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Health literacy, cancer literacy, comprehensions and knowledge among men attending a urology clinic

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Abstract

Health literacy (HL) is essential for men receiving urological treatment so that they can be involved in the shared decision making process. HL is supported by domain specific background knowledge which also informs cancer literacy and comprehension. Comprehension is in turn a determinant of HL. This study aimed to assess the level of HL among a group of men receiving urological treatment and to investigate if there were any correlations between the two different measures of HL, cancer literacy and comprehension, and prostate cancer knowledge. A survey was mailed to 200 men attending a urological clinic. The survey included: demographic questions, two validated tests of HL, (1) the Brief Health Literacy Score (BHLS) and (2) the Health Literacy Management Scale (HeLMS); a test of cancer comprehension; the Cancer Message Literacy Tests Reading (CMLT); and a prostate cancer knowledge test. Descriptive statistics were used to analyse the data. Surveys from 72 respondents, average age of 65 years, were included in the final analysis. Based on the BHLS, 22% of respondents had inadequate HL and 50% of respondents had inadequate HL in one or more of the HeLMS domains. Overall, the study participants had relatively high cancer literacy, comprehensions, and knowledge. However, for men with inadequate HL, based on the BHLS and the HeLMS, there were strong correlations with poor cancer literacy, comprehension, and knowledge. Our study highlights that many men receiving urological treatment with inadequate HL, require additional support to access health information which they can understand and act on to be part of the shared decision-making process.

Keywords

Health literacy; Prostate cancer; Knowledge; Cancer literacy and comprehension

1. Introduction

Nearly half of all adults have difficulty understanding and acting on health information [1]. Similarly inadequate health literacy is common with the Adult Literacy and Life Skills survey from the Australian Bureau of Statistics (ABS) reporting that 46–53% of Australians lack basic literacy skills [2]. This places them below the "minimum required to meet the complex demands of everyday life and work" [2]. The results from this survey are even worse for more complex areas of literacy, with 70% of Australian adults having inadequate problem-solving skills.

Modern healthcare places complex demands on the patient with individuals asked to seek information and participate in treatment decisions for themselves and others. This requires a degree of health literacy (HL), which has been defined as the ability to access, understand, and use health related information to make informed decisions and manage health [1, 3]. Basic health literacy involves what Nutbeam [4] describes as "task-based" literacy (the ability to read and write) and is an important first step to "skill-based" literacy associated with the knowledge and skills required to perform these tasks. This means that even individuals with high levels of general literacy may not be able to apply their knowledge and skills in unfamiliar situations, especially those requiring specific content knowledge, such as healthcare. This skills-based literacy is a prerequisite to the more complex "interactive HL" which allows participation and control of an individual's healthcare by applying information to changing situations [5]. HL is thus a broad construct involving a complex relationship between basic literacy, knowledge, and comprehension [6].

Chin and associates [7] have suggested that HL reflects the interplay of cognitive abilities (what they call "processing capacity") and background knowledge. As such, background knowledge of subject matter has been shown to be essential for literacy and especially comprehension of information, including information provided by clinicians during consultations, and to facilitate shared decision making [6, 7]. Specific background knowledge of a topic has been shown to allow individuals to process information more quickly, recall infor-

mation more readily and understand information at a deeper level [8]. Therefore, domain specific knowledge (and general knowledge) are essential for interactive HL [6]. In addition, a combination of general and specific knowledge enhances comprehension [9, 10]. Comprehension requires integration of the meaning with prior background knowledge [9]. Therefore, comprehension determines an individual's capability to access complex health information, interpret health advice critically, navigate the healthcare system and communicate with healthcare professionals [11, 12]. Thus, there is a vital interconnection between HL, knowledge and comprehension.

The capacity to be engaged, involved in discussions, and ask questions of the physician is a measure of interactive HL, which is critical to allow men to be actively involved in their healthcare [13]. This is particularly important for men with urological conditions, such as prostate cancer, where the treatment decisions are not always simple and depend on a choice made by a patient clinician in a model of shared decision making [14]. Therefore, it is important for clinicians to consider HL during their patient interactions because inadequate HL is often associated with less knowledge and understanding of illness management, poorer communication between patient and physician, and decreased ability to take part in shared decision making [14].

