



Patient Engagement in the Management of Benign Prostatic Hyperplasia

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Abstract

Purpose of Review Benign prostatic hyperplasia (BPH) is an ideal disease model to consider the utility and impact of patient engagement since treatment choices, outcomes, and side effects are complex. The aim of this review is to evaluate existing research from 2015–2021 to identify established ways patient engagement has been applied to BPH as well as areas for improvement.

Recent Findings Several studies describe the development and implementation of decision aids and new forms of informed consent to better facilitate patient engagement and decision-making. It has also been demonstrated that existing publicly available information about BPH is either difficult for patients to understand or is inaccurate.

Summary There are many medical and surgical options available for BPH management. Increased patient engagement, through patient education, decision aids, and shared decision-making, can address some of the unmet needs in BPH care.

Keywords Patient engagement · Benign prostatic hyperplasia

Introduction

Benign prostatic hyperplasia (BPH) is a highly prevalent disease, affecting 70% of men aged 60 to 69 years old and over 80% of men older than 70 years in the USA [1]. Lower urinary tract symptoms (LUTS) associated with BPH evolve over the course of the disease and can have a significant impact on quality of life. Severe LUTS secondary to BPH have been associated with a higher risk of depression as well as increased healthcare costs [2, 3].

Over the past decade, a patient-centered approach to care has been emphasized in many contexts and specialties

including the field of urology, with evidence supporting improved patient satisfaction and outcomes [4]. Given its prevalence and progressive nature, BPH presents many opportunities along the course of its natural history for patient engagement, education, and shared decision-making. The World Health Organization defines patient engagement as supporting the capacity of patients, families, and health care providers to facilitate and support the active involvement of patients in their own care in order to enhance safety and quality [5].

Because of numerous treatment algorithms and guidelines, there is the need for patient involvement when selecting from the variety of available medical and surgical treatment options. The aim of this study is to systematically review the recent literature on patient engagement in BPH management.

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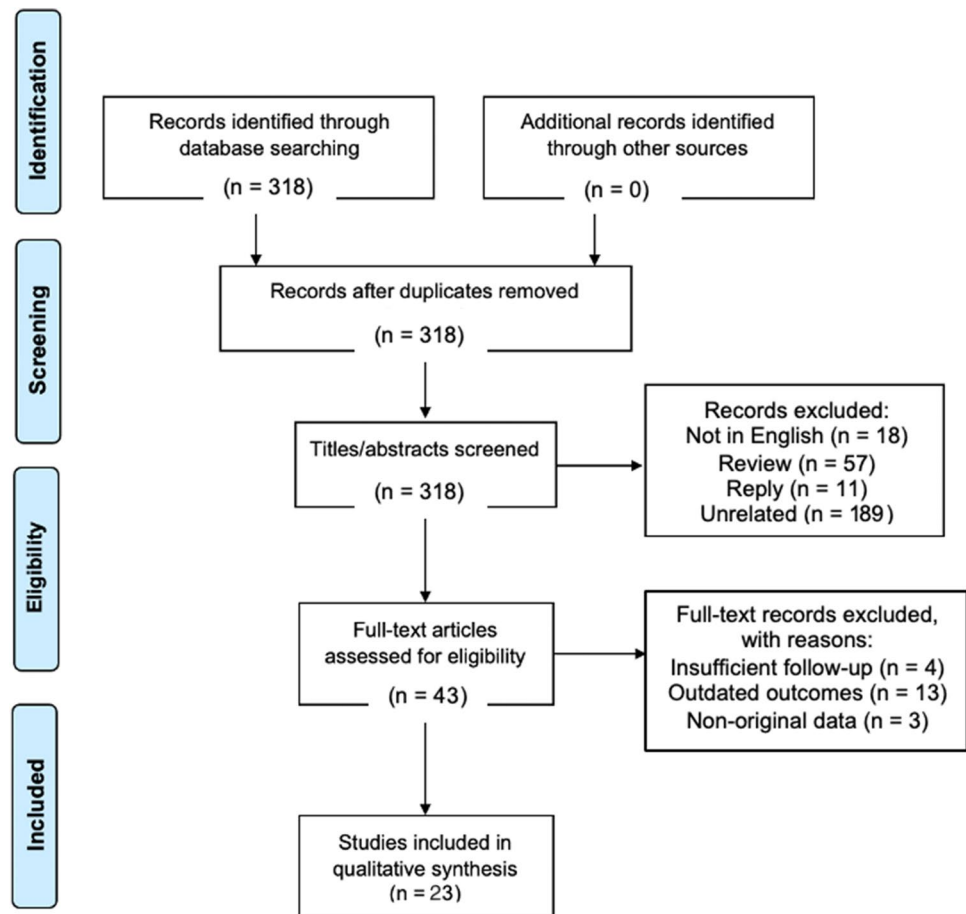
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Methods

