2. Acceptance & usability

- How user-friendly did you find the app (navigation, language, clarity)?
- How well did the app fit into your daily life?
- Were there moments when you did not want or were not able to use the app? Why?

3. Accessibility

- Did you experience any technical problems (logging in, notifications, compatibility)?
- Was the app understandable and suitable for your personal situation (age, digital skills)?

4. Value & effectiveness

- Did the app help you better understand your health condition?
- Did the app support you in communicating with your healthcare provider?
- Did the app influence how you deal with uncertainty related to prostate cancer?

5. Points for improvement

- What would you change or add to make the app better suited to your needs?
- Would you recommend the app to other men in a similar situation? Why or why not?

Part B. Healthcare professionals (urologists, nurses, nurse practitioners, general practitioners)

1. Experiences with the app

- How did you experience the app in relation to your work?
- How well did the app align with the way you guide patients undergoing active surveillance?

2. Acceptance & feasibility

- What did you think about the user-friendliness of the app (for yourself and for patients)?
- Did the app make your work easier or more difficult?

3. Integration into the care process

- How did the app fit within the existing care pathways for active surveillance?
- Were there any barriers during implementation (e.g., time, communication, ICT systems)?

4. Value & effectiveness

- Do you think the app supports patients in self-management and treatment adherence?
- Did the app influence the quality of consultations or the relationship with patients?

5. Improvements and future use

- What changes would be needed to make the app more widely applicable?
- Do you see possibilities for sustainably integrating the app into routine care?
- Would you recommend the app to colleagues or in other settings? Why or why not?

Closing (for both groups)

- Are there any topics we have not discussed that you think are important to mention?
- Thank the participants for their contribution.

Statistical analysis

All quantitative analyses were conducted using IBM SPSS Statistics version 25. Descriptive statistics were used to summarize study data, given the feasibility design and limited sample size. Continuous variables were reported as means and standard deviations (SD), while categorical variables were summarized as frequencies and percentages. Missing data were handled using an available-case approach, and the extent and patterns of missingness were explored descriptively. Retention and dropout were examined over time by describing attrition across study intervals. Adherence data from self-report questionnaires and system analytics were analyzed descriptively to assess patterns of web application use and participant engagement. For AIM and PSCC, descriptive analyses were performed at both scale and item level. No inferential statistics or hypothesis testing were conducted.

Qualitative analysis

Qualitative data from interviews were analyzed using thematic analysis following the five-step approach described by Wæraas, including coding, theme generation, development of subthemes, identification of aggregate dimensions, and construction of a hierarchical coding tree.[32]

The transcripts were read and re-read prior to analysis. The analysis was primarily inductive, allowing themes to emerge from participant narratives, with abductive interpretation informed by existing frameworks on self-management and technology acceptance. This qualitative component was used to contextualize and explain quantitative feasibility findings.

Ethical Considerations

The study was approved by the Open University Ethics Committee (No. CETO_RP943/U202409047) and conducted in accordance with the Declaration of Helsinki. All participants provided written informed consent before participation. Data were pseudonymized using hospital-based participant codes and securely stored on protected research servers of HAN University of Applied Sciences and the Open University in compliance with the General Data Protection Regulation (GDPR). An independent expert is available for potential participants to discuss participation.

RESULTS

Participant flow and baseline characteristics

Between March 2025 and May 2026, a total of 41 patients were approached for participation in the study. Of these, 35 patients were included, resulting in a recruitment rate of 85% (see Fig.2). Recruitment was distributed across four Dutch clinics: Andros Clinics (n=13; 37.1%), ZGT (n=13; 37.1%), Franciscus (n=7; 20%), and UMCU (n=2; 5.7%). A total of 6 patients were excluded from the study (see figure 2).

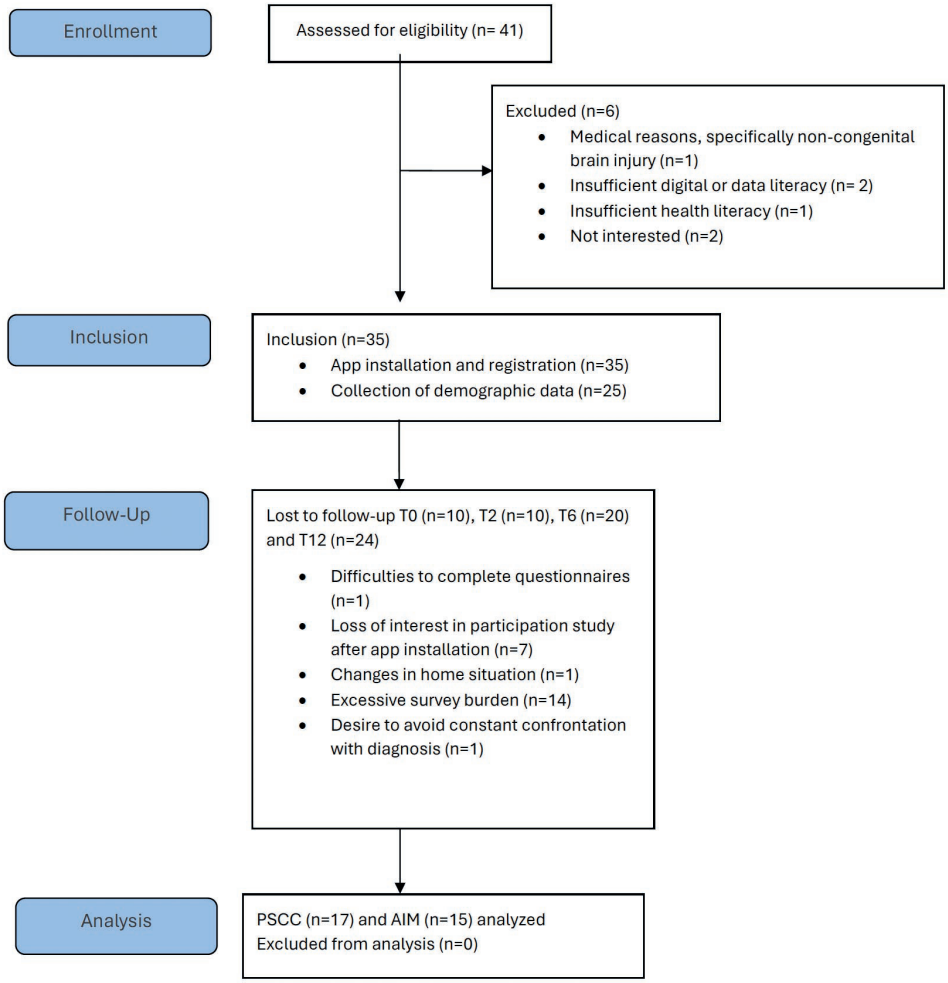

FIGURE 2. CONSORT Flowchart

The baseline characteristics of the study population are summarized in table 1. Analyses were conducted on the 25 participants who completed the baseline demographics. The mean age of the participants was 69 ± 7.5 years. The majority of the cohort was highly educated. The percentage is notably higher than the national average for Dutch men in this age category (~37.8%).[33] Regarding relationship status, a large majority of participants were married. In terms of employment status, the largest group consisted of pensioners, reflecting the age demographic of men undergoing AS for prostate cancer.

TABLE 1. Baseline characteristics of the participants (N=25)

Characteristic	Value
Age in years, mean (SD)	68.61 (7.47)
Educational level, n (%)	
Primary education	0 (0%)
Secondary education	0 (0%)
Vocational education	7 (30.4%)
Higher professional education	9 (39,1%)
University education	7 (30.4%)
Other	0 (0%)
Partner status, n (%)	
Single	0 (0%)
Married	20 (87%)
Divorced	0 (0%)
Widower	1 (4,3%)
Other	2 (8,7%)
Employment status, n (%)	
Employed	4 (17,4%)
Self-employed	2 (8,7%)
Unemployed	0 (0%)
Retired	17 (73,9%)
Other	0 (0%)

Missing data

At baseline, 35 participants were included. Demographic data were obtained from 25 participants and largely complete: age was available for 25 participants, while educational level, partner status, and employment status were available for 23 participants, indicating item non-response of 2 participants (8%).

Within follow-up questionnaires, selective item non-response was limited at T2, mainly affecting average duration of use (5/25; 20%) and frequency of use (1/25; 4%). At T6, non-response increased, with 3 of 15 participants (20%) not answering several app-use items and 4 of 15 (26.7%) missing data on average

duration of use. At T12, non-response decreased again, ranging from 0–2 participants per item, with the highest proportion for average duration of use (2/11; 18.2%). Overall, missing data was primarily due to attrition over time rather than selective item non-response.

Primary feasibility outcomes

Recruitment and retention

Participant retention declined progressively over the study period, resulting in an overall retention rate of approximately 50% (see figure 2). Participants who discontinued the study most commonly reported perceived high burden from the frequency of surveys, loss of interest, difficulties completing online questionnaires, changes in personal circumstances, and avoidance of continuous confrontation with the prostate cancer diagnosis.

Utilization and adherence

Usage of the application and adherence to the questionnaires was evaluated at the two-week mark (T2), after 6 weeks (T6) and 12 weeks (T12). Usage was measured via self-report questionnaires focusing on the frequency, duration, and nature of application interaction. First analysis was conducted at T2 and demonstrated that 25 participants completed the questionnaire. At T6 this dropped to 15 participants and at T12 only 11 participants remained.

During the first two weeks (T2), the majority of participants (56%) reported using the self-management web application 1–3 times (see figure 3). A smaller group (12%) showed higher engagement, logging in 4–7 times, while 28% of participants had not used the application at all. Over time, a general decline in both the frequency and intensity of use was observed. The proportion of participants using the application 4–7 times decreased from 12% at T2 to 6.7% at T6 and 0% at T12, whereas the proportion reporting no use increased from 28% at T2 to 40% at T6 and 45.5% at T12. Nevertheless, the majority of active users across all time points continued to report limited use of 1–3 times (56% at T2, 46.7% at T6, and 54.5% at T12).

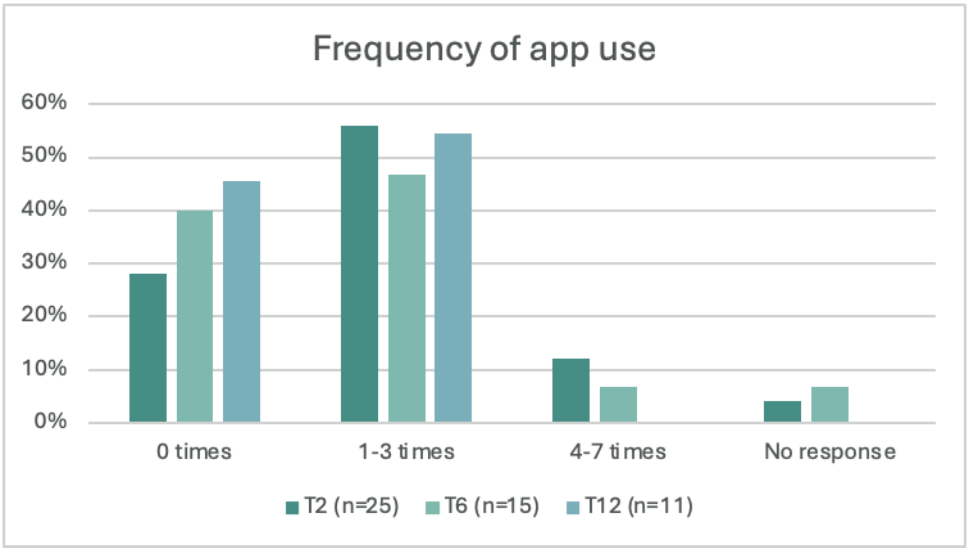

FIGURE 3. Frequency of app use

Regarding the average duration per session, usage was characterized by relatively brief interactions throughout the study period (see figure 4). At T2, 64% of participants spent 10 minutes or less on the application per session (0–5 minutes: 28%; 5–10 minutes: 36%). This pattern persisted at later measurements, with short sessions remaining the most common at T6 (53.3% spending 0–5 minutes) and T12 (36.4% spending 0–5 minutes and 36.4% spending 5–10 minutes). Longer sessions became increasingly uncommon over time: sessions lasting more than 15 minutes decreased from 8% at T2 to 0% at both T6 and T12.