In diverse health situations, lower HL has been shown to be associated with lower levels of knowledge about the health condition, a lack of social empowerment and self-efficacy (perceived health competence), and significantly worse health outcomes [15]. A 2011 study by Song and associates [16], investigated 1500 American men (median age 63: range 41–79) with clinically localised prostate cancer. In this study, 37% of the study participants were found to have low or intermediate HL which correlated with worse Health-Related Quality-of-Life scores. Similar results were obtained in a smaller study of American men with newly diagnosed prostate cancer (n = 40, mean age 67.0 years) [17] where overall low HL was suggested to contribute to low prostate cancer knowledge.

Inadequate HL is also associated with poorer health outcomes and lower self-reported health status [1, 16, 18]. Previous studies have suggested that inadequate HL is associated with lower socioeconomic status, lower education level and increasing age [19, 20]. There is also evidence which suggests that men exhibit lower levels of HL than women, even with respect to male specific health issues [2, 21]. Compounding the problem, men have been found to be less able to assess, interpret and apply health information [22].

The aim of the study was to assess the level of health literacy among a group of men attending a urological clinic and to investigate if there any correlations between two different measures of health literacy, cancer literacy and comprehension, and prostate cancer knowledge.

2. Materials and methods

This study utilised a cross-sectional research design. Patients aged 18 years and over, who were referred to an Australian based urology clinic between February and July 2018 were invited, by mail, to complete a paper-based survey.

2.1 Survey questions

The mailed research survey consisted of demographic questions, two independent HL tools, a cancer literacy and comprehension test, as well as a Prostate Cancer Knowledge test. The surveys were completed anonymously. The demographic questions in the survey included age and residential postcode. The participants' residential postcodes were used to assess their socioeconomic status (SES) status using the Socioeconomic Index for Areas (SEIFA), which ranks areas in Australia according to socioeconomic advantage, with lower scores indicating higher socioeconomic disadvantage [23].

The two health literacy tools included in the survey were the Brief Health Literacy Survey (BHLS) [24] and the Health Literacy Management Scale (HeLMS) [25]. The BHLS included three questions: Question 1: "How often do you have someone help you read hospital materials?"; Question 2: "How often do you have problems learning about your medical condition because of difficulty understanding written information?"; and Question 3: "How confident are you filling out forms by yourself?" [24, 26, 27]. Response options for Questions 1 and 2 included: Always (1), Often (2), Sometimes (3), Occasionally (4) and Never (5). While response options for Question 3 were: Not at all (1), A little bit (2), Somewhat (3), Quite a bit (4) and Extremely (5). The overall BHLS score is the sum of the scores for these three items. A higher score indicates better health literacy with a maximum score of 15. Men who scored ≤ 3 for any of the 3 questions were regarded as having low overall HL [28, 29]. These three questions have been reported to be effective in detecting individuals with inadequate HL (receiver operating characteristic (ROC) curve 0.87 Q1; 0.80 Q2 and 0.76 Q3) [26].

The multidimensional HeLMS tool consists of 29 subjectively rated questions within eight independent domains each of which measures different constructs related to HL [25]. Confirmatory factor analyses undertaken by the original authors indicated good fit of the survey results for eight HL domains (Cronbach alpha >0.82) [25]. Five of the eight domains focus on individual abilities: Domain 1, patients' attitude towards health; Domain 2, ability to access and understand health information; Domain 6, ability to communicate with health professionals to get the information they want about their health; Domain 7, ability to be proactive and seek and understand information about their health and Domain 8 on ability to understand and use information to make informed health decisions [30]. The remaining three domains focus on broader factors that influence these abilities: Domain 3, ability to seek social support to manage health; Domain 4 on socioeconomic factors influencing ability to access health care and Domain 5, ability to access General Practice (GP) healthcare services and knowing where to seek health information. For each question in each domain, participants were required to score themselves on a five-point Likert scale, with options varying from 5 "able to do without any difficulty" to 1 "unable to do so". For each domain item scores were averaged and used for data analysis [30]. As previously reported by Jayasinghe [31], an average score of <4, on any domain, was classed as inadequate HL for that domain.