Evidence Acquisition

A National Center for Biotechnology Information (NCBI) PubMed search to identify articles assessing patient engagement in BPH management published from 2015 to February 1, 2021, was performed by combining the following terms:

Fig. 1 Study flow diagram



benign prostatic hyperplasia, patient engagement, patient education, patient-centered care, literacy, and shared decision-making. We followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) protocol [6]. After studies were identified, titles and abstracts were screened for eligibility. Articles that were not in English, review articles, reply articles, and unrelated articles were excluded. The remaining studies were reviewed in their entirety and were included in our study if patient engagement or patient-centered care in the context of BPH or LUTS was a primary topic of discussion or area of inquiry.

Evidence Synthesis

The initial search identified a total of 318 articles, of which 275 were excluded because the abstracts were deemed not relevant to the topic or not otherwise meeting the aforementioned criteria. Full texts were analyzed, which further excluded 20 articles deemed not relevant to the topic, resulting in 23 articles included in this review. The flow chart of the systematic search strategy is demonstrated in Fig. 1.

Results

Overall, 23 articles published between 2015 and 2021 were selected for this review, which included a variety of study designs (Table 1). The most common studies were survey-based. Study periods ranged from 2005 to 2016. Surveyed outcomes included LUTS symptom scores, awareness of BPH and other prostatic diseases, care-seeking behavior, diagnoses made, treatment versus no treatment, type of treatment received, treatment satisfaction, and quality of life. Independent variables included age, race and ethnicity, education level, income, health insurance status, type of profession, and country or region of origin [2, 7–11]. In general, younger men, less educated men, and men less engaged in the health care system should be targeted more specifically by programs that aim to educate about BPH [2, 7, 8]. Examples of men who are “less engaged” in the health care system include those who do not regularly visit a physician or consult with a provider when not feeling well [7].

Waller et al. observed that 41% of over 9,000 surveyed men in the USA who did not have BPH or significant LUTS at baseline reported moderate to severe symptoms

Table 1 Summary of key findings

Study and year	Key findings
Randomized controlled trials	
Ham et al. [12]	No difference in patient understanding but higher satisfaction in multimedia rather than standard written informed consent
Prospective Studies	
Wallner et al. [2]	Most men do not seek care for BPH or LUTS and should specifically be targeted
Taneja et al. [13]	A visual prostate symptom score could be completed by more patients without help
Kajimoto and Bowa [14]	A single-question nocturia score correlates with the standard IPSS
Van der Wijden et al. [15]	A decision aid improves the decision quality and should be implemented in routine care
Cross-sectional studies	
Foster et al. [7]	Older men with higher education and rates of engagement with medical system are more likely to report BPH diagnosis
Ertel et al. [11]	Asian and Latin American men also have areas of discordance between patient and physician perceptions of BPH
Retrospective Studies	
Kesari et al. [16]	Age and education are more likely to influence treatment decisions rather than personality
Li et al. [17]	Personalized education rather than uniform education and informed consent before surgery reduces perioperative anxiety
Descriptive Studies	
Clarke et al. [18]	Patient preference should be included in quality metrics
Tanwar et al. [19]	Negative correlation between quality of publicly available videos about BPH and search result ranking
Mankowski et al. [20]	Treatment decision may be optimized by understanding what benefits and side effects are of greatest concern
Lamers et al. [21]	Patients should be involved in development of decision aids
Koo and Yap [22]	Most online information about BPH is at a reading level too advanced for most adults
Moses et al. [23]	The AUA symptom score is frequently not completed or takes longer to complete for men with low health literacy
Ojewola et al. [10]	There is poor level of knowledge and screening for BPH in Nigeria
Kosilov et al. [9]	Positive correlation between level of education and health-related quality of life among men with BPH
Huang et al. [24]	Online information about prostate embolization is of low to moderate quality
Sare et al. [25]	Online information about BPH is written at a level too difficult for the average adult
Lee et al. [8]	Numerous unmet needs exist in patients with BPH across age and level education
Betschart et al. [26]	Most videos on the surgical treatment of BPH are low-quality and provide misinformation
Gaines and Malik [27]	The majority of questionnaires about BPH are too advanced for most adults
Selman et al. [28]	Men with LUTS report and prefer different kinds of decision-making support from clinicians

BPH benign prostatic hyperplasia, *LUTS* lower urinary tract symptoms, *IPSS* International Prostate Symptom Score

at follow-up within four years. However, the vast majority (91%) had no medical or surgical treatment recorded [2]. Indeed, many men do not seek care for these symptoms; therefore, efforts should be made to specifically promote the discussion of LUTS during clinic visits [2].