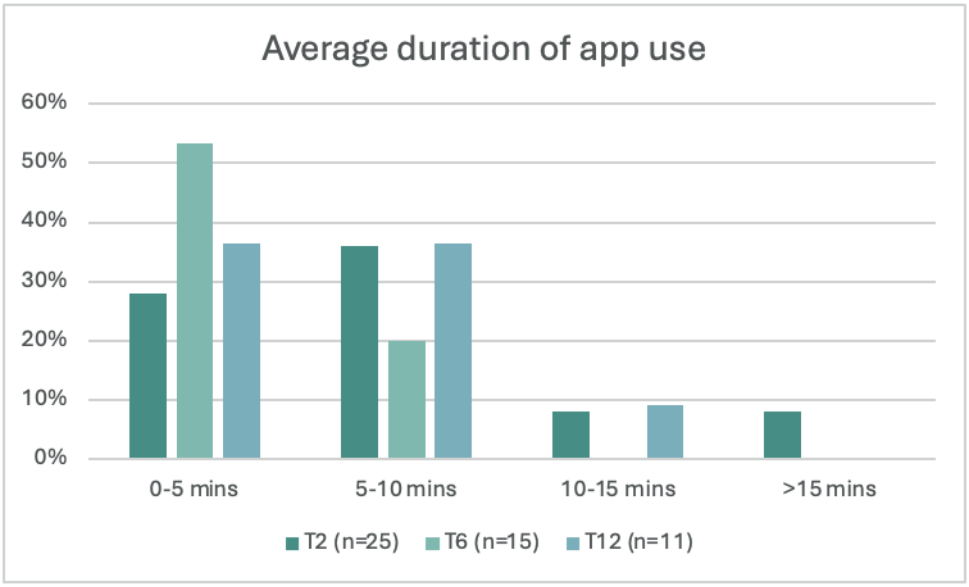

FIGURE 4. Average duration of app use

Analysis of the nature of usage demonstrated that the 'Information' and 'Lifestyle' modules were the most frequently accessed features during the early phase of use (see figure 5). At T2, 68% of participants consulted the information section at least "sometimes," including 12% who reported using it "every time" they logged in. However, use of this feature declined substantially over time, as the proportion reporting no use increased from 32% at T2 to 53.3% at T6 and 63.7% at T12, while "every time" use decreased to 0% at both follow-up measurements. Similar trends were observed for the lifestyle advice module. At T2, 52% of participants reported using this component at least sometimes, but non-use increased from 48% at T2 to 60% at T6 and remained high at T12 (54.5%).

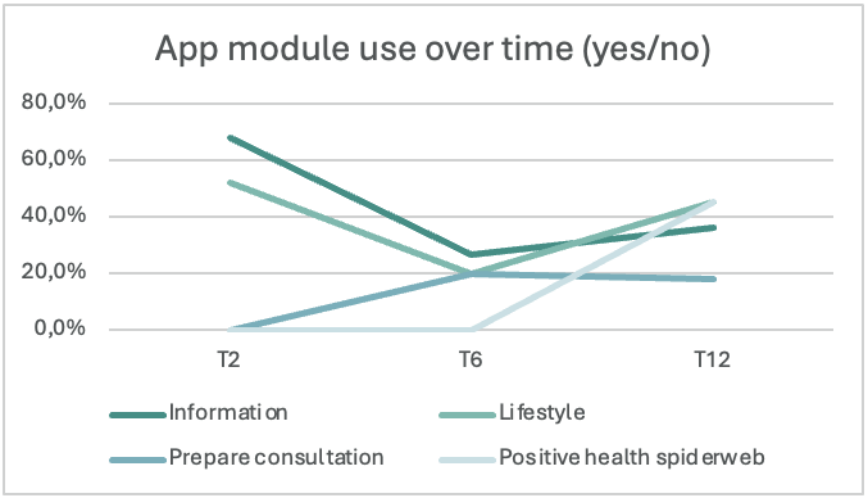

FIGURE 5. App module use over time (yes/no)

The feature allowing participants to log or review medical results, such as PSA values, was used by 32% of participants at T2. This dropped to 0% at T6, although some recovery was observed at T12, where 27.3% reported using this feature. Access to contact details for healthcare providers or peer support remained limited throughout the study period, with positive responses ranging between 6.7% and 12%. Notably, none of the participants used the application to prepare for consultations or to complete the Positive Health Spiderweb during the initial two-week period. Over time, however, use of consultation preparation features increased modestly, from 0% at T2 to 20% at T6 and 18.2% at T12. The most pronounced increase was observed for the Positive Health Spiderweb, which was not used at T2 or T6 but was completed by 45.5% of participants at T12 (see figure2). These findings suggest that although overall engagement with the intervention decreased over time, specific reflective and consultation-supporting components may have gained relevance during longer-term use (see table 2).

Table 2. Adherence to the intervention

Variable	T2 (n=25)	T6 (n=15)	T12 (n=11)
Frequency use, n (%)			
0 times	7 (28%)	6 (40%)	5 (45,5%)
1-3 times	14 (56%)	7 (46,7%)	6 (54,5%)
4-7 times	3(12%)	1 (6,7%)	0
No response	1 (4%)	1 (6,7%)	0
Average duration, n (%)			
0-5 mins	7 (28%)	8 (53,3%)	4 (36,4%)
5-10 mins	9 (36%)	3 (20%)	4 (36,4%)
10-15 mins	2 (8%)	0	1 (9,1%)
>15 mins	2 (8%)	0	0
No response	5 (20%)	4 (26,7%)	2 (18,2%)
Information, n (%)			
Not	8 (32%)	8 (53,3%)	7 (63,7%)
Sometimes	10 (40%)	4 (26,7%)	3 (27,3%)
Often	4 (16%)	0	1 (9,1%)
Every time	3 (12%)	0	0
No response	0	3 (20%)	0
Lifestyle, n (%)			
Not	12 (48%)	9 (60%)	6 (54,5%)
Sometimes	11 (44%)	2 (13,3%)	4 (36,4%)
Often	1 (4%)	1 (6,7%)	1 (9,1%)
Every time	1 (4%)	0	0
No response	0	3 (20%)	0
Contact details, n (%)			
Yes	3 (12%)	1 (6,7%)	1 (9,1%)
No	21 (84%)	11 (73,3%)	10 (90,9%)
I don't know	1 (4%)	0	0
No response	0 (0%)	3 (20%)	0
Results, n (%)			
Yes	8 (32%)	0	3 (27,3%)
No	17 (68%)	12 (80%)	8 (72,7%)
I don't know	0 (0%)	0	0
No response	0 (0%)	3 (20%)	0

Table 2. Continued

Variable	T2 (n=25)	T6 (n=15)	T12 (n=11)
Prepare consultation, n (%)			
Yes	0 (0%)	3 (20%	2 (18,2%)
No	25 (100%)	9 (60%)	9 (81,8%)
I don't know	0 (0%)	0	0
No response	0 (0%)	3 (20%)	0
Positive health spiderweb, n (%)			
Yes	0	0 (0%)	5 (45,5%)
No	25	12 (80%)	6 (54,5%)
I don't know	0	3 (20%)	0
No response	0	0	

To supplement the self-reported data, objective metadata from the application administrator was analyzed to provide a more comprehensive view of utilization across the full study period. System statistics reveal that 22 of the 35 users (65%) completed their profiles, and an identical number (22 users, 65%) registered at least one PSA value within the application. While the self-reported data at T2 indicated that no participants used the consultation preparation features in the first two weeks, the objective metadata shows that over the course of the full study, 11 users (32%) did create items to prepare for their appointments. Additionally, 15 users (44%) logged one or more appointments, 10 users (29%) added biopsy data, and 6 users (18%) utilized the note-taking function. A smaller portion of the cohort (4 users, 12%) used the application to record other medical results.

Acceptability (AIM)

The Acceptability of the Intervention Measure (AIM) was assessed in 15 participants. Overall, the results indicate a generally positive perception of the application. A total of 11 participants (73.4%) indicated approval of the application, while 4 participants (26.7%) reported a neutral stance and none reported disapproval.

In terms of specific acceptability dimensions, responses were predominantly neutral to positive. Regarding whether the application was appealing, 8 participants (53.4%) agreed that the app was attractive, 6 (40%) were neutral, and 1 participant (6.7%) strongly disagreed. Similarly, 6 participants (40%) reported that they found the app enjoyable, while 8 (53.3%) were neutral and 1 (6.7%) strongly disagreed. Finally, when asked whether they welcomed the use of the application, 8 participants (53.3%) responded positively, 6 (40%) were neutral, and 1 (6.7%) indicated a strong negative response, which consistently reflected the response of a single participant.

Overall, these findings suggest that while the majority of participants viewed the intervention as acceptable and generally positive, a substantial proportion remained neutral across different acceptability dimensions, indicating room for improvement in perceived engagement and user experience.

Secondary outcomes

Patient Satisfaction

The Patient Satisfaction with Cancer Care (PSCC) questionnaire was used to assess patients' perceptions of the quality and coordination of oncological care. Items were rated on a 5-point Likert scale ranging from 1 (strongly disagree, SD) to 5 (strongly agree, SA), with higher scores indicating greater satisfaction (see table 3). Across all PSCC items, responses indicated generally high levels of satisfaction with oncology care, with scores predominantly in the "agree" and "strongly agree" categories. Most domains were rated positively, particularly provider availability, perceived quality of care, and communication aspects. Some variability was observed in patient encouragement to talk and self-care instruction, which showed relatively more neutral responses. Overall, the findings suggest a consistently positive evaluation of the cancer care received across all measured domains.

TABLE 3. PSCC questionnaire results

Item	1 (SD)	2 (D)	3 (N)	4 (A)	5 (SA)	N
Understood, n (%)	0 (0%)	1 (5,6%)	2 (11,1%)	10 (55,6%)	5 (27,8%)	18
Respected, n (%)	0 (0%)	0 (0%)	1 (5,6%)	9 (50%)	8 (44,4%)	18
Involvement, n (%)	0 (0%)	0 (0%)	3 (16.7%)	8 (44.4%)	7 (38.9%)	18
Self-care instructions received, n (%)	0 (0%)	0 (0%)	6 (33.3%)	8 (44.4%)	4 (22.2%)	18
Encouraged to talk, n (%)	0 (0%)	3 (16,7%)	5 (29.4%)	7 (41.2%)	2 (11.8%)	17
Sufficient time from healthcare provider, n (%)	0 (0%)	0 (0%)	2 (11.8%)	10 (58.8%)	5 (29.4%)	17
Questions answered well, n (%)	0 (0%)	0 (0%)	2 (11.1%)	9 (50.0%)	7 (38.9%)	18
Ease of making appointments, n (%)	0 (0%)	0 (0%)	4 (22.2%)	12 (66.7%)	2 (11.1%)	18
Next step clearly explained, n (%)	0 (0%)	0 (0%)	4 (22.2%)	9 (50.0%)	5 (27.8%)	18
Confidence in healthcare system, n (%)	0 (0%)	0 (0%)	3 (16.7%)	13 (72.2%)	2 (11.1%)	18
Advice on health problems, n (%)	0 (0%)	0 (0%)	3 (16.7%)	11 (61.1%)	4 (22.2%)	18
Clear contact person, n (%)	0 (0%)	0 (0%)	2 (11.1%)	11 (61.1%)	5 (27.8%)	18
All necessary care received, n (%)	0 (0%)	0 (0%)	3 (16.7%)	11 (61.1%)	4 (22.2%)	18
Satisfaction with received care, n (%)	0 (0%)	1 (5.6%)	0 (0%)	12 (66.7%)	5 (27.8%)	18
Communication between healthcare providers, n (%)	0 (0%)	0 (0%)	5 (27.8%)	10 (55.6%)	3 (16.7%)	18
Quality of standard care provider, n (%)	0 (0%)	0 (0%)	2 (11.1%)	11 (61.1%)	5 (27.8%)	18
Quality of specialist care	0 (0%)	0 (0%)	0 (0%)	12 (66.7%)	6 (33.3%)	18
Standard care provider well informed, n (%)	0 (0%)	0 (0%)	2 (11.1%)	10 (55.6%)	6 (33.3%)	18

Patient interviews

Ten semi-structured interviews with patients were conducted via Microsoft Teams or telephone. In two interviews a partner was present during the interview. Interviews had an average duration of approximately 26 minutes with a minimum duration of 12 minutes and a maximum duration of 40 minutes. The analysis revealed four dimensions concerning the feasibility and acceptability of the self-management web application (see table 4).