Two Cancer Message Literacy Tests—Reading (CMLT)

from the National Cancer Institute were included in the survey to identify the participant's cancer literacy and comprehension [32]. The "Citizens Guide to Radon" and "What do I Need to Learn about Getting Tested for Prostate Cancer?" messages were selected by the authors as being the most appropriate because they provided scenarios, which would be relevant to men attending a urology clinic. Both CMLTs consisted of a written passage of information (the message) and subsequent statements to test cancer literacy and comprehension. Participants were instructed to read the passage and determine if each corresponding statement was the "same", "different" or "not sure". For the purposes of analysis, "not sure" was scored as an incorrect answer. There were four statements requiring answers for the "Citizen's Guide to Radon" (maximum score of four) and three statements requiring answers for "What do I Need to Learn about Getting Tested for Prostate Cancer?" (Maximum score of 3). Higher scores for these messages were assumed to suggest higher cancer comprehension and literacy.

The survey also included the Prostate Cancer Knowledge test [33]. The test is comprised of 14 questions, divided into six domains, assessing knowledge about screening, side effects from treatment, symptoms, risk factors, screening age guidelines and screening controversy. Each question was recorded to be either correct (1) or incorrect (0). Total correct responses were between 0–14 and in the absence of published cut scores, it was assumed that higher scores indicated higher knowledge levels.

2.2 Data analysis

Descriptive statistics were used to provide an overview of respondents' sociodemographic characteristics. Correlations between continuous data with two numerical variables were analysed using linear regression with p values indicating the extent to which the deviation of the slope from zero was significant (p values < 0.05 were taken as significant) and the "goodness of fit" represented by r^2. The Kruskal-Wallis test was used to determine if there were significant differences between multiple groups and the Mann-Whitney test if only two groups were compared. All analysis was performed using GraphPad Prism (Version 7 for MacOSX, GraphPad Software Inc., San Diego, CA, USA).

3. Results

Ninety of the 200 mailed surveys were returned by participants (response rate 45%). Eighteen of the 90 responses were incomplete and not included in the final analysis, which included 72 survey responses. Thirty of these men attended the urology clinic for assessment after screening for prostate cancer, twenty-five required assessment of lower urinary tract symptoms and seventeen for consideration of vasectomy. The average age of respondents was 65 years (Range: 33–95 years) with 56% (40/72) being over 65 years old. Most of the respondents (40.3%) were in the third decile of the Index of Relative Socio-economic Disadvantage (IRSD) (Table 1).

3.1 Health literacy results

Despite the average BHLS score being 12.7 (out of a possible 15), 16 of the 72 men (22%) were classified as having low HL based on this measure. There was an approximate equal spread of respondents with inadequate HL in each of the SEIFA codes (Table 1) indicating that there was no correlation between socio-economic status and HL in this patient population.

The average scores for each of the HeLMS domains are highlighted in Table 2. Even though the average score for each domain was greater than 4 (out of a possible 5), the individual HeLMS domains with the highest proportion of scores of less than 4 (indicative of inadequate HL) were: Domain 1 (patient's attitude towards their health, 26.4%); Domain 3 (ability to seek social support to manage health, 16.7%); and Domain 7 (ability to be proactive and seek and understand information about their health, 13.9%). Based on the HeLMS criteria 50% (36/72) of the respondents were assessed as having inadequate HL in one or more of the eight domains (not visible in Table 2). Of the respondents with inadequate HL, 55% (20/36) were aged over 65 years.

3.2 Cancer literacy and comprehension and prostate cancer knowledge

The average score for the two CMLT messages were 85% for Radon and 83% for the prostate cancer messaging test. The average score for the Prostate Cancer Knowledge test among the 72 respondents was 11 out of a possible 14 (range 4–14). Based on these scores it appears that the study participants had relatively high cancer literacy, comprehension, and knowledge scores.

3.3 Correlations between health literacy, cancer literacy and comprehension

There was concordance between our two measures of HL with a strong correlation between the average score for seven of the eight HeLMS domains and the total BHLS score (Fig. 1). Only HeLMS Domain 3 (ability to seek social support to manage health) did not correlate with the BHLS scores.

There was a positive correlation between scores on the CMLT (measuring cancer literacy and comprehension) and Domain 2 (ability to access and understand health care information, $p = 0.0128$, $r^2 = 0.8535$), Domain 4 (socio-economic factors influencing ability to access health care, $p = 0.0116$, $r^2 = 0.0876$) and Domain 5 (ability to access GP health care services and knowing where to seek health information, $p = 0.0025$, $r^2 = 0.0123$) of the HeLMS. There was also a positive correlation between the BHLS score and the CMLT total ($p = 0.0087$, $r^2 = 0.0943$).