International survey-based studies reflect similar unmet needs. A cross-sectional study of European men with LUTS found that older men with higher education levels and higher rates of engagement with the medical system were more likely to report a diagnosis of BPH, demonstrating the need to engage younger men outside the traditional medical context [7]. Comparable results were seen in surveys of Africa and Asia [8–10]. A survey of Nigerian men found that less than a third of respondents were aware of BPH, and educational and occupational status were significantly associated with knowledge level of prostatic diseases [10]. A Korean survey also found

that higher education was associated with lower likelihood of experiencing unmet medical needs for BPH, as was health insurance status [8]. Another survey of men in Asia and Latin America reported that older men were more likely to seek care for symptoms, yet over half of patients avoided or delayed care because they believed symptoms were an inevitable part of aging [11]. Almost 20% of men felt embarrassed about their symptoms, demonstrating the need for clinicians to proactively raise the topic of LUTS and BPH. [11].

Surveys may be instructive in identifying factors beyond clinical symptoms that influence patient choice of treatment. The authors classified men along three personality dimensions: novel-seeking, harm avoidance, and reward dependence [16]. They found that age and level of education were more influential in treatment decisions, rather than personality factors. Another survey used discrete choice experiments

to determine the most important factors for men in choosing pharmacologic therapy. Authors found that a medication must provide improvement in more than one symptom to compensate for side effects [20]. Thus, survey-based studies are instructive in engaging patients, helping them to better understand their needs and facilitate the decision process.

A second category of studies described the development or implementation of decision aids to help patients navigate a context of numerous treatment options and lack of clear-cut guidelines [15]. A group from the Netherlands involved both clinicians and patients in creating its online BPH decision aid, surveying patients in the initial phase as well as performing usability testing. The aid starts with the International Prostate Symptom Score (IPSS) and routes patients based on their use of medication in guiding next steps. It also provides a printable summary that can be brought to a clinic visit to discuss with a urologist. [21].

The only randomized controlled trial relevant to this review assessed the efficacy of a multimedia-based informed consent for patients undergoing photoselective vaporization of the prostate. It found no difference in understanding as measured by a post-consent exam covering basic knowledge regarding prostate anatomy and function and treatment modalities, but higher rates of satisfaction with the consent process [12]. In addition to alternative modes of informed consent, another group found that personalized preoperative education before surgery for BPH significantly lowered perioperative anxiety beyond basic patient education and informed consent [17].

More broadly, Clarke et al. described how one center implemented an approach to health delivery that emphasized a “patient-centric scope”, focusing on the full course of treatment to better reflect patient experiences. The Department of Urology at the University of California, Los Angeles (UCLA), defined what was most meaningful to patients undergoing surgery for BPH, including complications, cost, and improvement in LUTS. These measures were operationalized to better understand how patients defined “success” in BPH treatment [18].

Some studies specifically examined the landscape of public websites and social media containing information about BPH, especially pertaining to how well patients understood material about BPH readily available to patients. Two studies found that across multiple tests of literacy, online information about BPH was almost universally too difficult for the average American adult to understand [22, 25]. Other studies found that the American Urologic Association (AUA) symptom score is frequently not completed or takes longer to complete for men with low health literacy, and that other questionnaires have similar shortcomings [23, 27]. Potential solutions include a visual prostate symptom score or a single-question score assessing nocturia, both of which have been found to correlate with the standard IPSS [13, 14].

Finally, although the majority of patients seek out information about BPH online, most publicly available videos about BPH provided very basic or incorrect facts about the disease and its treatment options, and one study even found a negative correlation between the quality of videos and the displayed order of search results, or search rank [19, 24]. These findings emphasize the importance of clinician-directed guidance and accurate patient education materials [26].