TABLE 4. Hierarchical coding tree participant interviews

Aggregate Dimensions	Main Themes	Subthemes
Psychosocial context	Validation of care path	Reminder of illness vs. "normal life"
	Confrontational nature	Reassurance through confirmation
Functional utility	Empowerment tools	Security warnings and user experience hurdles
	Technical friction	Preparation and memory aids
Health literacy	Self-actionability	Taboos regarding sexual health
	Knowledge gaps	Lifestyle and nutritional agency
Ecosystem fit	Centralized info source	Fragmentation and lack of EHR integration
	Digital overload	Consolidating trusted links

Psychosocial Context

The application served as a critical psychological anchor, providing essential validation for the "active surveillance" (AS) approach during the vulnerable period following a diagnosis. For many patients, the initial news of having prostate cancer was experienced as a "what now?" moment once they left the clinical setting.

> *"Then you come home and you think: 'yeah, what now?' And then you get that app and you start reading and you think: 'okay, that is a huge reassurance.'"*

In this context, the app functioned as a stabilizing force by offering a reliable reference that confirmed and mirrored the specialist's advice. This consistency across multiple information sources was fundamental to building confidence in the AS trajectory, as it reassured patients.

> *"It confirms things you hear in your environment. It also confirms what the treating physician told me."*

Conversely, the app could force a constant confrontation with the disease. Some patients preferred to compartmentalize their diagnosis to maintain a sense of normal life.

> *"On the one hand it gives you a foothold... on the other hand, you don't want to be constantly occupied with it"*

Although partners were fundamentally integrated into the shared decision-making process and clinical consultations, evidence suggested that direct engagement with the digital application remained a largely individual activity for the patient.

"I did inform my partner about the app, that it was there, so that any questions could potentially be addressed there. But no, nothing further. No content shared"

Functional Utility

Users generally commended the application for its structural clarity and organized presentation. The division into six distinct chapters allowed for efficient navigation, and the integration of multimedia elements, such as instructional videos, was perceived as both functional and engaging.

"You can easily see the results... the PSA... that it's going up very slowly"

"I find it very organized. You immediately enter the six chapters (...) just complete."

While patients recognized the intrinsic value of the application, some technical friction arose from user experience design flaws and security perceptions. Specifically, the calendar interface for data entry was described by one participant as burdensome, and browser-based security warnings created a high threshold for the entry of sensitive medical data for another participant. Furthermore, the lack of a native mobile app led to persistence issues and frequent logouts.

"Every time you click once next to it [the birth date], it resets to the day of today. I really had to make an effort to get it right."

"I have not installed it for security reasons... if I get a message that it is not a secure website... that is a bridge too far"

The participants generally assessed their digital proficiency as average to above average compared to their peers, with many demonstrating the ability to navigate the application independently while occasionally relying on family members for technical support or experiencing hardware-related challenges such as typing on mobile interfaces.

"I guess I'm above average"

"I believe I am reasonably digitally proficient; because to give you an idea, my oldest son once worked for Apple in the United States, and he certainly didn't get those skills from a stranger"

Health literacy

Most patients reported that the application provided actionable information on the disease, treatment options, lifestyle and nutrition. This empowered patients to take an active role in their health trajectory rather than passively waiting for the next medical intervention thereby fostering patient agency. Additionally, it helped patients contextualize clinical statistics, such as mortality risks versus stable outcomes and helped patients feel "better prepared" during doctor visits.

> *"Those nutritional tips, I looked at those a lot, I found that very interesting. The idea that you can do something yourself was very stimulating."*

> *"Then you read that one in a hundred gets sicker (...) and the rest don't. That gave me a bit of perspective, which I found pleasant."*

A recurring critique was the absence of information on sexuality and erectile function, topics often considered taboo but highly relevant to the patient's future quality of life.

> *"When it comes to sexuality and everything related to that (...) that isn't in the app at all. (...) That felt like a bit of a lack."*

Ecosystem Fit

Almost all patients expressed that the app helped them to improve their knowledge base, patients felt better informed and more confident during medical appointments, enabling them to ask more targeted and critical questions. Thus, the app served as a valuable consultation preparation tool. Some patients stated the app provided a reliable alternative to the "confusing" and "unreliable" information found on the general internet.

> *"You become a bit more specialized in prostate cancer yourself (...) that makes you better prepared when you have contact with your doctor."*

The majority of patients reported that the primary systemic barrier was fragmentation. Some patients found it redundant to manually transfer results and appointments from hospital portals into the app, viewing this "double registration" as inefficient. Additionally, in cases of high physician trust or stable clinical outcomes, patients perceived the app as unnecessary and eventually forget to use it.

> *"The annoying thing is that nothing is in there... no data from my exams or values. Then I have to go to the other app"*

Caregiver's interviews

Seven caregivers from the four participating clinicals were interviewed. Three caregivers were interviewed live, three caregivers via Microsoft Teams and one caregiver via telephone. The mean interview duration was 29 minutes (ranging from 19 to 41 minutes). The qualitative analysis yielded four overarching dimensions (see table 5).

TABLE 5. Hierarchical coding tree caregiver interviews

Aggregate Dimensions	Main Themes	Subthemes
Clinical integration and workflow impact	Workload neutrality	Absence of increased patient inquiries.
	Standardization of care	Unified information base regardless of provider quality.
Patient inclusion and digital readiness	The generational divide	Generational differences in digital engagement. Higher perceived adoption among patients aged 60–70.
	Selection bias	Caregiver intuition on who to "burden" with technology.
Educational and psychosocial utility	On-demand use	Variation in app engagement due to fluctuation in distress levels
	Decision reinforcement	Validation of the AS choice post-diagnosis.
	Behavioral modification	Activation of lifestyle changes (nutrition/ alcohol).
	Content lacunae	Taboos and gaps in sexual health information.
Systemic sustainability	Digital fragmentation	App overload, need for a single-platform approach.
	Interoperability needs	Integration with hospital portals

Clinical integration and workflow impact

Caregivers found that the application did not increase their professional workload. Contrary to initial fears that digital access might lead to constant inquiries, the tool was perceived as a neutral and reliable information source that standardized the baseline of patient knowledge across different hospital settings.

"I haven't experienced the app making my work heavier. People were not hanging on the phone more."

"It is a neutral, good possibility to orient oneself without fuss."

Patient inclusion and digital readiness

Caregivers perceived the app to be particularly suitable for the "just retired" generation (ages 60–70), who appeared motivated and able to integrate the tool into daily life. Some older patients required more support or showed greater reluctance towards additional digital demands. One caregiver described patients over 75 often experienced "complete panic" when confronted with additional digital

requirements. Four caregivers admitted to sometimes being prejudiced in who they invited to the study based on perceived intelligence or digital skills.

"The older patient... when they get an app on top of everything else, they get into complete panic."

"You are quickly biased... if you think someone won't handle it, you don't even ask."

Educational and psychosocial utility

Caregivers observed that patients' experiences of stress, anxiety, and uncertainty fluctuated over the course of Active Surveillance and could at times be absent, leading to varying levels of information needs and app engagement. According to the majority of caregivers, the app served as an on-demand reference resource rather than a continuously used intervention. Some caregivers described that patients found it especially effective at reconfirming the initial decision to choose Active Surveillance, providing a safety net of information that reassured patients they were on the right track.

"They went through the decision aid again... they experienced a kind of extra reassurance in that."

"It is a useful supplement to information provision... it fosters self-management."

"I felt a bit of a gap... regarding sexuality and intimacy. The anonymity of the app makes men pause more easily on those themes."

Systemic sustainability

To support long-term implementation, caregivers described integration with existing hospital platforms as desirable. Rather than introducing an additional standalone application, they perceived embedding the app's specific AS content into established digital environments as potentially adding value for both patients and care delivery.

"We must really get it into one [system]... not another extra app."

"It would be beautiful if you can embed such a thing in something else... like the 'Better Nearby' app."

DISCUSSION

This study evaluated the feasibility and acceptability of a co-created self-management web application for men with prostate cancer (PCa) undergoing active surveillance (AS).[20,26] Overall participants perceived the application positively. Questionnaire data demonstrated favorable acceptability scores, while interviews revealed that the application provided reassurance, increased understanding of the active surveillance trajectory, and supported preparation for consultations. Participants particularly valued access to reliable information and the opportunity to reflect on their health and disease management. Together, these findings suggest that the application addressed several informational and supportive needs experienced during active surveillance.

Comparison of self-reported questionnaire data with objective application metadata revealed both convergent and divergent patterns. Qualitative findings generally supported the quantitative adherence data, indicating that engagement with the application was highest shortly after initiation of active surveillance and around clinical follow-up moments. Self-reported use declined over time, with the proportion of participants reporting no use increasing from 28% at T2 to 45.5% at T12. Metadata demonstrated that 63% of participants completed their profile and registered at least one PSA value. While self-reported use of consultation preparation features remained low throughout the study, metadata showed that 32% of participants used these functions. Questionnaire responses showed limited use of medical result tracking, whereas metadata indicated that 65% of participants registered PSA values and substantial proportions entered appointment, biopsy, and other clinical data.

In contrast, the feasibility of sustained use appeared more challenging. Although participants recognized the potential value of the application, long-term engagement declined over the course of the study. Qualitative findings suggest that this decline was influenced by multiple factors, including technical barriers, perceived burden associated with repeated data entry and questionnaires, and limited integration with existing hospital systems. For some participants, continued use also resulted in unwanted confrontation with their cancer diagnosis, reducing motivation to engage with the platform over time.

The findings further suggest that participants did not view the application as a tool for continuous day-to-day self-management. Rather, it appeared to be used most meaningfully during specific phases of the care trajectory, particularly following diagnosis and in preparation for clinical consultations. This pattern is consistent with participants' descriptions of the application as a source of information, reassurance, and reflection at moments when support needs were greatest.

Taken together, the results indicate that the application was acceptable to users and fulfilled several supportive functions during active surveillance. However, its long-term feasibility was constrained by practical and emotional barriers to sustained engagement. These findings suggest that future

implementation efforts may benefit from positioning the application as a targeted supportive intervention integrated within routine care processes, rather than as a stand-alone platform intended for continuous use throughout the surveillance trajectory.

Our findings are broadly consistent with previous literature on digital self-management interventions in oncology and active surveillance (AS) populations.[18,34] The relatively high initial willingness to participate in this study is in line with earlier work suggesting that men undergoing AS are open to supportive interventions that may reduce uncertainty and enhance self-management during follow-up.[35] However, despite positive initial uptake, sustained engagement declined over time, with reductions in both retention and frequency of use.[29,36,37] This pattern reflects the commonly described "law of attrition" in eHealth interventions, where engagement often decreases after initial adoption.[34,36,37]

Importantly, our findings add nuance to this pattern by suggesting that engagement with the application was not entirely linear or continuous, but appeared to be more episodic and context-dependent.[19,35] Both self-reported use and qualitative findings indicated that specific functionalities, such as consultation preparation and reflective components (e.g., the Positive Health Spiderweb), became more relevant at later stages of follow-up.[11,12] This supports earlier qualitative work indicating that supportive care needs in AS may fluctuate across the surveillance trajectory and may be particularly salient around monitoring or consultation moments, when uncertainty or informational needs increase.[12,16]

In line with prior research on digital supportive care, participants valued the application primarily as a trustworthy source of information, reassurance, and preparation for clinical interactions.[17,35] These findings resonate with studies emphasizing the role of digital interventions in promoting patient empowerment, health literacy, and confidence in disease management among men with prostate cancer.[12,13,18,38] At the same time, our qualitative results highlight barriers frequently reported in broader eHealth literature, including usability issues, emotional burden associated with repeated confrontation with illness, and digital fragmentation caused by limited integration with existing healthcare systems.[32,39]

Compared with more intensive behavioral interventions, such as the ERASE trial, which demonstrated reductions in prostate cancer–specific anxiety through structured exercise support, our intervention was designed as a low-intensity, self-guided self-management tool.[40] Although acceptability was generally favorable, neutral responses across several AIM domains and declining long-term engagement suggest that acceptability alone may not be sufficient to ensure sustained use.[23,34] Similar to broader digital health research, these findings underscore that successful implementation may depend not only on content relevance, but also on usability, integration within existing care pathways, and alignment with how patients naturally engage with support throughout the AS trajectory.