There was a positive correlation between scores in the Prostate Cancer knowledge test and average scores in Domain 3 (ability to use social support to manage health, $p = 0.013$, $r^2 = 0.085$), Domain 5 (ability to access GP health care services and knowing where to seek health information, $p = 0.048$, $r^2 = 0.055$) and Domain 6 (ability to communicate with health professionals to get the information they want about their health, $p = 0.048$, $r^2 = 0.070$). There was no correlation between the Prostate Cancer Knowledge test

TABLE 1. Relationship between the index of relative socioeconomic disadvantage (IRSD) and the health literacy of respondents.

IRSD Quintile*	1	2	3	4	5
Number of men in each quintile	7	7	29	14	15
Percentage of men in each quintile	9.7	9.7	40.3	19.4	20.8
Percentage of men with inadequate HL on BHLS (Number of men with inadequate HL)	28% (2)	28% (2)	17% (5)	28% (4)	20% (3)

**IRSD [23] results are recorded as deciles, and we have amalgamated these into quintiles with lower scores indicating higher socioeconomic disadvantage.*

TABLE 2. Health literacy of respondents in each of the eight HeLMS domains.

Health Literacy Focus	HeLMS Domain	Description	Av. HeLMS score	Number of men with inadequate HL in each domain*	% with inadequate HL
Individual	Domain 1	Patient's attitudes towards their health	4.22	19	26.4%
Individual	Domain 2	Ability to access and understand health information	4.58	7	9.7%
Broad	Domain 3	Ability to seek social support to manage health	4.46	12	16.7%
Broad	Domain 4	Socioeconomic factors influencing ability to access health care	4.61	7	9.7%
Broad	Domain 5	Ability to access GP healthcare services and knowing where to seek health information	4.9	1	1.4%
Individual	Domain 6	Ability to communicate with health professionals to get the information they want about their health	4.75	3	4.2%
Individual	Domain 7	Ability to be proactive and seek and understand information about their health	4.49	10	13.9%
Individual	Domain 8	Ability to understand and use information to make informed health decisions	4.73	3	4.2%

**Inadequate HL determined by a HeLMS score <4 in that domain. HL: health literacy; HeLMS: Health Literacy Management Scale; GP: General Practice.*