Discussion

BPH is a progressive and prevalent disease and presents numerous opportunities along the course of its natural history for engaging different patient populations in different contexts. Given the variety of medical and surgical treatment options and the high economic burden of the disease, it is not only beneficial for patient satisfaction but also essential for the healthcare system to facilitate decision-making processes that lead to improved outcomes. This systematic review found that there is a relative paucity of published research specifically examining patient engagement in BPH management.

The vast majority of studies with some direct relevance to patient engagement are survey-based, and authors from a range of geographic and practice settings found that there is insufficient patient engagement and understanding of topics related to BPH. Rather than evaluating the impact of patient engagement approaches, most studies illustrate the clear need for it, as men with BPH or LUTS have a significant knowledge gap. Patients less typically engaged include younger men, less educated men, and men with otherwise decreased involvement in the health care system. These patients should be proactively educated about their symptoms and looped into the health care system at appropriate times to allow for early assessment and management. Both primary care practitioners and urologists should play a role in supporting these efforts, setting the starting point of a patient engagement model of care at the beginning of disease symptoms rather than later in its course [4].

Treatment options for BPH are numerous, ranging from pharmacologic to office-based procedures, ambulatory to inpatient surgery. Guidelines exist but are largely directed at practitioners, and, even so, treatment algorithms for BPH are often not clear-cut given the wide range of options and heavy role patient and provider preference play [4, 29]. Indeed, physician preference for certain BPH surgical treatment technologies may influence and even bias patient decision-making. The AUA guidelines on BPH management specifically recommend that choice of treatment is reached in a shared decision-making process, while an AUA white paper on shared decision-making in urology found that overall it

is underutilized in clinical practice and should be more consistently implemented [29, 30]. Several studies analyzed the role of decision aids as one avenue of patient engagement; however, data were limited on actual implementation and outcomes [15, 21, 30].

Other authors also examined the scope of publicly available information about BPH, such as websites and online videos, and found many barriers to accurate, comprehensive, and readable material [19, 22, 24, 25]. As the majority of patients with LUTS start to learn about their symptoms by obtaining information online, these findings point to a major challenge that exists before even the first clinic appointment, namely, that material specifically directed for patients is difficult to understand. Clinicians can nonetheless support a proactive patient-centered approach by working to develop and ensure more accessible, accurate, and understandable material about BPH. Giving patients a better knowledge base will ultimately help their decision-making once they are seen in clinic, and public information would ultimately continue to be of benefit to patients even when they are already engaged in care.

More research is necessary to better elucidate how patients understand and benefit from shared decision-making. Existing literature in the urology context weighs more heavily toward patient involvement in prostate cancer decisions, in which there are many more randomized studies. Such work is relatively lacking in BPH [31, 32]. Studies of multiple methodologies would be helpful, including qualitative and even ethnographic reports and, of course, well-performed prospective and randomized studies. For example, Selman et al. interviewed 41 men with LUTS about how treatment decisions were made and found that men prefer different kinds of decision-making support from their clinicians, some doctor-led, some patient-led, and some shared [28]. Nonetheless, it is incumbent upon the clinician to gauge patient needs and offer a shared decision-making approach when necessary.

Our study is not without limitations. First, the studies included are heterogeneous with respect to their design, and many are descriptive or survey-based studies. Second, there is a lack of randomized controlled trials, with only one identified in the review period. Third, this review only analyzed articles found on PubMed versus Embase/Medline and is limited to 2015–2021. Nonetheless, there were some consistent findings in these relatively few studies.

Finally, patient engagement exists on the individual clinician-patient level but should also be adopted at the institutional and system levels to better facilitate patient care, satisfaction, and outcomes. Research is lacking in this area and, other than one briefly described article at UCLA, more studies should examine the impact of a patient-centered approach to BPH care as defined by a department or practice

group. These studies could be particularly telling especially when disseminated across a variety of practice settings.

Conclusion

Men with BPH and LUTS are frequently underinformed or even misinformed about the evaluation and management of their symptoms. Patient decision-making involves gathering information on their own as well as in dialogue with clinicians. Each point in time over the long natural history of BPH presents an opportunity for better engaging patients via more accurate and understandable written and verbal information. Existing research on patient engagement in BPH largely highlights numerous areas of unmet need. Younger men, less educated men, and men less engaged in the health care system in general are target populations that stand to benefit from patient engagement efforts relating to BPH and LUTS. Much more research is needed, however, to more systematically understand and address those gaps through a patient-centered approach.

Declarations

Human and Animal Rights and Informed Consent This article does not contain studies with human or animal subjects performed by any of the authors.

Competing Interests The authors declare no competing interests.

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