Strengths and limitations

A major strength of this study was its mixed-methods design, which enabled triangulation of quantitative and qualitative findings and provided a more comprehensive understanding of the intervention's feasibility and acceptability.[28,31] By combining self-reported questionnaire data, objective application metadata, and semi-structured interviews with both patients and caregivers, we were able to capture not only patterns of use, but also the contextual factors underlying engagement, attrition, and implementation barriers.[20,31] In particular, the inclusion of objective usage metadata strengthened the interpretation of adherence outcomes by demonstrating that some application functionalities were used more frequently than self-reported data suggested, thereby reducing sole reliance on subjective recall. Furthermore, the multicenter inclusion of participants across several Dutch urology clinics increased variation in clinical context and may enhance the transferability of feasibility findings to comparable active surveillance care settings.[25]

Several limitations should also be considered. First, the study population consisted primarily of highly educated men, with a relatively large proportion holding higher vocational or university-level qualifications.[33,38] This may have resulted in a sample with above-average health and digital literacy, limiting generalizability to men with lower educational attainment or lower digital confidence, who may experience different barriers to adoption. This concern is reinforced by caregiver interviews, which suggested potential selection bias during recruitment, as clinicians occasionally reported making assumptions about whether older or less digitally skilled patients would be willing or able to participate.[41] Such gatekeeping may also partly explain the relatively high recruitment rate observed in this study. Nevertheless, accessibility for users with varying levels of health literacy was explicitly considered throughout the co-creation and development process, which may partially mitigate concerns regarding usability across different educational backgrounds.

Second, attrition was substantial, with retention declining to approximately 50% over follow-up.[29,36] Although missing data were primarily attributable to dropout rather than selective item non-response, this may have introduced response bias, particularly for acceptability outcomes, as participants who remained in the study may have been more motivated or more satisfied with the intervention. Relatedly, repeated questionnaires were explicitly identified by participants as burdensome, suggesting that questionnaire fatigue may have contributed to attrition and should be addressed in future evaluations through more streamlined data collection strategies.[29]

Third, while the inclusion of objective metadata was a methodological strength, some quantitative outcomes relied on self-reported app use, which may have been affected by recall bias or underreporting.[20,39] The discrepancy between self-reported use and system-generated data illustrates the importance of interpreting adherence outcomes with caution. The availability of both objective metadata and qualitative interview data enabled triangulation of these findings and strengthened confidence in the overall interpretation of engagement patterns.

Fourth, the interpretation of acceptability and satisfaction outcomes warrants consideration. The AIM provided insight into intervention acceptability, but responses were predominantly neutral to positive and were assessed in a relatively small subgroup of retained participants.[23,24] Similarly, the PSCC measured satisfaction with cancer care more broadly, rather than satisfaction specifically attributable to the intervention itself.[25] Given the already high baseline trust in healthcare providers described in the qualitative interviews, these measures may have had limited sensitivity to detect intervention-specific effects.

Finally, as a single-arm feasibility study, the present findings do not allow conclusions regarding efficacy, clinical effectiveness, or causal impact on outcomes such as health-related quality of life, anxiety, self-management behavior, or continuation of active surveillance. Rather than evaluating effectiveness, the primary aim of this study was to explore acceptability, usage patterns, and implementation challenges in a real-world setting. In this regard, several of the identified limitations, including attrition, discrepancies between self-reported and objective use, and barriers to sustained engagement, provided valuable insights into how the intervention was experienced and where further optimization is needed. These findings offer important guidance for refining the application, improving implementation strategies, and informing the design of future effectiveness studies.

The findings of this feasibility study suggest that digital self-management tools for men undergoing active surveillance may be most valuable when integrated within existing clinical pathways rather than offered as standalone interventions. Both quantitative and qualitative findings indicated that participants primarily engaged with the application as an episodic resource for reassurance, information, and consultation preparation, rather than as a continuously used self-management platform. This suggests that digital support may be particularly relevant around key clinical moments, such as diagnosis, follow-up assessments, or consultation preparation.

For urologists and oncology nurses, implementation efforts should therefore focus on embedding such tools within routine active surveillance care and aligning functionalities with patients' practical informational and monitoring needs. Features related to consultation preparation, PSA tracking, and access to trustworthy disease-related information may be especially relevant, given their perceived value in supporting preparedness, reassurance, and informed clinical interactions. At the same time, reducing digital burden through improved usability, minimizing duplicate data entry, and integration with existing electronic health systems may be essential to support sustained engagement and feasibility in routine practice.

Future development of the intervention should build on the barriers and facilitators identified in this feasibility study. Further refinement of the application in collaboration with patients, caregivers, and healthcare professionals may improve usability, reduce perceived burden, and strengthen integration

with existing care pathways. Given the relatively highly educated study population, additional pilot testing among patients with lower educational attainment and potentially lower health and digital literacy is warranted to evaluate accessibility and relevance across a broader range of users. Following further optimization, the intervention should be evaluated in a larger-scale effectiveness study, preferably using a less burdensome research design with streamlined data collection procedures and targeted strategies to support participant retention and sustained engagement. Such work is needed to determine whether the application can improve patient-reported outcomes and support implementation within routine active surveillance care.

Conclusions

This feasibility study indicates that a co-created self-management web application is acceptable and relevant for men with prostate cancer undergoing active surveillance, particularly in the context of diagnosis and routine follow-up care. Although substantial attrition occurred over time, largely related to perceived survey burden, objective usage data demonstrated that participants continued to engage with key functional components of the application, such as PSA tracking and consultation-related features. These findings suggest that engagement with the intervention is primarily episodic and aligned with specific clinical moments rather than continuous use.

While informational and lifestyle content appeared most relevant in the early phase of use, longer-term engagement was more concentrated around features that support monitoring and preparation for clinical encounters. Qualitative findings further support this pattern, indicating that the application may contribute to reassurance and perceived preparedness, and may support patients in navigating uncertainty associated with active surveillance. At the same time, sustained use was limited by usability issues, perceived redundancy with existing digital systems, and the emotional burden of repeated confrontation with disease.

Overall, the findings suggest that the primary value of the intervention lies in its role as a supportive, context-dependent tool embedded within the active surveillance trajectory, rather than as a continuously used self-management platform. To improve feasibility and implementation, future iterations should focus on integration within existing care systems and reduction of digital burden.

These results provide a basis for future research, including a larger-scale evaluation of the intervention following refinement based on previous recommendations, and its effectiveness on patient-reported outcomes such as health-related quality of life, fear of progression, and active surveillance adherence.

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CHAPTER 7

General discussion

GENERAL DISCUSSION

This discussion integrates the collective findings of this dissertation to provide a comprehensive perspective on the development, optimization, and evaluation of a nurse-led digital intervention aimed at improving psychosocial support for men with low-risk and favorable intermediate-risk prostate cancer (PCa) undergoing active surveillance (AS).[1-6] Throughout this dissertation, the central focus has been on addressing the unmet psychosocial needs associated with AS and translating these needs into a structured, evidence-based intervention that can be implemented in routine clinical care.[2] To achieve this, a complex intervention was systematically developed and evaluated in line with the Medical Research Council (MRC) framework.[7]

Synthesis of findings

The studies included in this dissertation reveal a comprehensive evolution from identifying the unmet psychosocial needs of men with prostate cancer (PCa) on Active Surveillance (AS) to the systematic development and feasibility testing of a digital self-management solution.[1-6] This discussion synthesizes the research presented in this dissertation, which was rigorously guided by the Medical Research Council (MRC) framework for the development and evaluation of complex interventions.[7,8] Moving from the foundational understanding of the patient's lived experience to the creation of the 'MijnAS' application, a patient-centered tool designed to bridge the gap between clinical monitoring and psychosocial well-being.[5]

The point of departure for this work was the recognition of a profound psychological paradox: the clinical reality of harboring a malignant tumor while adopting a strategy of "no immediate treatment".[2] Our exploratory qualitative study (Chapter 2) was part of the MRC frameworks' development phase.[2] It confirmed that while many men adapt well, a significant minority (25–30%) experiences uncertainty and "PSA anxiety".[9,10] Patients often describe AS as living with a "time bomb", where distress typically peaks around recurring medical examinations such as PSA tests and biopsies.[2,10] Importantly, these episodes of unmanaged distress may contribute to "off-criteria" discontinuation, whereby some men transition from surveillance to invasive treatment in the absence of medical evidence of disease progression. Previous studies suggest that approximately 10–13% of men discontinue AS for reasons other than disease progression, including psychological burden and treatment preference.[11,12]

To further expand on the MRC development phase and address these needs, a scoping review (Chapter 3) mapped the existing evidence base and identified three critical pillars for support: tailored information, effective coping strategies, and lifestyle adjustments.[3] The review confirmed a limited availability of interventions specifically developed for the AS population, with existing support often being fragmented or transitory.[3,5] Furthermore, it emphasized that education must involve partners and family members, whose risk perceptions significantly influence the patient's commitment to the protocol.[3,15]

Building on this evidence, we established stakeholder consensus through a modified Delphi study (Chapter 4) and further enriched the development phase. This study prioritized 13 essential intervention components.[4] Stakeholders emphasized a shift toward the structural assessment of both psychosocial well-being and physical symptoms during routine consultations, combined with the provision of just-in-time, tailored information.[4] This highlights that simply providing information is insufficient; patient-centered care requires a behavioral change in caregivers and standardized monitoring tools.[4,16]

These consensus-driven insights were operationalized using a Design Thinking process (Chapter 5). To finalize the MRC development phase, the MijnAS web application was developed in close collaboration with patients and clinicians.[5] The application featured functional modules for information, lifestyle, appointment preparation, medical results (i.e. PSA log), and a personal profile based on the Positive Health spider web.[5] To ensure inclusivity and accessibility, the app integrated simple, non-medical language, text-to-speech functionality, and visual aids to support users with varying levels of health and digital literacy.[5]

Finally, the mixed-methods feasibility study (Chapter 6) shaped the MRC's feasibility phase. It demonstrated a high recruitment rate (85%) and high patient acceptability (73.4%), suggesting that the application is welcomed.[6] Qualitative insights demonstrated patients perceived the application as a relevant "psychological anchor" that provided reassurance following diagnosis.[6] However, the study also revealed a "digital dilemma": a 50% attrition rate highlighted that excessive measurement burden and frequent questionnaires may have led to "questionnaire fatigue".[6,14] For some men, the high frequency of reporting may have even functioned as a constant, unwanted confrontation with their diagnosis.[6] In addition, this study demonstrated the app content must be integrated into hospital existing portals.[6]
By framing Active Surveillance (AS) through the lens of salutogenesis and agency, as explored in our qualitative research (Chapter 2) and scoping review (Chapter 3), this dissertation suggests that providing men with the tools to actively manage their health can transform the surveillance trajectory from a passive state of "doing nothing" into a proactive path toward health promotion.[2,3,13] The development of the MijnAS application (Chapter 5) was a direct response to the stakeholder-prioritized need for such action-oriented coping strategies (Chapter 4), integrating functional features like the PSA log and Positive Health spiderweb to help men regain a sense of control.[4,5] Nevertheless, our feasibility findings (Chapter 6) underline that for digital support to be successful, it must transition from a standalone tool toward a fully integrated component of a hybrid care model.[6]

The paradox of living with an untreated tumor

A central theme of this of this PhD research was the recognition that, although Active Surveillance (AS) is considered an oncologically safe and guideline-supported management strategy for men with low-risk and increasingly favorable intermediate-risk prostate cancer, its success depends on more than clinical safety alone.[1,12,17] AS requires patients to accept and live with the knowledge of having a diagnosed malignancy that is intentionally not treated immediately.[2,9] This creates a fundamental

psychological paradox that formed the rationale for developing the intervention evaluated throughout this dissertation.[2,11]

Our qualitative exploration (Chapter 2) demonstrated that, while many men adapt well to AS, a clinically relevant subgroup experiences persistent uncertainty and emotional burden throughout follow-up.[2,9,18] Importantly, distress was not experienced continuously but appeared to fluctuate around surveillance moments, particularly PSA testing and repeat biopsies, which often acted as recurring triggers of anxiety.[2,10,11] Some participants additionally described how terminology used in clinical encounters, such as "watching" or "observation," unintentionally reinforced perceptions of passivity and undermined confidence in the active nature of surveillance.[2]

These findings align with previous literature describing uncertainty as one of the defining experiences of men on AS.[12,17] Kinsella et al. demonstrated that uncertainty regarding disease progression and difficulty tolerating ambiguity were major determinants of psychological burden during surveillance, while Beckmann and colleagues similarly described how men often experience AS as psychologically demanding despite recognizing its clinical benefits.[12,19] European studies have repeatedly identified themes such as "living with cancer" and feeling caught between reassurance and fear, suggesting that distress during AS is less related to objective disease characteristics than to patients' interpretation of risk and uncertainty.[17-28]