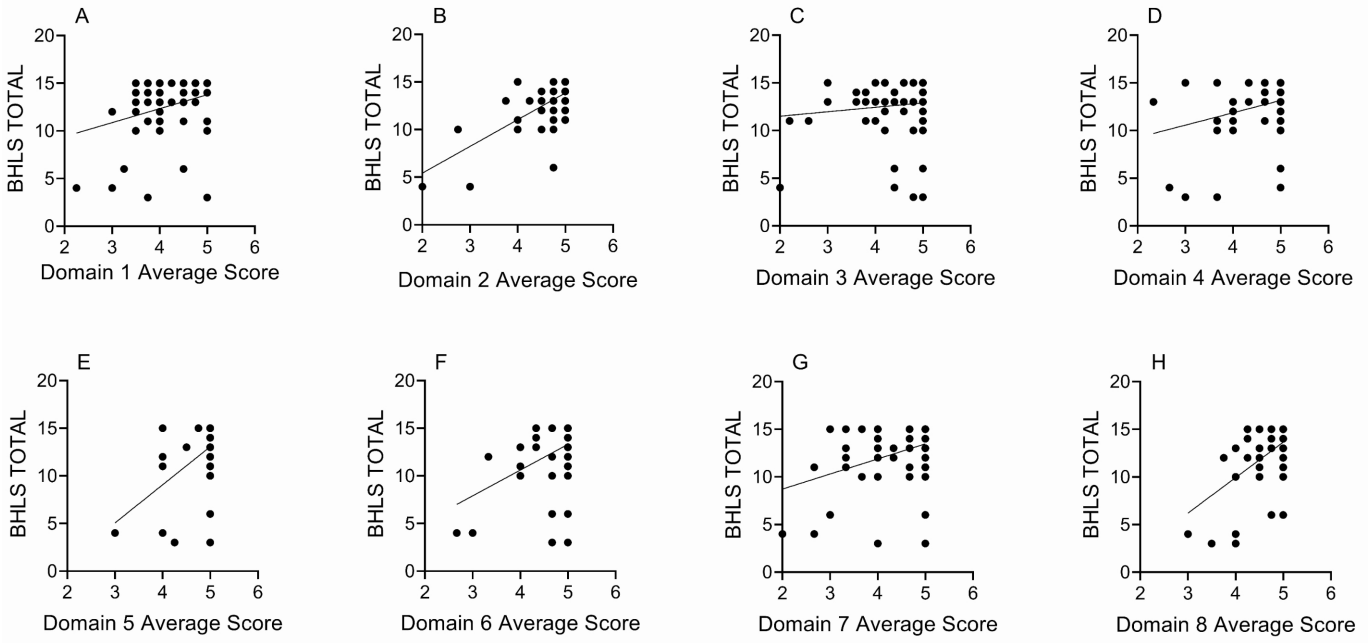

FIGURE 1. Correlation between the BHLS and the average scores for each of the HeLMS Domains. There was strong correlation between BHLS and Domain 1 (A, patients' attitude towards health; $p = 0.013$, $r^2 = 0.084$), Domain 2 (B, ability to access and understand health information; $p < 0.0001$, $r^2 = 0.622$), Domain 4 (D, socioeconomic factors influencing ability to access health care; $p = 0.018$, $r^2 = 0.078$), Domain 5 (D, ability to access GP healthcare services and knowing where to seek health information; $p < 0.0001$, $r^2 = 0.199$), Domain 6 (F, ability to communicate with health professionals to get the information they want about their health; $p = 0.0001$, $r^2 = 0.194$) Domain 7 (G, ability to be proactive and seek and understand information about their health; $p = 0.0009$, $r^2 = 0.146$) and Domain 8 (H, ability to understand and use information to make informed health decisions; $p < 0.0001$, $r^2 = 0.274$). The only HeLMS domain that did not correlate with BHLS was Domain 3 (C, Ability to seek social support to manage health; $p = 0.328$, $r^2 = 0.014$). BHLS: Brief Health Literacy Score.

and the other HeLMS domains or the BHLS total scores. There was also no correlation between age with either of the two HL measures, the CMLT, or the prostate cancer knowledge test (see **Supplementary Table 1**). In addition, there was no correlation between CMLT (cancer literacy and comprehension) and the Prostate Cancer Knowledge test scores. The only correlation between SEIFA codes and any of the measures of HL was for Domain 4 (socio-economic factors influencing ability to access health care, $p = 0.0046$, $r^2 = 0.055$).

4. Discussion

Based on the findings of this study, at least one fifth of men (22%) presenting to a urology clinic may have inadequate HL and almost half of them men had inadequate health literacy in one or more of the HeLMS domains. Overall, the men in our study had relatively high cancer literacy, comprehension, and cancer knowledge. However, those with inadequate HL were more likely to have lower cancer literacy and comprehension, as well as lower knowledge about prostate cancer.

Our findings regarding the proportion of men with inadequate health literacy are in concordance with published literature [25]. The highest proportion of those with inadequate HL was identified in the HeLMS domains that measure men's ability to access, understand and apply information to manage their health. Deficits in these domains (Domain 1, patients' attitudes to their health; Domain 3, ability to seek social support and help to manage their health; and Domain 7, ability to be proactive in seeking and understanding information about their health) appeared to be deficient for a high proportion of our study participants. These domains also relate to "interactive HL" which is essential for men to applying health information and participate in discussions relating to their healthcare [5].

This study found that there was a strong positive correlation between the BHLS and seven of the eight HeLMS domains (all except Domain 3, ability to use social support to manage health). These findings are important because busy clinicians can choose to quickly ascertain their patient's HL using the three-question BHLS tool [24], which can also be delivered verbally. Alternatively, they could use the HeLMS [25], a more comprehensive and time-consuming measure, to identify specific HL domains which can be targeted as part of their patient interactions. Using the HeLMs [25] would allow clinicians to focus more on HL constructs which could help improve their patients' ability to seek, understand and use health information.

Overall, the participants in our study had high levels of cancer literacy and comprehension. However, the positive correlations between cancer literacy and comprehension, and inadequate HL based on the BHLS and the HeLMS domains that specifically measure ability to seek, understand and access health information and healthcare services, including socio-economic factors (Domains 2, 4 and 5) are major findings.