Importantly, the relatively low rates of discontinuation without medical progression reported in routine practice should not be interpreted as evidence that psychosocial burden is absent.[11,12] Our findings suggest that distress in AS may remain largely invisible within standard follow-up pathways, as consultations predominantly focus on biomedical indicators rather than systematic assessment of patient-reported experiences.[2,4,10,19,28] This observation is supported by literature indicating that clinician assessment often underestimates psychosocial concerns compared with patient-reported outcomes.[1,10,11,12,25] Furthermore, survivorship bias may contribute to this discrepancy: men experiencing greater anxiety may discontinue surveillance earlier or seek active treatment despite stable disease, leaving a relatively psychologically resilient population in long-term AS cohorts.[20-25]

The scoping review (Chapter 3) further demonstrated that, despite growing recognition of psychosocial burden in AS populations, existing supportive interventions remain fragmented and are rarely designed specifically for the surveillance context.[3,19] Most available interventions focus on isolated domains such as education or lifestyle, while failing to address the dynamic interaction between uncertainty, coping behavior, information needs, and patient activation.[3,19,26,29,30] To address this gap, the Delphi study (Chapter 4) established consensus among stakeholders that psychosocial support in AS should consist of an integrated approach combining tailored information provision, psychosocial monitoring, coping support, and lifestyle guidance.[4,19]

These principles subsequently informed the co-creation and development of the MijnAS intervention (Chapter 5), which was designed not to eliminate uncertainty since it is an unavoidable component of AS, but to support men in managing uncertainty more effectively.[5,12,26] Findings from the feasibility study (Chapter 6) demonstrated that patients valued accessible information, transparency around monitoring, and tools that increased their sense of control and engagement.[6,27] At the same time, implementation challenges highlighted that psychosocial support should not simply be digitized but embedded within routine care pathways and supported by healthcare professionals.[6,19,26,28]

Taken together, this dissertation suggests that addressing the psychological paradox of living with an untreated tumor should not be regarded as an optional enhancement to AS but as a prerequisite for sustainable, person-centered surveillance care.[1,19,28] Supporting patients in managing uncertainty may improve not only psychosocial well-being but also trust in the surveillance strategy itself, thereby enabling patients to remain engaged with AS and reducing the risk of unnecessary treatment driven primarily by anxiety rather than clinical progression.[1,11,12,28,29]

Shaping AS through salutogenesis and agency

If the central challenge of AS is the psychological burden of living with an untreated tumor, an equally important question becomes how men can be supported in managing uncertainty while preserving the clinical benefits of surveillance.[1,6,12,21] Based on the findings of this dissertation, one potential answer lies in reframing AS through the concepts of salutogenesis and agency.[18,26,29-31]

Salutogenesis, originally introduced by Antonovsky, shifts attention from disease and pathology towards the factors that enable individuals to maintain health, meaning, and well-being despite illness or adversity.[13,30] Central to this perspective is the concept of a sense of coherence, referring to the extent to which individuals perceive life events as comprehensible, manageable, and meaningful.[13] Applied to AS, this suggests that adaptation may depend not solely on objective disease risk but also on patients' ability to understand surveillance, experience some degree of control, and integrate uncertainty into daily life.[2,28,30]

This perspective resonated strongly with the findings from the qualitative study (Chapter 2).[2] While many participants accepted the medical rationale for AS, several simultaneously described discomfort with the perceived passivity of "doing nothing.[2,23,27] For these men, uncertainty was not only related to cancer itself but also to the absence of visible treatment action.[2] Lifestyle modifications including dietary changes, physical activity, stress reduction, and broader health-promoting behaviors, were frequently described as practical ways to regain a sense of influence over the disease trajectory.[2,3,26,29-32] Rather than aiming to cure the tumor, participants described these behaviors as a way to remain engaged and psychologically active during surveillance.[26,29-32]

These findings align with previous qualitative work showing that men on AS frequently seek opportunities to maintain identity, autonomy, and control after diagnosis.[12,21,26,28,29] Kinsella et al. reported that men often reframed surveillance as an active decision rather than passive waiting in order to preserve psychological equilibrium.[12,21] Similarly, Oliffe and colleagues described how action-oriented coping strategies may reflect broader masculine ideals of self-reliance and responsibility, helping men maintain continuity of self despite living with cancer.[25] Studies in prostate cancer populations have further shown that perceived control is associated with lower anxiety and greater decisional satisfaction during treatment trajectories.[29-33]

This emphasizes the need for agency in this population. Agency is defined as an individual's capacity to act intentionally and make informed decisions while maintaining a sense of control over their health and well-being.[13,33-39] At the same time, the literature suggests that promoting agency requires nuance. While behavioral engagement may support coping, there is limited evidence that lifestyle interventions directly reduce prostate cancer progression during AS.[3,32,33] Several reviews indicate that physical activity and healthy lifestyle behaviors contribute to improvements in quality of life, fatigue, and emotional well-being, yet evidence for oncological benefit remains limited.[29-33] This distinction is important because interventions should support adaptive coping without unintentionally reinforcing beliefs that disease progression is primarily under personal control.

Our scoping review (Chapter 3) reflected this complexity.[3] Existing interventions frequently targeted isolated domains such as information provision or physical activity but rarely addressed the interaction between uncertainty, self-management capacity, and emotional adaptation.[3,26,29] This highlighted the need for a more integrated approach to supportive care for men undergoing active surveillance.

The Delphi study (Chapter 4) further refined these insights.[4] Stakeholders consistently emphasized that support for men on AS should move beyond education and symptom monitoring alone and instead strengthen patients' capacity to participate actively in decision-making and daily disease management.[4,19,26,29,33] Importantly, agency was not conceptualized as patient independence but as supported participation within the clinical relationship.[4,34]

These principles informed the development of the MijnAS intervention (Chapter 5).[5] Rather than functioning solely as an educational tool, the intervention was designed to operationalize agency by combining tailored information, longitudinal monitoring, consultation preparation, lifestyle support, and reflection through the Positive Health spiderweb.[5,37] In this way, the intervention sought to transform surveillance from passive observation into an approach that supports adaptive engagement with health.[5,13,29,30]

However, findings from the feasibility study (Chapter 6) also revealed the limits of this approach.[6] Although participants appreciated opportunities to gain insight and structure, not all men benefited

equally from increased engagement.[6,34,35] For some, repeated monitoring and frequent self-reporting became burdensome and intensified awareness of illness.[6,14] This finding aligns with broader literature on digital self-management, which suggests that empowerment strategies can unintentionally increase psychological burden when they generate excessive self-focus.[14,34,35]

Taken together, these findings suggest that shaping AS through salutogenesis and agency is not about encouraging patients to take control over cancer itself, but about supporting their ability to live well despite uncertainty.[1,26,33] In this context, agency emerges not as an alternative to clinical surveillance, but as a complementary mechanism that may strengthen psychological adaptation, support engagement with surveillance protocols, and help sustain AS as a person-centered treatment strategy.[1,6,33]

Paradigm shift towards person-centered care

The preceding sections argued that uncertainty is not a complication of Active Surveillance (AS), but an inherent component of living with an untreated malignancy, and that supporting agency may help men adapt to this uncertainty.[1,6,26,29,30,33] Enabling patients to become active participants in surveillance cannot rely solely on patient motivation or self-management capacities.[1,33,36-38] The findings of this research project suggest that achieving sustainable psychosocial support in AS requires a broader paradigm shift: from a predominantly biomedical model focused on tumor monitoring towards a person-centered model that systematically incorporates patients' lived experiences into routine care.[1,36-38]

Although concepts such as patient empowerment, health literacy, self-management, and Shared Decision-Making (SDM) are now widely embedded in policy and guideline documents, implementation in daily clinical practice remains inconsistent.[1,39-43] Person-centered care assumes that patients are able and supported to actively participate in decisions and ongoing disease management, while healthcare professionals adapt care to individual needs, preferences, and coping capacities rather than applying standardized follow-up uniformly.[39-43]

Our qualitative findings (Chapter 2) illustrated that patients' information needs and psychosocial concerns extended beyond the clinical agenda of surveillance consultations.[2] Men described uncertainty surrounding PSA fluctuations, concerns about progression, questions regarding lifestyle, and the desire for reassurance and contextual interpretation of medical results.[2,19] At the same time, participants frequently reported reluctance to raise emotional concerns during routine consultations, perceiving these appointments primarily as moments to evaluate biomedical outcomes rather than discuss well-being.[2,12]

These findings correspond with broader literature showing that psychosocial needs often remain under-recognized in routine oncology care.[1,11,12,19,21,22,24,28] Studies on decision-making in prostate cancer demonstrate that although SDM is widely endorsed, consultations continue to be strongly shaped by clinician framing, consultation time, and assumptions regarding patient preferences.[12,16,17,24,27]

Evidence suggests that communication style, risk presentation, and professional assumptions may unintentionally influence how patients perceive the acceptability and safety of AS.[1,16,40-43]

Our scoping review (Chapter 3) reflected this broader challenge.[3] Existing supportive interventions predominantly focused on delivering information but rarely addressed how psychosocial concerns could be structurally integrated into surveillance pathways.[3,15,19,30] Interventions were often temporary, fragmented, or delivered outside routine care structures.[3] This fragmentation may inadvertently reinforce the traditional separation between biomedical surveillance and supportive care.

The Delphi study (Chapter 4) provided further insight into how this gap may be addressed.[4] Stakeholders consistently prioritized routine assessment of psychosocial well-being longside physical monitoring and emphasized the importance of integrating support into existing consultations rather than creating parallel care pathways.[4,19]

These principles informed the co-creation process and development of the MijnAS intervention (Chapter 5).[5] Rather than replacing clinical encounters, the intervention was designed to facilitate more meaningful interactions by helping patients prepare for consultations, reflect on their well-being, and structure questions and concerns in advance.[5,45] This approach aligns with literature suggesting that digital health interventions may strengthen Shared Decision-Making (SDM) not by reducing contact with professionals but by improving the quality of conversations during clinical encounters.[43-48]

Findings from the feasibility study (Chapter 6) demonstrated that implementation remains challenging.[6] While participants valued increased insight and accessibility of information, successful use depended heavily on whether the intervention was embedded within existing clinical workflows.[6] Patients repeatedly emphasized that digital support alone was insufficient and that interpretation, reassurance, and continuity remained essential.[6,47,49]

This finding highlights a particularly important role for the specialized nurse within future AS pathways.[1,49,50] Positioned at the intersection of clinical monitoring and supportive care, specialized nurses may function as translators between digital data and patient experience.[6,50] By contextualizing patient-reported outcomes, facilitating reflection, and addressing concerns that may otherwise remain invisible, they can help operationalize person-centered care in daily practice.[1,44,48-50]

Taken together, this dissertation suggests that the future of AS depends not only on empowering patients but equally on redesigning care systems and professional roles. Psychosocial monitoring should therefore become as structurally embedded within surveillance pathways as PSA testing itself, not because psychological outcomes replace oncological outcomes, but because sustainable surveillance requires attention to both.

The hybrid care model, a digital dilemma

The development of the MijnAS intervention reflects a broader shift in healthcare systems towards hybrid care models, in which digital health technologies are integrated with face-to-face clinical encounters to support scalable, person-centered care.[5,6,44-50] Within the context of AS, such models are particularly relevant, as increasing patient volumes, workforce shortages, and time constraints make it difficult to provide comprehensive psychosocial support during routine consultations alone.[1,5] eHealth interventions, defined as the use of digital technologies to support healthcare delivery, self-management, and communication, have therefore been widely proposed as mechanisms to extend care beyond the clinic, improve self-management, and enhance patient engagement.[34,46]

Despite these theoretical promises , the findings of this dissertation suggest that digitalization in AS is accompanied by a fundamental "digital dilemma". While digital tools may enhance access to information and support, they may simultaneously introduce new forms of inequality, burden, and disengagement if not carefully embedded within clinical care pathways.[1,6,48]

The MijnAS application was developed in close collaboration with patients and healthcare professionals (Chapter 5) and structured around six functional domains (information, lifestyle, appointments, results, contacts, and personal health profile).[5] This design directly responded to needs identified in the qualitative study (Chapter 2), where men expressed difficulties in interpreting PSA fluctuations, preparing for consultations, and maintaining a sense of control between hospital visits.[2,4,19] In this sense, the application was intended to extend the "window of opportunity" following diagnosis by supporting reflection, preparation, and lifestyle engagement during surveillance.[2,29]

Nevertheless, the feasibility study (Chapter 6) revealed important limitations in real-world implementation.[6] Although initial acceptance was high (73.4%), long-term engagement was substantially lower, with an attrition rate of 50%.[6] This finding aligns with broader digital health literature showing that high initial uptake does not necessarily translate into sustained use, particularly in older populations and in interventions that require repeated self-monitoring or questionnaire completion.[14,47,48] Importantly, dropout in this study was not solely related to technical barriers, but also to the experiential burden of continuous engagement.[6] For some participants, repeated interaction with the application intensified awareness of their disease status, transforming a supportive tool into an unwanted reminder of illness.[6]

In addition, the homogeneity of the study population, predominantly highly educated and digitally literate men, highlights a well-described risk in eHealth research: the "digital inverse care law," in which those most likely to benefit from digital interventions are also those least likely to access or sustain them.[6,46-48] This raises concerns that, without careful implementation strategies, digital AS support tools may unintentionally reinforce existing health inequalities rather than reduce them.[6,46-48]

These findings challenge the assumption that digital health technologies are inherently neutral or universally beneficial.[34,35,46-48] Instead, they suggest that effectiveness depends not only on usability and content design, but also on how technology is embedded within existing care structures and patient coping styles.[6,34,35,46-48] Similar concerns have been raised in prostate cancer survivorship literature, where self-management interventions have shown variable effects depending on patients' coping preferences, informational needs, and baseline distress levels.[33,49,50]

Within this context, the role of healthcare professionals, particularly specialized nurses, emerges as essential. Rather than replacing clinical contact, MijnAS was intended to function as an adjunct to care, with the specialist nurse acting as a bridge between digital data and clinical meaning. In the qualitative interviews (Chapter 2), patients emphasized the importance of interpretation and reassurance in relation to PSA dynamics, suggesting that digital information alone is insufficient to support adaptation to AS.[1,2,27] The Delphi study (Chapter 4) further supported the need for structured integration of psychosocial data into routine consultations.[4,34]

In a hybrid care model, the specialized nurse is therefore not only a coordinator of information but also an interpreter of digital signals such as PSA trends and patient-reported outcomes (e.g., Positive Health profiles). This role is consistent with emerging evidence in oncology digital health literature, which emphasizes that technology is most effective when it augments rather than replaces human care, enabling clinicians to provide more personalized, responsive, and empathic support.[36,45,47,50,51]

Taken together, these findings suggest that the value of hybrid care in AS lies in the harmonious integration of accessibility, empowerment, efficiency and relational care.[6,35,,49] Effectively managing these interconnected factors is therefore essential to ensure that digital interventions contribute to more equitable, sustainable, and person-centered surveillance pathways.[38,39,48,50]

The future of AS

The future of Active Surveillance (AS) must be understood within the context of rapidly evolving prostate cancer epidemiology and shifting diagnostic paradigms.[52] AS is increasingly no longer restricted to men with low-risk prostate cancer, but is progressively being extended to carefully selected patients with favorable intermediate-risk disease.[53] At the same time, ongoing debates surrounding population-based prostate cancer screening are expected to increase the number of men diagnosed with early-stage disease, further expanding the eligible AS population.[54-56,59,60] Together, these developments will substantially increase the demand for long-term surveillance pathways that are both clinically safe and scalable.

This growing demand coincides with a healthcare system already under structural pressure due to workforce shortages, increasing patient volumes, and the long-term nature of AS follow-up.[57] Within this context, the findings of this dissertation provide important insights into the conditions required for

sustainable AS care. Across Chapters 2 to 6, a consistent pattern emerged: while AS is oncologically safe and generally well accepted, a substantial subgroup of patients experiences fluctuating uncertainty, PSA-related anxiety, and a need for psychosocial support.[1-6,19] Importantly, Chapter 6 demonstrated that even when digital support is available and well received (73.4% acceptance), long-term engagement may be influenced by multiple interacting factors, including perceived burden, competing coping strategies, and the potential for increased illness salience.[6,14,47] These findings suggest that scalability in AS cannot be achieved through monitoring intensity alone, but may require a more fundamentally restructured approach to care delivery.[57]

International literature supports this observation. Studies from large AS cohorts, including PRIAS and Scandinavian registries, have shown that although long-term discontinuation rates due to medical progression remain low, psychological factors and decisional uncertainty contribute to variability in adherence to surveillance schedules and follow-up engagement.[11,12,24,25,50] Furthermore, as AS is increasingly applied in broader risk groups, heterogeneity in psychological resilience, coping style, and informational needs is expected to increase, making a uniform follow-up approach increasingly inadequate.[22,25,53,56,59]

These developments reinforce the need to move from protocol-driven surveillance towards an adaptive care ecosystem. In such a model, AS is not conceptualized as a linear monitoring pathway, but as a dynamic process in which clinical data, patient-reported outcomes, and contextual factors are continuously integrated.[19,56,57,58,59] The findings of this dissertation suggest that psychosocial dimensions, such as uncertainty, perceived control, and coping capacity, are not peripheral to AS, but central determinants of how patients experience and engage with surveillance over time (Chapters 2 and 4).[1,10,12,17,18,21,23,,24,26,,28]

Within this evolving ecosystem, the role of partners and informal caregivers is increasingly recognized as essential.[2,3,61] Literature shows that prostate cancer is a "shared illness experience," in which partner anxiety, risk perception, and communication patterns significantly influence patient coping and treatment decisions.[61,62] Our scoping review (Chapter 3) similarly highlighted that involvement of partners and family members shapes interpretation of PSA results and adherence to surveillance strategies.[3,12,61] However, current AS models rarely structurally incorporate partner support into routine care, representing a missed opportunity for system-level optimization.[4,61,62]

Digital health technologies may support this transition by enabling continuous, low-burden monitoring of both clinical and psychosocial outcomes.[63-66] However, as demonstrated in this dissertation, their effectiveness depends on careful integration into clinical workflows and alignment with patient capabilities and preferences (Chapter 6).[6] Without such integration, there is a risk that digital tools become parallel systems that increase fragmentation rather than cohesion in care delivery.

These findings collectively point towards a future in which AS is no longer solely a urology-led monitoring program, but a coordinated, nurse-led, multidisciplinary care ecosystem.[66-68] In this model, specialized nurses play a pivotal role in synthesizing digital health data, interpreting patient-reported outcomes, and providing continuity across time and settings.[35,50,66-68] This aligns with broader survivorship care literature, which emphasizes that sustainable long-term cancer management requires a shift from episodic physician-led encounters to continuous, relationship-based care models supported by digital infrastructure.[69]

In conclusion, the future sustainability of AS will depend not only on expanding eligibility criteria or improving oncological risk stratification, but on the capacity of healthcare systems to integrate psychosocial care, digital innovation, and relational support into a coherent and scalable care ecosystem. Only through such an integrated approach can AS remain a viable, patient-centered alternative in an era of increasing demand and clinical complexity.[41]

Methodological considerations

This dissertation adopted a systematic, phased approach to the development and preliminary evaluation of a nurse-led digital self-management intervention for men on Active Surveillance (AS), guided by the Medical Research Council (MRC) framework for complex interventions and informed by Design Thinking principles.[7,8,70] Rather than evaluating a stand-alone intervention effect, the studies included in this dissertation should be interpreted as an interconnected developmental trajectory, moving from needs assessment (Chapters 2 and 3), through stakeholder consensus (Chapter 4), to co-creation (Chapter 5) and feasibility testing in clinical practice (Chapter 6).[1-6]

A key methodological strength lies in the integration of extensive stakeholder engagement with an iterative, mixed-methods design, which allowed continuous refinement of intervention content based on patient and expert perspectives and context. Across the included studies, this resulted in a high degree of contextual fit between identified needs and intervention components, reflected in the high acceptability observed in the feasibility phase (Chapter 6).[6] Importantly, this suggests that co-creation processes are not merely participatory additions to intervention design, but may be essential for ensuring relevance in conditions characterized by uncertainty and long-term surveillance.[70]

At the same time, the findings of this dissertation should be interpreted as part of a broader developmental evidence base rather than as definitive outcome evidence. In line with the MRC framework, the current work represents early-stage feasibility and implementation research, in which the primary aim is to assess acceptability, usability, and preliminary engagement rather than clinical effectiveness.[7,8] As such, conclusions regarding long-term effects on anxiety, quality of life, or treatment decisions cannot yet be drawn. This reflects the natural progression of complex intervention research rather than a limitation of the study per se.[7,8]

A cross-cutting methodological consideration across the included studies relates to sample composition and engagement patterns.[12,48,71] While variation existed between study phases, the feasibility evaluation (Chapter 6) in particular included a relatively homogeneous group of participants, characterized by higher educational attainment, relatively high digital literacy, and a high proportion of individuals with partner support.[6,71] This pattern is consistent with a broader challenge in digital health research, where early adopters tend to represent more resource-rich populations.[48,71] As a result, findings likely reflect the experiences of men with relatively high capacity for engagement, which may limit transferability to populations with lower health literacy or reduced social support.[48]

In addition, engagement patterns observed in the feasibility study highlight an important methodological insight for digital intervention research in AS. While initial uptake and acceptance were high, sustained use declined over time, partly due to measurement frequency and perceived burden.[6,47] This finding should not be interpreted solely as an intervention limitation, but rather as an indication that intensive longitudinal data collection can itself become part of the intervention experience.[14] In the context of AS, where patients already navigate recurrent PSA testing and surveillance anxiety, additional structured self-reporting may inadvertently amplify illness salience.[6,47] This highlights the importance of carefully balancing data richness with participant burden in future iterations of digital follow-up models.

The conceptual frameworks underpinning this work, including the Technology Acceptance Model (TAM) and the Unified Theory of Acceptance and Use of Technology (UTAUT), provide useful explanatory lenses for understanding patterns of engagement observed in this dissertation.[71-73] In particular, perceived usefulness appeared strongly linked to features that supported perceived control over surveillance (e.g., PSA logging and preparation for consultations), whereas passive informational components were used less frequently.[6-71] These models are limited in their ability to capture the emotional and existential dimensions of living with uncertainty in AS, suggesting that traditional technology acceptance frameworks may be insufficient when applied to oncology populations experiencing chronic diagnostic ambiguity.[71]

Taken together, the methodological approach of this dissertation demonstrates both the value and the complexity of developing digital interventions within routine cancer care. The findings emphasize that feasibility, acceptability, and engagement are not fixed properties of an intervention, but dynamic outcomes shaped by population characteristics, care context, and the broader burden of surveillance. Future research should therefore move beyond evaluating whether digital tools "work," towards understanding for whom, under what conditions, and within which care ecosystems they can meaningfully contribute to sustainable AS follow-up.

Directions for clinical practice and future research

Clinical practice

This study demonstrates that Active Surveillance (AS) for prostate cancer should not be conceptualized as a passive "watchful waiting" strategy, but as a long-term care trajectory requiring active psychosocial support, symptom monitoring, and patient engagement. Within this context, specialized nurses are well positioned to play a coordinating role by integrating digital self-management support into routine care.[50,66-68]

The findings suggest that digital tools such as MijnAS may add value when implemented as part of existing care processes rather than functioning as standalone applications. Similar to findings from broader literature on digital oncology support interventions, the potential benefit of these tools lies not only in providing information but in facilitating person-centered care, supporting self-management, and strengthening communication between patients and healthcare professionals.[34,35,45,46,48]

A prerequisite for sustainable implementation is interoperability with hospital information systems and Electronic Health Records (EHRs). Integration of patient-reported outcomes with routinely collected clinical data, including PSA values, imaging outcomes, and biopsy results, may reduce administrative burden and improve data reliability. From the patient perspective, integrated access to clinical and self-reported data may enhance transparency and contribute to a greater sense of control during surveillance.[12,19,59]

Within such integrated workflows, the role of nurses extend beyond information provision. Digital dashboards such as MijnAS can support preparation for consultations by making patterns in patient-reported outcomes visible before clinical encounters.[63] This may allow earlier identification of concerns related to psychological distress, lower urinary tract symptoms, sexual functioning, or uncertainty regarding disease progression.[61] The added value therefore lies not in replacing professional contact, but in enabling more individualized and responsive support throughout the AS trajectory.

Future research

The systematic development and feasibility testing of the MijnAS application represents a critical phase in the Medical Research Council (MRC) framework for complex interventions.[7,8] While current findings confirm that the tool is highly acceptable and addresses core psychosocial needs, the transition from a "feasibility prototype" to a "standard of care" requires further empirical validation and strategic integration. The following directions for future research are essential to establish the long-term clinical value and sustainability of digital self-management in Active Surveillance (AS).