These findings demonstrated a correlation between inadequate health literacy and lower cancer literacy and comprehension. These would suggest that men would have problems seeking, understanding, and accessing health information and managing their health. Clinicians need to ensure that the information they provide to these men should be easy to read and understand and that they might need to tailor their communications and interactions with these patients to ensure that they can take part in the shared decision-making process. These findings also emphasise the need for clinicians, to be cognisant of the cancer literacy, and comprehension of their male patients, and to ensure that they consider factors such as their emotional state, the nature of the decision being made, and their relationship with the patient, all of which may impact on their ability to take part in shared decision-making [34].

Previous research has shown that there is a strong and positive correlation between HL and knowledge about a wide variety of health conditions [35, 36], that is, as knowledge increases so does HL. To the best of our knowledge this is one of the first studies which has investigated health literacy and prostate cancer knowledge among men attending a urology clinic. In our study, even though prostate cancer knowledge was high among the study participants, the positive correlations between the participants' prostate cancer knowledge and scores for the HeLMS' Domain 3 (ability to use social support to manage health) and Domain 5 (ability to access GP health care services and knowing where to seek health information) suggest that men with inadequate HL have poorer knowledge about prostate cancer than their counterparts with adequate HL. These men would also struggle to access health information, health care services and social support to manage their health. The positive correlation between the prostate cancer knowledge and HeLMS Domain 6 (ability to communicate with health professionals to get the information they want about their health) also suggest that men with inadequate HL would also have problems communicating with their health professionals. These findings suggest that clinicians can feel confident that patients with adequate HL are able to be involved in the shared decision-making process because they can comprehend and act on information provided to them. However, the same cannot be assumed for men with inadequate HL who would require information and education tailored to their individual needs.

Our study did not find an association between age with HL, which contrasts with evidence in the literature [37, 38]. Previously it has been highlighted that increasing age is associated with the tendency to seek less information, make decisions faster, prefer fewer choices, have increased difficulty understanding information, and a focus on emotional aspects when making decisions [39]. These factors may militate against a man's involvement in the decision-making process. The only positive correlation between levels of social disadvantage and HL was for Domain 4 (socio-economic factors influencing ability to access health care) but similar findings were not observed for other aspects of HL. Perhaps an explanation for this disparity is that the number of participants from low SES groups was limited in our study (with many coming from the middle SES group) and, as a result, our study findings may be limited in terms of their generalisability. Other factors that have previously shown to impact HL such as education level, occupation and social participation were not examined in the current study. Furthermore, men with inadequate HL, and those from non-English-speaking backgrounds may not have been able to respond to the survey questions. Other limitations of this study include the relatively small sample size (n = 72). This is particularly important given the number of comparisons and correlations that have been included in this study. In addition to these limitations, the strengths of this study need to be acknowledged. For example, to the best of our knowledge, this is the first time a study has investigated the HL, cancer literacy, comprehension, and prostate cancer knowledge among male urological patients. In order to enhance the generalizability of these findings it would be worthwhile to expand these findings in a larger more varied population.

5. Conclusions

Our study highlights that while many men attending urology clinics have adequate HL, cancer literacy and knowledge, at least a fifth of them have inadequate health literacy which negatively impacts on their ability to seek, understand, and access health information to manage their health. Clinicians could use the BHLS or the HeLMS to help identify these men with inadequate HL. While the BHLS is quick and easy to administer, the HeLMS is more comprehensive and provides information about specific HL domains which could be targeted to tailor health information to the needs of these men and thereby help to ensure that they can be part of the shared decision-making process.

ABBREVIATIONS

BHLS, Brief Health Literacy Score; CMLT, Cancer Message Literacy Tests Reading; HL, Health Literacy; HeLMS, Health Literacy Management Scale; SEIFA, Socioeconomic Index for Areas.

AVAILABILITY OF DATA AND MATERIALS

The data presented in this study are available on reasonable request from the corresponding author.

AUTHOR CONTRIBUTIONS

TAS, JRM and KJM—designed the research study. TAS and KA—performed the research. JRM and KJM—provided help and advice on research methods and analysis. TAS, KA and KJM—analyzed the data. TAS—wrote the manuscript. All authors contributed to editorial changes in the manuscript. All authors read and approved the final manuscript.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This project received ethics approval from the human research ethics committee (HREC2016/955) of the University of Wollongong. Tacit consent was assumed for participants who

completed the survey and returned it when they attended their initial urology consultation.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

SUPPLEMENTARY MATERIAL

Supplementary material associated with this article can be found, in the online version, at https://oss.jomh.org/files/article/1685854300190720000/attachment/Supplementary%20material.docx.

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