While this dissertation established the feasibility and high acceptability (73.4%) of the MijnAS application, future research must shift towards evaluating its clinical efficacy through robust experimental designs.[7,8] Large-scale RCTs should investigate whether the use of the tool leads to statistically significant

improvements in patient reported outcomes such as distress, uncertainty and health-related quality of life. It is critical to determine if the tool reduces premature AS discontinuation thereby validating MijnAS as a safety mechanism for protocol adherence. Future trials must prioritize a more heterogeneous population to mitigate the population bias observed in this feasibility study.[48] This includes intentionally recruiting men with lower (digital) health literacy or those from lower socioeconomic backgrounds to ensure that digital tools do not exacerbate the digital divide in oncology care. In addition to recruitment strategies, these findings also underscore the importance of adapting the design and accessibility of digital interventions themselves, ensuring that they are responsive to varying levels of health literacy, digital proficiency, and patient needs.

Furthermore, future research on how digital tools like MijnAS can be integrated seamlessly into diverse clinical workflows rather than being offered as standalone resources is therefore vital.

Maintaining patient activation over a surveillance trajectory that can last a decade or more is a major challenge, often hindered by the "law of attrition" in eHealth.[14] Future research should evaluate the impact of long-term engagement strategies, such as automated feedback based on PSA trends. To avoid "questionnaire fatigue", researchers should explore lighter monitoring techniques, such as the Experience Sampling Method (ESM) or simple "smiley" check-ins, which trigger deeper inquiries only when a decline in well-being is detected. Testing "just-in-time" notifications delivered around the "unsettling monitoring cycle" may help mitigate recurring peaks of distress. For example, delivering relaxation exercises or targeted FAQs in the week leading up to a medical examination could provide support exactly when the patient's sense of control is most threatened.

Conclusions

In conclusion, this dissertation demonstrates that the long-term success and sustainability of Active Surveillance (AS) depends not only on its established oncological safety but equally on the patient's psychological adaptation to the inherent paradox of living with an untreated tumor. By systematically following the Medical Research Council (MRC) framework, this research has mapped a comprehensive developmental trajectory: from the foundational identification of significant unmet psychosocial needs to establishing stakeholder consensus on essential intervention components.

The findings emphasize that the value of digital support lies in its ability to foster salutogenesis and agency, transforming AS from a perceived state of "doing nothing" into a proactive path toward health promotion. The co-created MijnAS application provides an important foundation for bridging the gap between clinical monitoring and the patient's lived experience. However, the "digital dilemma" identified in the feasibility phase, characterized by high initial acceptability but significant long-term attrition, indicates that this tool should be viewed as a promising prototype that requires further iterative optimization and large-scale validation in more heterogeneous populations.

Ultimately, this work advocates for a paradigm shift toward a person-centered, nurse-led hybrid care model. Digital tools are most effective when they are not standalone resources but are functionally integrated into existing clinical workflows and hospital portals, where specialized nurses act as essential "translators" between digital data and the patient's experience. By structurally embedding psychosocial care and digital innovation into the AS trajectory, healthcare providers can ensure that surveillance remains a truly safe, sustainable, and patient-centered choice for the growing population of men living with localized prostate cancer.

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Summary

Samenvatting

Acknowledgements

About the author

Appendices

SUMMARY

Active Surveillance (AS) has emerged as the preferred management strategy for men with low-risk and favorable intermediate-risk prostate cancer (PCa), aiming to avoid the morbidity associated with immediate radical interventions such as surgery and radiotherapy. AS presents a significant psychological paradox: patients must live with the clinical knowledge of harboring a malignancy while adopting a strategy of no immediate treatment. This "untreated" status often triggers significant distress, characterized by "PSA anxiety" and a latent fear of disease progression, which leads 5% to 13% of men to discontinue the protocol in the absence of medical progression.

This dissertation addresses the unmet psychosocial needs of men on AS by developing a nurse-led digital intervention. Guided by the Medical Research Council (MRC) Framework for Complex Interventions, the research utilizes stakeholder-driven co-creation to bridge the gap between clinical monitoring and the patient's lived experience. The overarching goal is to foster salutogenesis and agency, transforming the surveillance experience from a passive state of "doing nothing" into a proactive path toward health promotion.

The study in **chapter 2** employed an explorative qualitative design to investigate the psychosocial support needs of men on AS. Seventeen semi-structured interviews were conducted with low-risk PCa patients from two Dutch urology clinics, and data were analyzed using thematic content analysis facilitated by NVivo. The results revealed that while the initial diagnosis has a significant emotional impact, recurring medical examinations and waiting for PSA results are the primary triggers for long-term anxiety and uncertainty. Coping effectiveness was found to be dependent on the patient-physician relationship, the patient's locus of control, and disease acceptance. Effective coping strategies included proactive information seeking and social support, whereas ineffective strategies such as avoidance, denial, and substance abuse, impeded resilience. The findings highlighted an urgent need for reliable, early-stage, disease-specific information to facilitate acceptance and adaptation.

Chapter 3 describes a scoping review that was conducted to map existing evidence-based interventions capable of alleviating the psychosocial burden of AS. Following the PRISMA guidelines, six scientific databases were searched for studies published since 2009, resulting in the inclusion of 12 studies (9 quantitative, 1 qualitative, and 2 mixed-methods). The review categorized effective support into three major themes: information and education (tailored protocols and risk communication), coping and social support (peer engagement and professional psychological help), and lifestyle (physical activity, nutrition, and mindfulness). Key results indicated that providing transparent, just-in-time information to both patients and their partners significantly reduces distress. Furthermore, engaging in "self-health" through physical activity and dietary adjustments provided men with a vital sense of control and improved quality of life.

The consensus study in **chapter 4** adopted the RAND/UCLA Appropriateness Method to reach consensus among stakeholders on the components of a psychosocial support program. A panel of 31 stakeholders, including patients, nurses, urologists, paramedics, and mental health professionals, participated in three consensus rounds to rate the relevance of interventions on a 9-point Likert scale. After a focus group session to address discussion items, consensus was established on 13 key interventions. These components span four domains: information and education (e.g., decision aids and shared decision-making), coping and support (e.g., structural assessment of psychosocial burden), physical well-being (e.g., LUTS and ED screening), and lifestyle (e.g., standard provision of nutritional and exercise guidelines).

A digital support program was developed using the design thinking process in the study described in **chapter 5**. The consensus-driven interventions were operationalized into a digital prototype using Design Thinking principles. The process involved five phases: Empathy, Define, Ideate, Prototype, and Test. Empathy interviews with five experts and subsequent multidisciplinary brainstorming sessions led to the conceptualization of the "MijnAS" application. The prototype was developed iteratively with end-user input and subjected to heuristic testing by nine experts to evaluate usability. The final tool featured functional modules for logging PSA values, preparing for consultations using a "positive health" spider web, and accessing lifestyle advice and educational videos. While heuristic evaluations confirmed the application's strength in navigational clarity and consistency, they also identified critical areas for refinement, specifically regarding error handling and help documentation. Ultimately, this development phase transformed theoretical support components into a tangible self-management tool aimed at fostering patient agency and self-efficacy during the surveillance trajectory.

A single-arm mixed-methods study evaluated the feasibility and acceptability of the MijnAS application across four Dutch urology clinics with 35 participants in **chapter 6**. Data collection included online questionnaires, application metadata, and 17 semi-structured interviews with patients and caregivers. The results showed a high recruitment rate (85%), though retention declined to 50% by study completion, primarily due to "survey burden". Acceptability was generally positive, with 73.4% of participants reporting approval. Objective metadata revealed that 65% of users registered PSA values and 32% used appointment preparation features. Qualitative insights further characterized the application as a vital "psychological anchor," providing essential reassurance and validation of the AS care path during vulnerable diagnostic and follow-up periods. The study identified "digital fragmentation" and a lack of integration with hospital electronic health records (EHR) as critical systemic barriers, highlighting that for such tools to remain sustainable, they must be embedded within the existing clinical ecosystem rather than functioning as standalone platforms.

The synthesis of this research demonstrates that the long-term success of Active Surveillance is contingent upon addressing the psychological demands of the trajectory. Findings reveal that uncertainty remains an inherent challenge, driving a significant need among men for lifestyle information and a greater sense of agency, promoting the ability to actively participate in and influence their own

care. To address this, the developed application empowered participants, by facilitating consultation preparation, providing information and lifestyle guidance, thereby transforming the surveillance period into a proactive health trajectory. This shift toward self-management aligns with the framework of salutogenesis, which emphasize strengthening individuals' resources and capacity to maintain health and well-being, allowing men to move beyond passive monitoring toward a more resource-oriented and health-promoting experience.

The dissertation identifies a "digital dilemma": while tools like MijnAS are highly acceptable, their efficacy is limited if they remain standalone applications. To ensure sustainability, future efforts must move toward a hybrid care model where digital self-management is functionally integrated into hospital portals. In this model, the specialized nurse acts as a crucial "translator" between digital data, such as patient-reported outcomes or PSA trends, and the patient's lived experience. Finally, the dissertation advocates for AS to evolve into a multidisciplinary care ecosystem that structurally embeds psychosocial monitoring as a standard of care, ensuring it remains a safe and patient-centered choice

SAMENVATTING

Tegenwoordig kiezen steeds meer mannen met een milde vorm van prostaatkanker voor Actief Volgen (Active Surveillance). Dit betekent dat de tumor nauwkeurig in de gaten wordt gehouden met bloedonderzoek en scans, maar dat er niet direct wordt behandeld. Dit voorkomt vervelende bijwerkingen zoals incontinentie of erectieproblemen, maar het brengt een psychologische puzzel met zich mee: je weet dat je een tumor hebt, maar je wordt niet "echt" behandeld. Dit zorgt bij veel mannen voor onzekerheid en angst, vooral wanneer het tijd is voor het halfjaarlijkse bloedonderzoek. Soms is deze spanning zo groot dat mannen toch voor een actieve behandeling kiezen, terwijl dat medisch gezien niet nodig is. Dit proefschrift onderzoekt hoe we mannen beter kunnen ondersteunen, onder andere met een speciale app, zodat zij niet het idee hebben 'niets te doen', maar zelf de regie te voeren over hun gezondheid.

In **hoofdstuk 2** hebben we onderzocht waar mannen tijdens Actief Volgen behoefte aan hebben. In dit onderzoek is gesproken met 17 mannen die voor Actief Volgen hadden gekozen. Hieruit bleek dat vooral het wachten op de uitslag van het bloedonderzoek en de medische controles voor veel spanning zorgen. Mannen die goed met deze situatie om konden gaan, hadden vaak een sterke vertrouwensband met hun dokter en zochten zelf actief naar betrouwbare informatie. De belangrijkste conclusie was dat mannen direct na de diagnose behoefte hebben aan eerlijke, begrijpelijke informatie om de ziekte te kunnen accepteren en graag iets willen *doen* aan hun gezondheid.

In de studie die is beschreven in **hoofdstuk 3** is wereldwijd gezocht naar bestaande ondersteuning voor mannen in dit traject. Er werden 12 belangrijke onderzoeken gevonden. De resultaten laten zien dat drie dingen echt helpen: goede voorlichting, contact met lotgenoten en aandacht voor een gezonde leefstijl. Vooral gezond eten en meer bewegen gaven mannen het gevoel weer controle te krijgen over hun eigen lichaam en leven.

In **hoofdstuk 4** staat beschreven dat er samen met een team van experts is onderzocht hoe we mannen met prostaatkanker tijdens Actief Volgen het beste kunnen begeleiden. Om een goed ondersteuningsprogramma te maken, is de hulp ingeschakeld van 31 experts, waaronder patiënten, partners, psychologen, diëtisten, fysiotherapeuten, verpleegkundigen en artsen. Zij hebben samen bepaald welke onderdelen het belangrijkst zijn. Er was overeenstemming over 13 onderdelen, zoals het standaard bespreken van de psychische last tijdens een afspraak, het bieden van hulp bij het voorbereiden van het gesprek met de dokter en het geven van duidelijke adviezen over gezonde voeding en vitamines.

De 13 gekozen onderdelen zijn verwerkt in een digitale app: "MijnAS". In **hoofdstuk 5** wordt de ontwikkeling van deze app stap voor stap beschreven. De app is ontwikkeld samen met de mannen die hem gaan gebruiken. In de app kunnen mannen hun eigen bloedwaarden bijhouden in een grafiek, zich

voorbereiden op een gesprek met de dokter, een gezondheidsvragenlijst invullen en video's bekijken over prostaatkanker en leefstijl. Tests lieten zien dat de app makkelijk te gebruiken is en overzichtelijk aanvoelt.

In **hoofdstuk 6** staat beschreven hoe de app in de praktijk is getest. De app is drie maanden lang gebruikt door 35 mannen in vier verschillende ziekenhuizen. De meeste mannen (73%) waren erg positief en noemden de app een "psychologisch houvast". Uit de gegevens bleek dat mannen de app vooral gebruikten op belangrijke momenten, zoals direct ná hun diagnose of vlak voor een controle in het ziekenhuis. Een belangrijk verbeterpunt was dat de app in de toekomst direct gekoppeld moet worden aan het systeem van het ziekenhuis, zodat mannen hun uitslagen niet meer zelf hoeven over te typen.

De belangrijkste les van dit proefschrift is dat Actief Volgen geen periode van alleen maar afwachten hoeft te zijn. Hoewel onzekerheid een vast onderdeel is van het traject, blijkt dat mannen hier beter mee omgaan als zij zelf de regie pakken. De MijnAS-app ondersteunt dit door mannen voor te bereiden op afspraken in het ziekenhuis en informatie te bieden over leefstijl, waardoor 'afwachten' verandert in actief bezig zijn met je gezondheid.

De app vervangt de zorg van de dokter of verpleegkundige niet, maar helpt juist extra mee. De verpleegkundige kan de informatie uit de app gebruiken voor een persoonlijk gesprek dat echt over jouw behoeften gaat. Het is wel belangrijk dat de app voor iedereen makkelijk te gebruiken is, ook als je minder ervaring hebt met technologie. Ook moet de app in de toekomst verbonden worden met het ziekenhuisdossier. Zo draait Actief Volgen niet meer om onzekerheid, maar om je eigen keuzes en een fijn leven.

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Tijdens mijn opleiding tot bachelor verpleegkundige werd mijn ambitie verder aangewakkerd door de academische omgeving waarin ik mij mocht ontwikkelen. Al na het eerste studiejaar wist ik dat ik verdieping zocht en verder wilde kijken en begrijpen. Ik kreeg daartoe vele kansen en ontmoette onderweg inspirerende mensen. Toch waren het vooral de gesprekken met patiënten en hun naasten die mij het diepst hebben geraakt. De breekbaarheid en afhankelijkheid binnen de muren van een groot ziekenhuis, het zich moeten verhouden tot medische experts en de moed om jezelf te laten zien, je uit te spreken en je eigen behoeften, wensen en zorgen onder woorden te brengen, raakten me diep. Juist deze ervaringen hebben mij misschien wel het meest gemotiveerd om dit proefschrift te volbrengen: de wens om mensen, juist in deze bepalende momenten, een stem te geven en bij te dragen aan een gevoel van regie en gehoord worden.

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ABOUT THE AUTHOR



Kim Donachie was born in Johannesburg, South Africa, on September 4, 1986. She is a dedicated healthcare professional, researcher, and educator with a strong focus on psychosocial support in oncology nursing. She holds a Master of Science in Clinical Health Sciences from HAN University of Applied Sciences and is currently pursuing a PhD in Health Psychology at the Open University of the Netherlands. Her doctoral research, *The Development of a Nurse-Led Psychosocial Support Intervention to Optimize Support for Prostate Cancer Patients Undergoing Active Surveillance,* is conducted within the Technology for Health research group at HAN University of Applied Sciences in collaboration with the Faculty of Behavioral and Health Sciences at the Open University. This project is supported by a 2020 NWO PhD Grant. Her research primarily addresses the psychosocial challenges faced by men with low-risk prostate cancer undergoing active surveillance. Through her work, she aims to develop and implement a nurse-led psychosocial support program to enhance patient well-being and engagement. From 2010 to 2016, Kim worked as a Clinical Trial Coordinator and Manager, contributing to multidisciplinary, national, and international scientific studies. This experience provided a solid foundation for her transition into research and education. Since 2018, she has pursued a career in higher health education as a lecturer in the Bachelor of Nursing program. As an educator, she has developed study materials and several learning modules for Noordhoff Health Publishers and Bohn Stafleu van Loghum, covering topics such as critical appraisal, SOAP reporting, leadership in nursing, patient mobility, and tracheostomy care. These educational resources are widely used in nursing programs across the Netherlands. Kim has also been an active member of the Dutch Association of Urology Nurses (V&VN Urology) for over a decade. She has served as chairperson of the V&VN Urology Symposium and as a member of the symposium committee, contributing significantly to the advancement of urological nursing education and practice. In addition to her educational activities, she has been involved in various academic roles. This includes participation in national and institutional committees, such as the Comenius program review committee and the Research Committee of the Open University. She has also contributed as a peer reviewer for scientific journals and participated in expert panels related to healthcare and educational innovation. These activities reflect her broader engagement with the academic community and commitment to advancing research and education in nursing and health sciences. In her current role as a senior policy advisor, she operates at a more strategic level within higher education, focusing on quality assurance, the connection between education and the professional field, student and staff well-being, and organizational development. In this position, she integrates knowledge from education, research, and clinical practice to contribute to the development of future-proof healthcare professionals and to strengthen the link between academic training and practice.

APPENDICES

SCIENTIFIC OUTPUT

Peer-Reviewed Articles

Donachie K, Cornel E, Adriaansen M, Mennes R, van Oort I, Bakker E, Lechner L. Optimizing psychosocial support in prostate cancer patients during active surveillance. Int J Urol Nurs. 2020;14(3):115–123. doi:10.1111/ijun.12242.

Donachie K, Cornel E, Pelgrim T, Michielsen L, Langenveld B, Adriaansen M, Bakker E, Lechner L. What interventions affect the psychosocial burden experienced by prostate cancer patients undergoing active surveillance? A scoping review. Support Care Cancer. 2022;30(6):4699–4709. doi:10.1007/s00520-022-06830-z.

Donachie K, Adriaansen M, Nieuwboer M, Cornel E, Bakker E, Lechner L. Selecting interventions for a psychosocial support program for prostate cancer patients undergoing active surveillance: a modified Delphi study. Psychooncology. 2022;31(12):2132–2140. doi:10.1002/pon.6053.

Donachie K, Hansma M, Adriaansen M, Cornel E, Bakker E, Lechner L. Developing a digital psychosocial support program for men with low-risk prostate cancer during active surveillance. Internet Interventions. 2025;41:100853. doi:10.1016/j.invent.2025.100853.

Donachie KM, Cornel EB, van Soest R, de Ra B, van Elst M, Adriaansen M, et al. Feasibility of a self-management web application for men with prostate cancer undergoing active surveillance. Manuscript submitted for publication. 2026.

Other publications

Donachie K, Bakker E. Literatuurstudie naar het verminderen van psychosociale last bij prostaatkanker tijdens actief volgen. Tijdschrift voor Psychosociale Oncologie. 2022.

Donachie K, Lalleman PCB. The characteristics of three female leaders in healthcare: shattering the glass ceiling. 2018.

Book

Donachie K, Michielsen L, Peters M. Hoe maak ik een CAT: handleiding voor de verpleegkunde. Bohn Stafleu van Loghum; ISBN 9789036827348.

Book chapter

Donachie K, Michielsen L, Peters M. Evidence-based Diëtetiek. Houten: Bohn Stafleu van Loghum; 2022. Hoofdstuk 6, Beoordelen literatuur en Hoofdstuk 7 Evidence-Based Diëtetiek

Educational / learning modules

Donachie KM. Verwisselingen van en bij patiënten. Utrecht: Noordhoff Health Uitgevers; 2017.

Donachie K. Omgaan met agressie. Utrecht: Noordhoff Health Uitgevers; 2017.

Donachie K. Tracheostoma zorg. Utrecht: Noordhoff Health Uitgevers; 2017.

Donachie K. Blaasspoelen. Utrecht: Noordhoff Health Uitgevers; 2018.

Donachie K. Blaaskatheterisatie. Utrecht: Noordhoff Health Uitgevers; 2018.

Donachie K. Omaha. Utrecht: Noordhoff Health Uitgevers; 2018.

Donachie K. Veilig verplaatsen zorgvragers. Utrecht: Noordhoff Health Uitgevers; 2019.

Donachie K. Verpleegkundig leiderschap. Utrecht: Noordhoff Health Uitgevers; 2019.

Donachie K. Rapporteren volgens SOAP. Utrecht: Noordhoff Health Uitgevers; 2019.

Presentations, conferences & scientific dissemination

Oral presentations

- Presentation, Open Universiteit Promovendi Dag, 19 April 2018
- Presentation, V&VN Urologie Symposium, 9 November 2018
- Presentation, Kenniskring, 17 January 2022
- Presentation, Kenniskring, 5 February 2024
- Presentation, Kenniskring, 25 January 2025

Posters & conference contributions

- Abstract accepted, European Association of Urology Congress, Barcelona, 16–18 March 2019
- Poster presentation, NVPO Congress, 17 March 2023
- Poster presentation, V&VN Oncologiedagen, 30 May–1 June 2022
- Poster presentation, European Association of Urology Congress, 2026

Workshops & masterclasses

- Presentation Masterclass, Joost de Baaij, 28 September 2023
- Presentation Masterclass, Erik van Muilekom, 27 May 2024

Conference attendance

- IPOS World Congress of Psycho-Oncology, Tokyo, 2020
- European Association of Urology Congress, Milan, 2023
- European Association of Urology Congress, London, 2026

PHD PORTFOLIO

Grants

Comenius Teaching Fellowship, 2024

NWO Lerarenbeurs, 2020

HAN Promotiebeurs, 2019

Academic service

2026	Participation in the CLEAR-PC expert panel, 2026
2025	Member of the Research Committee, Open University of the Netherlands
2025-2026	Comenius Fellowship review committee, evaluating grant applications for educational innovation.
2024-2026	Peer reviewer for journals in field of oncology/prostate cancer

PhD training activities

2025	ARDA -HAN University of Applied Sciences
2025	Methods for the Design of Applied Clinical Research – Radboudumc
2021	OU graduate school – Open University
2021	Advanced Critical Writing – Maastricht University
2021	Intro to Critical Writing - Maastricht University
2019	BDB – HAN University of Applied Sciences
2019	Leadership in Healthcare – Utrecht University
2019	Master of Science, Clinical Health Sciences, Utrecht University
2014	ICH-Good Clinical Practice Cursus, CRCN
2014	Procesmanagement, Open Universiteit Nederland
2013	Organisatie en Management, Open Universiteit Nederland
2012	Managementvaardigheden, Open Universiteit Nederland
2011	ICH-Good Clinical Practice Cursus, Clinical Trial Services
2011	Basiscursus Marketing, Open Universiteit Nederland
2005	Bachelor of Nursing, HAN University of Applied Sciences

RESEARCH DATA MANAGEMENT

Ethics and privacy

This doctoral research was conducted in accordance with applicable ethical guidelines and received approval from the Open University Ethics Committee (Ref. Nos. U202104601 and CETO_RP943/U202409047). For the qualitative study presented in Chapter 2, additional ethical approval was obtained from the local Medical Research Ethics Committees (MREC number 2017-4008). All participants provided written informed consent prior to their inclusion in the various studies. Data handling and processing were fully compliant with GDPR regulations, with research data being pseudonymized to protect participant confidentiality. Key files linking participant identities to their respective pseudonyms were stored securely and separately from the primary research datasets.

Data collection and storage

Across the empirical chapters of this thesis, a wide range of data were collected and analyzed, including verbatim transcripts from semi-structured interviews and focus groups, self-reported questionnaire data (LimeSurvey), and objective application metadata. Quantitative analyses were conducted using IBM SPSS Statistics, while qualitative data management and coding were facilitated by NVivo and Atlas.ti. To ensure maximum privacy, raw audio recordings were destroyed immediately following transcription and member-checking. All digital research data were securely stored and backed up on the protected institutional network drive (R://) of the HAN University of Applied Sciences, which is restricted to the research team and includes a 16-week backup cycle. Research Drive was employed for secure data sharing within the project team, utilizing SSL encryption and a 30-day backup period. Furthermore, in line with institutional agreements, a copy of the raw data is maintained on the secure servers of the Open University.

Data sharing in accordance with the FAIR principles

To support the FAIR principles (Findable, Accessible, Interoperable, and Reusable), de-identified participant data and metadata will be made available via the DANS-EASY repository upon the project's completion and publication of results. Findability is supported by the application of the Dublin Core metadata standard and the assignment of a persistent Digital Object Identifier (DOI) by the repository https://doi.org/10.17026/LS/8PCIKW. The data are shared under a Creative Commons Attribution-Noncommercial 4.0 International (CC BY-NC 4.0) license, allowing for non-commercial reuse with proper attribution. All research data, including de-identified datasets, transcripts, and codebooks, will remain archived for a minimum period of 10 years.


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